Disability as Culture

Jericha Hopson

Introduction

Regardless of which perspective one takes, the definitions and meanings of disability are wide and varied; it is best defined by and with people with disabilities. Disability can also be defined from a cultural framework (Gilson & Depoy, 2000). The cultural view of disability presents the issue of disability from the perspective of group identity distinct from other groups who do not share the disability identity (Mackelprang & Salsgiver, 1996). Pride is taken in the "unique talents and attributes of each individual," grounding the person with a "positive disability identity" (Brown, 1995).

Fear of judgment, denial, embarrassment, and ignorance is one of the reasons persons with disabilities do not disclose, discuss, or seek understanding of their disabilities. These barriers stem from a negative disability identity and the destructive stigmatization of disability as a problem held by the larger society. A well-developed identity allows individuals to have a better understanding of their strengths, weaknesses, and unique attributes (Marcia, 1966).

When individuals are able to accept their disabilities, they have higher levels of self-esteem, better coping skills, higher goals, and more motivation (Arnold-Oatley, 2005).

Jericha Hopson is the Student Disabilities Services Coordinator for Tarleton State University, a member of the Texas A&M System, Stephenville, Texas.

There is extensive research in relation to racial identity. A healthy racial identity has been shown to have positive effects on physical health, such as lower levels of stress, anxiety, and suicidal ideation (Ai, Aisenberg, Weiss, & Salazar, 2014).

This article attempts to articulate the importance of disability identity, culture, and acceptance while advocating for the inclusion of disability culture in the conversation about diversity. By extending the same concepts of cultural competency that have been used for racec and ethnicity, cultural differences can be applied to disability culture.

In the minority group model of disability, people with disabilities may be viewed as a socially stigmatized minority group subjected to stereotypes, prejudice, and institutional barriers similar to those of an ethnic minority (Eddey & Robey, 2005). The inclusion of those with disability as a cultural group will open doors that have previously been shut to a population that has come up against many closed doors. Cultural groups are afforded respect and position in society, which allows for a cohesive community to develop.

Disability Culture

Awareness of the disabled population has increased over the last few years, and has prompted a call for the formation of a disability culture, with the goal of challenging the individualization and medicalization of disability, the essentialist and determinist definitions of disability, the idolization of "normalcy," and negative stereotyping and exclusion of the disabled

(Barnes & Mercer, 2001). The call for this formation is reinforced by outrageous and blatantly discriminatory "Ugly Laws" in the United States, which have placed social restrictions on those whose physical appearance might offend "normal" people (Gerber, 1996).

According to the Americans With Disabilities Act (ADA), a person with a disability is a person

> who, with or without reasonable modifications to rules, policies or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services of the participation in programs or activities provided by a public entity. (Section 12111)

Disability culture promotes a sense of common identity and interests that unites disabled people and helps to create and sustain meanings, identities, and the consciousness that takes a political movement forward (Barns & Mercer, 2001). Steven E. Brown (2003), cofounder of the Institute on Disability Culture, described the culture of disability as follows:

> People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. . . . We are who we are: we are people with disabilities. (pp. 80–81)

A disability culture movement can foster disability pride, the discovery of shared experiences and rituals, and the establishment of values, goals, and identity. When a strong image is presented, it motivates people to want to belong, to be part of something that is powerful (Johnson, 2015). Cultural competence goes beyond understanding the values, beliefs, and needs associated with age, gender, or racial, ethnic, or religious background (Eddey & Robey, 2001).

Disability culture extends across every other cultural boundary and can be found in every corner of the world and throughout history. Disability culture is one of the only cultures and protected populations that can be joined involuntarily, suddenly, and unexpectedly. Anyone can have an accident and suddenly no longer fit into the nondisabled world.

Previously, the disabled world was seen as abstract and ambiguous. The traditional psychological models of disability focused on disability as a deficit to be fixed (Schulz, 2009), but there has been a call for a move to a social model of disability that underscores the role of society in defining and perpetuating disability (APA, 2012). The social model of disability suggests that the stigma experienced by those with a disability renders them a socially marginalized group (Olkin & Pledger, 2003).

Disability Identity

Disability is commonly perceived as a misfortune that can lead to underestimation of existing abilities and a global devaluation of the person (Dembo, Leviton, & Wright, 1975). In psychology, the term *identity* is often used to refer to the self, expressions of individuality, and the groups to which people belong.

Dunn and Burcaw (2013) have posited that disability identity refers to the possession of a positive sense of self and connection to, and unity with, the disability community. An articulate disability identity is believed to help individuals adapt to disability, social stresses, and daily hassles (Dunn & Burcaw, 2013).

Those with visible disabilities may be viewed by others differently due to appearance; similarly, people of color have observable differences resulting in the perception not of the individual but of the person's race (McEwen, 2003). Just as people of color face obstacles unique to their race, people with disabilities often come up against barriers unique to themselves (Bentley-Townlin, 2002). Unlike racial identity, where there are often others who share one's race in close proximity and/or direct family, for persons with disabilities to interact with other people with disabilities, they typically face the challenge of seeking them out, placing the responsibility on the individual to find such persons (Forber-Pratt & Zape, 2017). This can be particularly difficult for those not located in a homogeneous society.

Putnam (2005) has offered a few aspects as being pertinent to political disability identity and disability activism: self-worth, pride, and awareness of discrimination. Putman also mentioned other aspects, but these three seem to be the most applicable here. A sense of self-worth allows people with disabilities to see themselves as possessing the same worth as nondisabled individuals. Pride emboldens people with disabilities not to deny or mask but to "claim" (Hahn, 1997).

Finally, discrimination necessitates awareness and recognition of the fact that people with disabilities are frequently the recipients of biased, prejudiced, and unfair treatment on a daily basis (Chan, Livneh, Pruett, Wang, & Zheng, 2009).

Disability Acceptance

Acceptance of disability does not focus on the "preference of one's own state over others" but the "conditions facilitating acceptance of one's disability as non-devaluing" (Wright, 1960, p. 108). Acceptance is a process in which an individual can "seek satisfaction in activities that befit his/her own characteristics as a person rather than those of an idolized normal standard" (Wright, 1960, p. 134).

Individual acceptance of disability may spark the move toward social acceptance (Li & Moore, 1998). The value shift needed for acceptance of disability is dependent on a person's ability to change the way he or she thinks about his or her disability, moving from a negative devaluing system to a system where retained values are emphasized (Dembo et al., 1975). Better acceptance of disability increases a person's belief that he or she is considered a member of society, resulting in increased social confidence (Li & Moore, 1998).

The degree to which an individual accepts his or her disability is directly related to the societal perceptions and stigmatization of disability. There is a widespread presumption that negative cultural and media stereotypes of disability and disabled people serve to reinforce and extend disability stereotypes held by the general public (Barnes & Mercer, 2001).

Personal affirmation of disability promotes a feeling of social inclusion, to be recognized and treated like everyone else within a group or society (Dunn & Burcaw, 2013). Finding meaning and affirmation entails searching for significance and positive attributes that can accompany disability, which can lead to personal acceptance (Dunn & Burcaw, 2013).

Social Justice

Many people with disabilities, like other minorities, desire to achieve acceptance and inclusion in society (Li & Moore, 1998). For this to be accomplished, there needs to be a fundamental change in how society treats and perceives disability as a whole. People with disabilities themselves have a vital role to play in changing the cultural representation of disability.

Courage is needed to recognize that there are challenges to being disabled but also positive things in which pride can be taken. This recognition can change the way nondisabled people make judgments about the lives of people with disabilities and truly challenge current representations of people with disabilities, taking charge of the way in which disability is defined and perceived (Morris, 1991).

Lummis (1992) has suggested that "equality of opportunity makes sense in a society organized as a competitive game, in which there are winners and losers. What is equal is not the people, but the rules of the game" (p. 43). Who created these rules and how can we change them? Is this not a concept that can be applied to multiple unjust situations? Recognition that disability is socially constructed through the societal and environmental obstacles that have been created will reinforce the understanding and feeling that having a disability is not a personal deficiency.

A significant social movement is possible when there is a reconsideration of the manner in which a specific group of people "looking at some misfortune, sees it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable to society" (Turner, 1969, p. 391).

Any advocate for social justice can attest to the fact that major change can be daunting and discouraging at times, but the key is to continue to chip away at the ice until it is gone. We must also accept that the change we want to see may not happen on a large scale in our lifetime, but

the work we do today will pave the way for additional work to be done in the future.

Conclusion and Discussion

It has been almost 30 years since the landmark signing of the *Americans With Disabilities Act* (ADA), and as a nation, we have made great strides toward equality. The ADA prohibits public entities from isolating or separating people with disabilities or denying them the opportunity to participate in the programs that are offered to others.

However, we still have a lot of work to accomplish. While not a revolutionary concept by any means, the inclusion of disability in the world of culture and diversity shifts the perspective away from the traditional medical model. When viewed as a culture rather than a clinical categorization of individuals, disability can be an empowering part of one's identity. The ability to connect to a group of people who may share similar thoughts, beliefs, and experiences can be life altering, particularly for those who do not reside in a highly diverse community.

The sense of belonging to anything can give renewed direction, hope, and confidence in the future. The hallmark of disability as culture is the network one builds by meeting other people with disabilities, particularly similar disabilities, and forming relationships that can help promote education, awareness, and acceptance. The disability culture movement is growing every day and is becoming a powerful vehicle for change.

However, people with disabilities are often left out when discussing cultural diversity or overlooked as an important cultural group—perhaps not intentionally, but yet it persists. In some institutions of higher education, disability is often housed in a different administrative department than diversity and inclusion. This sends the message that disability does not belong with diversity.

While I believe there should be an administrative aspect to disability services, I also strongly believe students with disabilities deserve their place. I hope that disability can be a source of pride and can be celebrated as a culture rather than as something secondary, with a "caution" label affixed.

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