

An Essay on the Beginnings of Disability Culture and Its Study
David Pfeiffer, Ph.D.
Center on Disability Studies
University of Hawaii at Manoa

Abstract: The formal study of disability culture began around 1985. Steven Brown, the editor of this Forum, was the pioneer. Of the many indicators of the existence of a culture the first article in the field emphasized artifacts and language. Out of sometimes heated discussions of disability culture emerged disability pride. The concept of disability culture is a vital and important one today for the disability movement.

Keywords: disability culture, disability pride, disability movement

Since before people with disabilities were recognized as something different there existed disability culture. There are many ways in which it could have started. Before speech was recognized and used for communication people used gesture and body language to communicate. People with hearing problems probably originated the first sign language even though today many persons who are deaf consider themselves to be part of the Deaf Community, that is, a linguistic minority who are not disabled. People with mobility problems developed means to get around. People with other disabilities developed what we would call assisted technology today, although it was not highly sophisticated at all.

The self-conscious study of disability culture, according to Steven E. Brown, the editor of this Forum on disability culture, began with an article published by the author of this essay, Pfeiffer (1985). It was a paper delivered at the 1984 conference of the Association on Handicapped Student Service Programs in Post Secondary Education, now known as the Association on Higher Education and Disability (AHEAD). Andrea Schein (1985) and I delivered identically titled papers raising the question of whether a culture of disability existed. The answer was affirmative.

In researching and writing that paper I discovered that there were many different definitions of the term culture, especially in the discipline of anthropology. The definitions ranged from identifiable music and literature to the existence of artifacts to behaviors which were supportive and related to the behaviors of others. There is no single definition of disability culture, but rather there are definitions. These definitions, while being distinct, have overlapping concepts.

In my original paper I emphasized artifacts and language. The artifacts consisted of things such as wheelchairs, crutches, brailled documents, hearing aids, stair lifts, and other things. Language consisted of sign language (although today I would respect the position of the Deaf Community that those of us not conversant with sign language are the ones with a disability), large sized print, signs like those indicating an accessible bathroom, slang and insider terms like survivor, and some professional jargon. There are publications, such as magazines, which are directed toward the disability community. There is music and there is poetry written by people with disabilities and for people with disabilities. There are performing arts groups composed entirely or almost entirely of people with disabilities.

There are pieces of written literature which are part of disability culture. While many persons in the Deaf Community would not agree that they belong here, there is sign language

literature available on video. There are terms like crip, blinkie, and deafie which only persons with certain disabilities can use with legitimacy. There is also disability humor, but do not ask for examples right now.

The most influential work which not only discussed and analyzed disability culture, but also is a representation of it along with many pieces of literature it contains, is Steven E. Brown's final report as a Mary E. Switzer Distinguished Fellow of the National Institute on Disability and Rehabilitation Research for the academic year 1993-1994. (Brown, 1994) It is titled *Investigating a Culture of Disability* and is the place to start in order to understand disability culture. Brown and his wife Lillian Gonzales Brown are the founders of the Institute on Disability Culture which was located in Las Cruces, New Mexico. They are both now associated (in various capacities) with the Center on Disability Studies, University of Hawaii at Manoa.

In his work *Investigating a Culture of Disability*, Brown presents a history of people with disabilities and their developing culture. He pays attention to the social situation of people with disabilities and other people's reactions. These reactions included oppression, institutionalism, paternalism, and asylums which gave way to ideas of rehabilitation, independence, rights, and the personal experiences of people with disabilities. He documents the fierce struggle within and outside of the Society for Disability Studies over the question of where or whether a culture of disability existed. Out of this milieu emerged disability pride and survival scenarios. He surveys disability culture as it existed in the 1990s.

Out of the sometimes heated discussion over disability culture there emerged three primary understandings of it. First, there are many people who equate disability culture with the arts which are by, for, and about disability. There is also, second, the contention by Jessica Scheer and others that no separate disability culture can exist because disability is vastly different from linguistic and ethnic identities. Instead, they argue, there is a shared consciousness by most people with disabilities which is a strong bond between them. And third there is the equating of disability culture with participation in the disability community. These three understandings dominate the discussion of disability culture at the start of the twenty first century.

No matter how it is approached and defined, disability culture is an extremely important concept for the disability community, the disability movement. It is that one thing which binds together many people with disabilities. It is that which sets us off from non-disabled people. It is at the core of our being. That is why *The Review of Disability Studies* chose to have a Forum on disability culture in its first issue.

References

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DAVID PFEIFFER was a Resident Scholar at the Center on Disability Studies at the University of Hawaii at Manoa. He had numerous publications in the field of disability studies and other

policy areas. His received his Ph.D. from the University of Rochester and he was a wheelchair user. He was a past president of the Society for Disability Studies and longtime editor of the *Disability Studies Quarterly*. He was a founder of *The Review of Disability Studies*.

