The History of Disability: A History of 'Otherness'

How disable people have been marginalized through the ages and their present struggle for their human rights.

by Jayne Clapton and Jennifer Fitzgerald

Black bodies, white bodies; male bodies, female bodies; young bodies, old bodies; beautiful bodies, broken bodies - right bodies and wrong bodies. Historically, our bodies have framed our futures and explained our past; our bodies write our stories. But it is not our bodies per se which write the story; rather it is the way in which we, as a society, construct our bodies which shapes our history and our future.

Bodily difference has for centuries determined social structures by defining certain bodies as the norm, and defining those which fall outside the norm as 'Other'; with the degree of 'Otherness' being defined by the degree of variation from the norm. In doing this, we have created an artificial 'paradigm of humanity' into which some of us fit neatly, and others fit very badly. Life outside the paradigm of humanity is likely to be characterized by isolation and abuse.

The story we have recorded of the lives of people with disability is a story of life lived on the margins. For people with disability, their history is largely a history of silence. The lives of people with disability have not only been constructed as 'Other', but frequently as 'the Other' of 'the Other'. People with disability are marginalized even by those who are themselves marginalized.

While it is difficult to know where our constructions end and the reality begins (for the constructions shape the reality), it is clear that other stories and constructions which might have created different realities have been selectively 'forgotten'. Models of inclusion - for example, among the Maori in Aotearoa where it is suggested that disability is accepted as being normal - have been erased from Western disability history. Disability activists are now facing the task of re-creating a culture which celebrates and embraces difference. In the West, however, the script we have written for people with disability is a narrow one.

The history of disability in the West has been characterized by the progressive development of several models of disability: the religious model of disability, the medical/genetic model of disability, and the rights-based model of disability. These models, or constructions of disability, have set the parameters for our response to people with disability. Through time, these models have become more sophisticated, yet their essence remains constant - otherness.

The Religious Model of Disability

In a Western Judea-Christian society, the roots of understanding bodily difference have been grounded in Biblical references, the consequent responses and impacts of the Christian church, and the effect of the enlightenment project underpinning the modern era. These embodied states were seen as the result of evil spirits, the devil, witchcraft or God's displeasure. Alternatively, such people were also signified as reflecting the "suffering Christ", and were often perceived to be of angelic or beyond-human status to be a blessing for others.

Therefore, themes which embrace notions of sin or sanctity, impurity and wholeness, undesirability and weakness, care and compassion, healing and burden have formed the dominant bases of Western
conceptualisations of, and responses to, groups of people who, in a contemporary context, are described as disabled. In the past, various labels have been used for such people. These include crippled, lame, blind, dumb, deaf, mad, feeble, idiot, imbecile, and moron.

In the nomadic and/or agrarian societies of pre-industrialisation, when time was cyclic, people perceived with limitations often lived with their families. They were ascribed roles and tasks in line with their capabilities, and which fulfilled the co-operative requirements for corporate survival. Others, though, could not stay with their families. Some were ostracised, and their survival threatened, because of a popular conception that such persons were monsters, and therefore unworthy of human status. Some became homeless and dislocated for other reasons such as poverty or shame. Religious communities, often within the local precincts or parishes, responded to these groups of people in various ways. These included the promotion and seeking of cures by such actions as exorcisms, purging, rituals and so on; or providing care, hospitality and service as acts of mercy and Christian duty to "needy strangers".

However, important changes were to occur with the evolvement of the modern era profoundly influenced by the enlightenment and industrialisation. During this time, religious values and modes were challenged by the uprising of reason and rationality.

**The Medical Model of Disability**

As medical and scientific knowledge expanded profusely, the doctor and the scientist replaced the priest as custodian of societal values and curing processes. Work and production became commodified, and time became linear. Human worth was then to be determined by perceived work value and profitability; and lifestyles and lives became dictated by the mechanistic practices and institutions of the nation state. Universality replaced particularity, reason replaced mystery, and knowledge and state of the mind superseded the lived experience of the body. 'Normality', then, became determined by the ideal of the white, youthful, able, male body; and otherness to this ideal became hierarchically placed as inferiority. Therefore, difference became redefined as deviance commanding control.

Events of this era were to have a major impact on the lives of those with bodily limitations. The lives of such people were reduced to little more than a medical label, and their futures defined by a medical prognosis. People with disability then became a class requiring physical removal from the "able-bodied" norms of what was developing as an urbanised society. As some commentators note, this was the era when cripples disappeared and disability was created.

As certain groups of people came to be viewed as unproductive and incapable, institutions were established as places with a dual purpose: (a) where such people could be placed whilst other family members could meet workers' obligations; and (b) where such people could be skilled to become productive members of society.

But, with the modern era, there was also an increasing emphasis on scientism and social Darwinism; and this resulted in the roles of special institutions shifting from agents of reform to agents of custody for social control and institutional segregation for those now described as sub-normal. Institutions became the instruments for the facilitation of social death. Through a presumed scientific status, care for people with disability became depoliticised, technicalised and professionalised, predicated on notions of tragedy, burden and helpless dependency.

In the post-industrial and post-enlightenment era, disability, in Western society, has been regarded as an individual affliction predominantly cast within scientific and medical discourses. Therefore, "disability" has come to be defined and signified as a power-neutral, objectively observable attribute or
characteristic of an "afflicted" person. According to this model, it is the individual, and not society, who has the problem, and different interventions aim to provide the person with the appropriate skills to rehabilitate or deal with it. However, in a culture, supported by modern Western medicine, and which idealises the idea that the body can be objectified and controlled, those who cannot control their bodies are seen as failures.

In recent years, and with the influence of normalisation principles since the 1970's, the locus of an individualised conceptualisation has shifted from the state-run (public) institution to community-based facilities and care. However, the medical perspective of disability remains wedded to the economy, whereby personal capacity and ability are often assessed as incapacity and inability so as to determine a person's eligibility for financial assistance and benefits, and access to personal resources. An economic view narrows the complexity of disability to limitations and restrictions, with implications of whether "flawed" people can be educated or productive.

Lack of access to adequate material resources perpetuates a charity discourse which depicts certain people as in need of help, as objects of pity, as personally tragic, and as dependent and eternal children. It is a discourse of benevolence and altruism; and like with the responses of early Christian communities, this discourse serves a complimentary relationship between perceivably helpless people as instruments for good and virtuous works of mercy and compassion by the more "privileged" members of society.

The Rights-Based Model of Disability

In more recent times, however, the notion of 'disability' has come to be conceptualised as a socio-political construct within a rights-based discourse. The emphasis has shifted from dependence to independence, as people with disability have sought a political voice, and become politically active against social forces of disablism. Disability activists, in engaging in identity politics, have adopted the strategies used by other social movements commanding human and civil rights, against such phenomena as sexism and racism. And these strategies have brought gains, but within certain limitations.

From the mid 1980's, some Western countries like Australia have enacted legislation which embraces a rights-based discourse rather than a custodial discourse; and which seeks to address issues of social justice and discrimination. The legislation also embraces the conceptual shift from disability being seen as an individualised 'medical problem' to rather being about community membership and participation, and access to regular societal activities such as employment, education, recreation and so on. Where access is inappropriate, inadequate, difficult or ignored, advocacy processes have been initiated to address situations and promote the people's rights.

Yet, rights-based discourse, although employed as a political strategy, has also become a way of constructing disability by locking people with disability into an identity which is based upon membership of a minority group. Entitlements thus become contingent upon being able to define oneself as a person with disability. And the conceptual barrier between 'normal' and 'abnormal' goes unchallenged, so that while one may have entitlements legislatively guaranteed, 'community' which cannot be legislated for, remains elusive.

Looking to the Future

While rights-based discourse, at a strategic level, has brought some additional entitlements to people with disability, it has not significantly altered the way in which disability is constructed and so, despite
legislative changes, some people's lives have not necessarily changed. In fact, new challenges such as genetic technology and reproductive technology threaten to further alienate the whole and integrated person (the body, mind and spirit) from the medically, or scientifically, diagnosed 'person' (the condition). We are now seeing the emergence of a genetic model of disability, a revamped medical model, which 'promises' to actually expand the population of people with disability to include people whose impairment is their 'bad' genes and their disability is the social response of avoidance, discrimination and even elimination which their impaired genes elicit in others.

Rights-based discourse fails to meet these challenges for, rather than seeking to dismantle the entire concept of disability, it actually relies upon such a construction to support its claims for rights and entitlements.

Some writers argue that we need to go beyond conceptions of constructed disability to a notion of universalism whereby, according to Canadian writer, Bickenbach, disability is actually a fluid and continuous condition which has no boundaries but which is, in fact, the essence of the human condition. And, as a condition which is experienced by us all, at some stage in our lives, disability is actually normal. This view is also supported by the Indian philosopher, Sarkar, who argues that bodily differences should not be allowed to mask our essential humanity.

At the level of our physical existence, diversity is a natural condition and the need is for us to welcome and embrace diversity outside of a hierarchical classification of difference. Yet, at another level, difference is simply a construction of ideology, not a state of reality - since we are all interconnected and have flowing through each of us the same life force. According to Sarkar, "the force that guides the stars you too". Yet, the history of disability has been a history of seeking to construct hierarchical difference out of an essential reality of oneness. The challenge is to create the reverse.

References


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