

A Way Forward: Presenting a Post-modern Framework for Disability
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Abstract: People with disability continue to be engaged in a rights struggle which is reinforced through processes of modernity. This paper reviews the modern framework and its far-reaching effects in influencing understandings of disability, using the Australian experience as an example. An alternative post-modern framework is then presented in contrast. A post-modern conceptualisation of disability is presented as a way forward for understanding disability and for application to disability studies and research.

Key Words: modern, post-modern, disability rights

A Modern Framework

Within modernity, binary notions that support an oppressive discourse are created and maintained. A binary involves two distinct, often polarised, elements. Position matters within binaries where people are categorised as either privileged or “other.” Within the position of privilege, people are politically and economically esteemed and supported by hegemonic advantage. The “other” are thought of as deviant, different, even undesirable, and are subsequently made inferior.

The maintenance of these binary notions creates a veil of concealment over the relationship inherent within such positionings, where categories of black/white, straight/gay, male/female, rich/poor, and disabled/abled hide the relationship of oppression and privilege between people within these groups (Carling-Burzacott & Galloway, 2004). Modernity separates people with disability as “other,” framing and defining them individually, excluding them from full participation in society, medicalising and commodifying their bodies and lives, and imposing deficit models with the purpose of reinforcing the existing hegemony¹. Disability in Australia has long been understood within such a deficit model produced within modernity. This understanding has subsequently infiltrated and undermined disability research, studies, and practice.

A modern framework for disability studies and research is supported by individual and medical models of disability--models that rely on meta narratives² of deviance, tragedy and the separation of “normal” from “abnormal” (Corker & Shakespeare, 2002). At the core of this framework is an oppressive discourse. Within disability studies and research, binary notions adopted through modernity’s influence result in the elevation of the privileged researcher who uses his/her position to accrue social, economic, political and linguistic privilege over people with a disability as the “other.” In this instance, researchers’ needs are promoted and advanced at the expense of people with disability. Exclusion is reinforced and consideration of systemic issues such as discrimination is nominal at best (Newell, 2005). Extreme examples of this are often cited such as the medical research in Nazi Germany where people with disabilities were exploited, experimented upon, and often exterminated.

Australian Struggles rooted within Modern Framework

Australia does not have a proud disability history. Historical struggles can be traced to the early settlement of Australia by European invaders who segregated the “insane” on hulks (large ships used to transport convicts from England) until buildings could be erected to accommodate them (State Records NSW, 2006). People with a physical disability were portrayed in terms of a “lack of worth” throughout Australian history, which depicted them as invalids and as defectives. The Eugenics movement had a strong influence in Australia in the early 1900s through to the 1930s, where widespread practices of Social Darwinism separated people with disability from definitions of humanity (Carlson, 2001).

Today, within Australian society, people with disability continue to be located as “other” and therefore remain stuck within modernity. Australians with disability are more likely to be imprisoned, institutionalised, or assaulted, receive welfare benefits, or to be restrained, sterilised, or aborted (Bolt, 2004; Dowse, 2004; Frohmader, 2002; Sherry, 2008). In contrast, their non-disabled counterparts are more likely to be found in places of higher education, in their own homes, and in paid positions of power, including positions within the disability sector (Leipolt, 2005; Goggin & Newell, 2005).

Australian disability history is characterised by objectification and control supported by tyrannical medical and professional discourses which imposed regimes, restricted opportunities, and reinforced poverty (Carling-Jenkins, 2008). People with disability in Australia have been fragmented, institutionalised, marginalised and commodified as a result. In addition, there has been no cohesive movement of influence, power and identity to support them in their rights struggles (Newell, 1996; Russell, 1998). Research into the positioning of disability and the Disability Rights Movement in Australia, revealed that the historical and continuing struggles of people with disability have been reinforced through processes of modernity (Carling-Jenkins, 2008). These processes were evident through four main themes: the denial of citizenship; segregation within institutions; living on the margins and the ‘disabled body’.

Denial of Citizenship

Within Australia there has been a disparity between the experience of the privileged who enjoy full citizenship rights without question (i.e., full political and economic enfranchisement and full participation in society) and people with disability (as the “other”) who have routinely had their humanity and capacity questioned and cost-effectiveness calculated through criteria not imposed upon people without disability (Cocks, 1996; Goggin & Newell, 2005; Jolley, 1999; Meekosha, 2000). Such questioning and calculation has led to the denial of full citizenship. While historical seclusion within institutions represented a physical separation from these rights, post-deinstitutionalisation Australia continues to routinely deny full citizenship to many people with disability.

One example of this denial is evident through the separation of privilege and other which exists within the Australian system of political enfranchisement where different rules apply to different people. This was codified originally within the *Commonwealth Franchise Act 1902* which denied voting rights to people judged to be of “unsound mind” (Goggin & Newell, 2005). There is a continued denial of the right to vote for many people with an Intellectual Disability,

Acquired Brain Injury, or with a mental illness for example (Cocks, 1996; Goggin & Newell, 2005). In addition, people with physical and sensory disabilities are faced with inaccessible voting processes and procedures (Physical Disability Council of Australia, 2000). Subsequently, people with physical disabilities have been asked to vote in venue car parks or asked to post their votes, while people with sensory disabilities have been forced to use a third party to record their vote (Crane, Clark, & Simpson, 2005; Goggin & Newell, 2005; Ozdowski, 2002). Each of these solutions has raised concerns regarding the privacy of the secret ballot system.

Another example exists within the widespread practice of routine exclusion from immigration to Australia on the basis of disability. Provisions are made for this under the Federal Disability Act and under migration laws (*Disability Discrimination Act*, 1992; Jolley, 1999). Australian immigration policies have been described as having a “eugenicist prologue, with close connections made between physical appearance, cultural capital and moral hygiene” (Jakubowicz & Meekosha, 2000, p. 6). Children and adults with disability are assumed to be a financial burden to the Australian community, and thus entry to such applicants is routinely denied (MDAA, 2005). In 2000, Shahrzad Kiane, a man granted refugee status, died as a consequence of setting himself on fire on the steps of the Australian parliament, after his attempts to have his family immigrate to Australia were rejected on the basis of one of his children having a disability (Goggin & Newell, 2005; MDAA, 2005; Newell, 2005). Kiane had reportedly worked for six years to have his family join him in Australia, but the government refused his application on the basis that his daughter’s disability would be too much of a drain on the health system (MDAA, 2005; Newell, 2005).

Segregation within Institutions

Australian institutions represented sites of total, long-term segregation from society which allowed the privileged to gain full control of public spaces, while people with disability were forced into an economic, political, and social form of invisibility. A modern framework which advocates the active favouring of the privileged at the expense and devaluation of individuals who are “othered” underlies and supports such segregation. Many different institutions were established, including The South Australian Institution for the Blind, Deaf, and Dumb for destitute people with sensory disabilities (1874), Woogaroo Lunatic Asylum for people with mental illness (1878), Kew Cottages Idiot Colony for people with intellectual disability (1887), Societies for Crippled Children for children with polio or tuberculosis (1929 – 1951), Janefield Colony for mentally deficient children (1937), and the Spastic Children Society of Victoria for children with cerebral palsy (1948). These institutions received a legislative base in such acts as the Lunacy Act 1928, the Mental Hygiene Act 1933, Mental Health Act 1959, and the Health Commission Act 1977.

The impact of such segregation included exclusion from public spaces, such as exclusion from the workforce. Within institutions, people with disability were placed outside of the receipt of welfare benefits and denied many opportunities to attain skills, including basic life skills. Institutions imposed medical, custodial, and protective models of care. Mass institutionalisations occurred, initiated through the medical framing of people with disability as biologically sick, dependent, and deviant. Parents were encouraged to leave their “sick” babies with disabilities such as Down Syndrome and cerebral palsy in hospitals and not take them home. Infants were

then ‘cared for’ within large hospital settings where staff were encouraged not to embrace or comfort them (McDonald, 2009).

Many Australian institutions have been exposed as sites of exploitation, abuse, and neglect. People were locked in cages, exposed to unsanitary conditions (such as maggots found in feeding tubes), had their teeth removed to prevent biting, were commonly raped, routinely sterilised, and were denied both medical attention and pain relief (e.g. regular pap smears or prostrate checks were not offered, and reports of children with life threatening diseases left to scream without comfort or relief have been recounted) (Grace, 2005; Dyke, 2004; Meekosha, 2000; McDonald, 2009).

Living on the Margins

The process of deinstitutionalisation, rather than heralding a new era of community inclusion and participation, introduced fresh challenges for people with disability in Australia, many of whom were moved from one form of segregation to another form on the margins of society. This exemplifies the continued influence of a modern framework – and the binaries which work to separate the privileged from the “other.” Within Australia, many people with disability were displaced without adequate resources—either personal or communal—to support their transition from institutional care. The decision to initiate de-institutionalization was based not only on the demand for social inclusion, raised through the International Year of Disabled People (IYDP), but also “reflected the greater use of pharmaceutical control agents...and the fiscal crises of the states unable to maintain high standards of large scale institutions” (Hallahan, 2001; Jakubowicz & Meekosha, 2000, p.3). This displaced people into the community which was ill-equipped, under-resourced, and inaccessible both physically and economically. In addition, the community was without a commitment to enhancing the lives of people with disability (Hallahan, 2001), and exposed many people with disability to further abuse, exploitation, inappropriate living arrangements, and homelessness (Burdekin, 1993).

In this climate, people were often isolated from each other, forced to adopt “normal” social roles, reframed as clients rather than patients, and denied their identity as disabled people. Many were placed in group homes which were often run as private ventures with a one-size-fits-all mentality (McVilly & Parmenter, 2006). Social workers and other health professionals became the experts over disability, further denying people with disability the freedom to create identities for themselves. This further exemplifies the continued influence of a Modern framework and the binaries which work to separate the privileged professional from the “other” who is denied the role of expert within his or her own life.

“Disabled Body”

The body of people with disability has historically been, and continues to be, a site of oppression in Australia. The “disabled body” is defined and controlled by the privileged, and subsequently placed in a paradoxical position. For example, people with disability are framed as an inspirational super cripp who has overcome many challenges to achieve a goal; or as a tragic burden to be pitied, medicalised, treated, and cured (Shapiro, 1994; Egan, 1998). Another example lies in the portrayal of people with disability as either a harmless child, asexual,

innocent, eternal child, needing to be protected and looked after; or a dangerous criminal who is oversexed, and from whom society needs protection (Perry & Whiteside, 2000).

The “disabled body” is used as a derogatory descriptor within Australian society, where terms such as “crippled” and “deranged” continue to be an accepted part of colloquial language (Mowbray, 2005), as well as being employed within parliamentary discourse (Goggin & Newell, 2005).

The “disabled body” continues to be vulnerable to abuse—both within the womb and throughout life. The privileged continue to control the lives of people with disability, claiming the domain of medical cures and holding the role of professional gatekeeper by controlling access to resources such as income support, accommodation, and equipment aides. People with disability (especially babies and children) are often denied simple life-saving procedures such as transplants—rejected on the basis of pre-existing disability (Mowbray, 2005).

A Post-modern Framework Alternative

This application of a modern framework to the history of disability in Australia, led me to question: what is the alternative? I began to consider elements of a post-modern framework, in contrast to those contained within a modern framework, using them to reframe disability as a modern then a post-modern concept (see Table 1.1 developed by Carling-Jenkins, 2008).

Table 1.1 Disability as a Modern and Post-modern Concept

<i>Elements</i>	<i>Modernity</i>	<i>Disability as a modern concept</i>	<i>Post-modern</i>	<i>Disability as Post-modern concept</i>
<i>Economy</i>	Manufacturing based economy	Commodified	Post material interests	Considered outside of economy
<i>Knowledge</i>	One truth	Defined by dominant	Many or no truths	Defined in many ways including by people with disability themselves
<i>Subject</i>	Autonomous, transcendental subject: unified, centred sense	Defined externally, binary notions	Fragmented, de-centred sense of self, Multiple,	Rejection of functional definitions, Focus on

	of self		conflicting identifies	identity
<i>Reality</i>	Objective reality, Logic, science and reason	Discussed in scientific, economic, medical, individualized terms	Socially constructed, Subjects created by social world, Subjectivity	Socially constructed reality imposes barriers and defines disability

References: Berger, 2003; Corker & Shakespeare, 2002; Fitzpatrick, 2001; Giddens, 2006; Giddens, Duneier and Appelbaum, 2007; Irvine, 1998 as cited in Berger, 2003; Kincheloe & McLaren, 2003; Oliver, 1993; Rader & Rader, 1998; Solomon, 2001, as cited in Berger, 2003.

Economy

Consideration of *economy* (see Table 1.1) is integral to the modern framework. Modernity was characterised by a shift from an agrarian economy to that of capital (Carling-Burzacott & Galloway, 2004). Disability as a modern concept must therefore be conceptualised within manufacturing terms, as exemplified in the treatment of people with disability as objects within medical and later within professional systems. The modern element of economy offers a limited, narrow understanding of disability.

In contrast, a post-modern framework focuses on post material interests (see Table 1.1). Post-modernity emerged as a school of thought, initially in reaction to modernity in the late 1970s, including a transformation from mass production to information technologies; a shift towards global rather than national economies, with an accompanying weakening of the nation state as a local regulator; and a decline of class politics and a subsequent rise in new social movements (Giddens, 2006). This shift removed disability from being an individualised economic consideration and invited an exploration of definitions of acceptance outside of the economy. Disability as a post-modern concept embraces the complex, interactive dynamics of disability. The implication of this framework is particularly pertinent to people with severe developmental and physical disabilities who, under the modern framework, have been ignored for their apparent lack of economic contribution. Historically, this led to routine institutionalisation.

Knowledge

A modern framework focuses its understanding of *knowledge* (see Table 1.1) on one truth, defined by the privileged. This truth for people with disability has involved the imposition and maintenance of essentialist descriptors, limiting the power of people with disability to claim anything other than these restricted definitions for themselves, as exemplified within each of the four themes in the previous section. Socio-politically these descriptors have been used to “rationally” explain the inferior health, economic, political and social status of people with

disability. Operating within this modern framework, disability is conceptualised by hegemonically esteemed groups who claim a position of social, economic, political, and linguistic privilege at the expense of those people with disability who were subsequently disenfranchised (from the polity) and dispossessed (of resources including those of psycho-materiality).

A post-modern framework portrays knowledge as embracing many or no truths (see Table 1.1). Accompanying post-modernity was a shift in emphasis from scientific absolutisms to narratives, and from expert-knows-best to a shared basis for knowledge (see Lyotard, 1979). Within the post-modern framework, definitions give way to descriptions, absolutes give way to fluidity, and constricted narrowed views give way to opportunities for inclusivity. Disability as a post-modern concept is therefore more fluid and less descriptively-defined concept that opens up and explores opportunities for genuine inclusion and engagement in relationship. Disability is conceptualised and defined through multiple identities, including most significantly by people with disability themselves. A post-modern framework enables definitions that explore the paradox of disability (Dempsey & Nankervis, 2006). Knowledge within this framework is a process and a journey, rather than a set entity.

View of Society

Society, as viewed through the modern framework, is portrayed in terms of certainty, progress, absolutisms, and reductionist philosophies (see Table 1.1). When disability is considered within such a framework, functional definitions, prescriptive treatments, categorisations, and narrowed operating agendas are imposed. Institutions emerge to segregate people with disability, and strict definitions guide entrance to social systems such as receipt of welfare benefits and immigration.

In contrast, a post-modern framework views society within multiple meanings, ambiguity, diversity, difference, and even contradiction (see Table 1.1). A post-modern society is characterised by dynamic and fluid interactions (Giddens, Duneier, & Applebaum, 2007). A breaking up of grand narratives occurs (see Lyotard, 1979). Disability within this context celebrates difference, embraces fluidity, and can be understood in terms of relativity, and social and cultural contexts. This framework emphasises the need for micro theories to understand the nature of “difference” (Barnhart, 1994). Sherry (2008) exemplifies this application of a post-modern framework to disability in his discussion of disability and diversity:

“Disability is a diverse experience. It affects some people’s minds, some people’s senses, other people’s bodies, and so on. Someone who is hard of hearing is likely to have very difference life experiences from someone who is blind, or another person who has a developmental disability. And they all will have different life stories to another person who has a serious mental illness or someone who has end-stage cancer. Even among disabled people, there are huge differences. We need to be mindful of the diversity among disabled people as one of the starting points for understanding any particular disability” (p. 5).

Subjects

A modern framework categorises *subjects*, bounding them within limited binary positionings (see Table 1.1). Subjects are autonomous, unified, and have a centred sense of self—external definitions are imposed, accepted, and adopted internally. For disability the implication is that people, both categorised within disability and without disability, are left with nothing but this language with which to define themselves (Carling-Burzacott & Galloway, 2004). Hierarchical social relations where disability is portrayed undesirably are reinforced. A binary positioning of powerful/powerless is perpetuated through the modern framework.

As an alternative, a post-modern framework promotes a more fragmented, decentred sense of self, which accepts multiple, conflicting identities (see Table 1.1). This framework frees subjects from the modern binaries and the power relations they perpetuate. Lyotard (1979) explained the mobility of self and the accompanying fluidity of power:

“A *self* does not amount to much, but no self is an island; each exists in a fabric of relations that is now more complex and mobile than ever before... No one, not even the least privileged among us, is ever entirely powerless.”

Foucault contested the traditional (modern) view of power with its equation to control, as well as institutional forms of power (embraced within the modern framework), presenting power as decentred, pluralistic, and mutually constitutive (Racevskis, 2002; Seidman, 2004). The application of this to disability involves the rejection of externally imposed definitions, replacing this with a focus on identity.

Definitions of disability are “unstable and open to contestation” according to Sherry (2008, p. 11) who advocated exploring the nuances, subtleties and contradictions inherent within (a post-modern understanding of) disability, rather than consolidating disability as a fixed identity (as a modern understanding). In addition, a post-modern understanding acknowledges that disability “occurs alongside multiple other identities (such as sexuality, race and ethnicity, socioeconomic status, etc.)” (Sherry, 2008, p. 75). This enables the concept of disability to be freed from essentialist descriptors.

Reality

Reality within a modern framework is ruled by objectivity, logic, science, and reason (see Table 1.1). The reality of disability then is couched in scientific, economic, medical, and individual terms. This underlies all four themes previously discussed.

A post-modern framework promotes reality as socially constructed, views subjects as creations of the social world and embraces subjectivity (see Table 1.1). Disability within this frame is then considered as involving social construction. The implication is that we are encouraged to embrace subjectivity, and to focus, for example, on the deconstruction of the binaries created within modern society.

A Way Forward

Considering disability within this framework reveals a way forward for conceptualising and understanding disability within disability studies and research. Disability becomes a relationship not a binary, an actor in power not exclusively bound within institutional systems, a complex, multi-faceted dynamic not an entity summarised within narrow functional definitions, a fluid existence (that intersects with gender, religion, and other characteristics) not a static category, and an embrace of difference, identity, diversity and culture not a prison of hegemonically-imposed assumptions. Within this new framework, our focus in understanding disability shifts from categories, functions, oppressive discourses, and reductionist philosophy. Disability becomes understood through actions and relationships that promote a personal, political, and moral commitment to a post-modern conceptualisation of disability. Teaching disability studies from a post-modern conceptualisation becomes a “way of knowing,” an imparting of multiple knowledges rather than a prescriptive schedule of facts and theories (as supported by McRuer, 2009). Within Australia, there are very few disability specific courses, and where such curriculum does exist it is often placed within Faculties of Medicine with an inevitable emphasis on healthcare. Australian publications representing disability studies are also limited (Lester, 2004).

Students of disability studies should be led to identify and confront the binaries, barriers and oppressive discourse surrounding disability within the context of the complex societies in which we live. Conway’s (2009) work on multiculturalism and disability is an important contribution to this way forward, where an emphasis is placed on preparing students to recognise and conceptualise diversity and therefore on the oppression experienced within diversity. Disability studies must challenge the deficit models which individualise disability and actively display a commitment to a post-modern agenda for disability. Jakubowicz and Meekosha (2000) described the role of disability studies as opening-up “ways of examining cultural diversity that cannot otherwise be approached” (p. 1).

The role of disability studies must include the encouragement and facilitation of an alternative world view which embraces disability as a diversity, moving beyond borders and pathology. Such a curriculum needs to be tied to action, or it is “parasitic” (Mackelprang, 2009). Within disability studies the role of academic and activist becomes a fluid category—a partnership (Mackelprang, 2009).

Closely linked to the study of disability is its research. There is a long history of challenging the role of researchers, particularly researchers without a disability. Stone and Priestly (1996), for example, advocated that researchers without disability needed to adopt a position tied to political action, where oppression is challenged and there is a commitment to the emancipation of people with disability through research (see also Priestly, 1997; Swain & Cameron, 1999). Oliver (1999) also stressed the importance of disability research where researchers position themselves clearly within society. The post-modern framework gives disability researchers such a position.

Disability research when conceptualised through a post-modern framework demonstrates a commitment to action. This action involves an active engagement in relationship through challenging the binary of researcher/researched for example. This also means engaging actively with other social movements and interacting with the nexus of oppression (e.g. women with

disability) (see Carling-Jenkins, 2008). Post-modern disability research values studies of the past that propose to prevent repeating mistakes in the future. Disability research should increase consciousness and expand knowledge as defined by multiple dimensions (see Mackelprang, 2009). Post-modern disability research becomes a platform from which dynamic definitions can be practiced, barriers which exclude and marginalise can be challenged, and the nature of difference can be explored encompassing identity and diversity.

Conclusion

This paper has presented the Australian experience of disability through four themes – the denial of citizenship, segregation in institutions, living on the margins and the “disabled body.” Each of these themes represented an understanding of disability that was founded within a modern framework. Modern and post-modern frameworks and conceptualisations of disability were then contrasted, with an emphasis on themes that will enable understanding of disability, as well as studies, research and practice, to move forward.

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End Notes

¹Hegemony represents the projection of a world view which permeates the social consciousness and becomes accepted within society as common sense.

²A meta narrative is a story (narrative) that provides a generalised, unifying explanation of the structure of society, including the justification of power structures within society.