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Challenging the Authority of the Medical Definition of Disability: an analysis of the resistance to the social constructionist paradigm

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ABSTRACT *This article attempts to explain why the social constructionist paradigm has failed to replace the medical model in American disability theory. The social movement led by American disability activists attempted to reframe the definition of disability using a minority group model based on the social constructionist paradigm. This paper argues that the disability movement was unable to successfully advance the social constructionist paradigm because the activists accepted the Americans With Disabilities Act (1990) despite its ideological basis in the medical model of disability, and the social constructionist theory does not adequately account for the importance of structural constraints to redefinition.*

Introduction

Over the past century, the analytical frameworks that have been applied to disability theory have undergone numerous alterations. Many of the paradigms once used to define disability have not only been rejected, but in some cases, characterised as indicative of narrow-mindedness or even prejudice. Oliver (1996) describes these metamorphoses in the literature as evidence of a major transformation in disability theory from a strictly medical definition of disability to a host of new paradigms that have yet to fully develop. In the wake of these changes, Oliver predicts the emergence of three types of inquiries into disability (the ontological, the epistemological and the experiential), each attempting to replace the traditional, medical approach. One ontological method that would have seemed likely to take a strong hold on the discipline is one that would define a disability not as a medical condition residing in the individual, but as a social construction that may even be legitimating a systematic form of inequality between the disabled and the non-disabled. Yet, although this school of thought sometimes referred to as the minority group model is rich in sociological tradition and has, indeed, been applied by many theorists to disability studies (Gergen, 1985; Fine & Asch, 1988; Scotch, 1988; Oliver, 1996; Brzuzy, 1997), it has not been successful in completely usurping the

authority of the medical interpretation. Gordon and Rosenblum (2001) have contended that this is largely a shortcoming of American sociology, quite unlike the British literature, which has placed greater emphasis on the view that a disability is a social construction. This paper will argue that the social constructionist doctrine on disability has failed to replace the medical model in America for two major reasons. First, despite the momentum that was achieved in redefining disability among academics and political activists, the landmark civil rights declaration, the Americans with Disabilities Act (1990), was won only through a costly compromise that effectually led to an ideological surrender to the same medical model of disability that it had attempted to replace. Secondly, although the social constructionist view of disability has been well articulated by many theorists, there has been a general neglect of the importance of social structure in dictating the legitimate definition of what it means to be disabled and how disability arises.

These two interrelated points will be used to explain a theory of why the social constructionist definition of disability has not earned the same legitimacy that the medical model definition has possessed throughout most of modern history. The first argument which is essentially a critique of the ideological basis of the Americans With Disabilities Act, seeks to explain why the American disability movement may have accomplished an important legal victory, but lost in its broader effort to transform the way in which most people conceptualise disability. The second argument that the minority group paradigm did not adequately account for structural resistance to a redefinition of disability, examines some key difficulties that were encountered by the disability activists who sought to develop a minority group perspective on disability with a basis in the theory of social constructionism. Those problems will be shown to center primarily upon the weakness of structural considerations not in the essential framework of the social constructionist theory, but rather in its compatibility with a progressive social movement.

The Dominance of the Medical Model

Early twentieth century sociological discourse on health and illness generally did not consider a disability as a defining state. Disabling conditions such as blindness, 'mental retardation', or paraplegia were generally lumped together with other conditions that were not necessarily capable of causing disabilities. Those conditions that were disabling were often referred to in crude terms that described physical appearances or functional inabilities in a very simplistic manner. Terms such as 'cripple', 'mongoloid', 'dwarf', 'peg-leg' and 'deformed' were somewhat commonplace in the most academic of literature. Parsons (1951) took a functional approach to health and illness. He treated an illness as a social role with precise expectations and limitations. According to the theory, the sick are exempt from the obligations and responsibilities that most members of society are expected to hold. Their state is generally considered to be undesirable and, for that reason, they are expected to seek professional assistance to bring relief to their situation. For several years, Parson's work was considered to be the authority on disability research, but his functional approach to health and illness came under harsh criticism in the 1960s

and 1970s, partly due to its overly reductive nature. More recently, Oliver (1996) has claimed that his work does not consider the actual experiences of people with disabilities and that it holds a bias to medical institutions.

Deviance theorists also began to emerge as major contributors to disability theory. Lemert (1951) made a distinction between primary deviance and secondary deviance, the latter of which may cause rejection of the deviant person by society as a result of labelling and stereotyping. Goffman (1963) saw the abnormal nature of people with disabilities as a source of stigma among the non-disabled. He believed that stigma acted like a mark or a sign that the person was different and perhaps harmful to the non-disabled. Friedson (1965) helped to popularise the notion that people with disabilities are social deviants, by using the term in the context of rehabilitation. His overall premise was that if it can be identified what it is about some people that bring them into conflict with society's morals or values, it will be evident what needs to be changed in order for them to become accepted by the non-disabled.

Despite the popularity that the deviance writers enjoyed, their theories were firmly based on the notion that a person with a disability has been inflicted with a personal tragedy (Oliver, 1996). In time, this characterisation of the disabled became a matter of heated debate. In the 1970s and 1980s a new perspective on disability began to materialise that considered external factors as the source of disability, rather than individual impairments or deficiencies. At this time, the disability movement was coming alive in America. People with disabilities had begun to fight private institutions and the United States Government for their civil rights. As a part of that process, they successfully transformed the traditional notions of disability that treated it as a personal phenomenon, into a new wave of disability theory that treated people with disabilities as members of a minority group that have been discriminated against and prevented from becoming 'normal' members of society. They pointed to stereotypes and prejudice as the culprit behind the construction of 'handicaps' and barriers in society that keep certain people from becoming fully integrated and accepted. It is at this juncture that the issue of how disability should be defined became a popular political issue, much as it had become so among disability theorists. By 1990 the disability movement had achieved an apparent victory with the signing of the Americans With Disabilities Act. The legislation was soon touted as an overwhelming achievement of hard earned civil rights for people with disabilities.

The Americans With Disabilities Act targeted the elimination of discrimination against people with disabilities in four major areas: employment, state and local government, products or services offered in the private sector, and telecommunications. On the subject of employment, questions such as whether or not a person has a disability, or examinations that would explicitly test for the existence of a physical impairment were to be eliminated. In addition, it required that employers make 'reasonable accommodations' in the workplace to people with disabilities, however, this is true only to the extent that it does not cause 'undue hardship' to the employer. This is a gray area of the title that has been the subject of some controversy. The legislation further required that state and local governments ensure

that none of their services are discriminatively offered to the non-disabled majority. To this end, it mandated that state and local buses, trains, parks, programmes and other services be made accessible to the disabled, as well as public buildings or meeting places. It also required that local governments assess their accessibility status on a regular basis and make the reports of their progress public. In the private sector, businesses were deemed responsible for making reasonable accommodations to ensure that all goods and services are available to people with or without disabilities. Finally, the law held that all public telecommunications be made accessible to people with disabilities. This was to include modifications such as volume control devices on telephones, easier access to the buttons on public phones and expanding the allotted space in phone booths.

The Americans With Disabilities Act is a finely crafted piece of legislation that is not simply reflective of only one political ideology. Instead, it is a combination of various political schools of thought wrapped up into one piece of legislation. Its strongest asset is probably the bi-partisan angle that made lobbying somewhat easier than might have been anticipated. It was appealing to liberals because it spoke to the notions of freedom and liberty being available to all citizens, and because it called for the government to take a role in ensuring that the disabled would be granted equal rights. At the same time, however, it was not entirely unappealing to conservatives, who normally are opposed to such an expanded role of the government. This was likely due to the fact that it did not include an Affirmative Action plan, or any other such measure that would have required private businesses to expend too many additional resources. Furthermore, there were exact lines in the legislation, such as the requiring of only 'reasonable accommodations' and the prevention of 'undue hardship' to employers, that guaranteed that the private sector would not need to sacrifice too much of their freedoms or devote an excess amount of resources in order to be in compliance. To the extreme conservatives, and perhaps, the owners of some private businesses in America, this still might have seemed to be a case of the government overstepping its bounds. With the growing success of lobbyists for people with disabilities gaining the support of many policymakers, however, it may have seemed somewhat anti-American to refuse the idea that people with disabilities should be granted such freedoms.

The passing of the law was, indeed, a historic achievement for disability activists because it granted legitimacy to the civil rights of people with disabilities. Nevertheless, its approach to the issue of discrimination against people with disabilities is still grounded in the medical paradigm. Silvers (1996) has contended the opposite, that through the passage of the Americans With Disabilities Act, there has, indeed, been an acknowledgment of society's culpability in creating disability. Although it is true that this revelation about the origin of disability has inspired some academics and disability activists to reject the medical model of disability, a critical examination of the legislation and its early years of enforcement may be argued to reveal that the medical model has remained largely intact, despite the apparent victory for the disability movement.

Instead of defining disability as a result of the barriers and 'handicaps' created by society, the Americans With Disabilities Act reproduces the medical definition by

defining it as an inability to perform a 'normal' life activity. By maintaining this medical terminology, the idea that a disability is an individual problem is reinforced by the legislation. In addition, it suggests that the physical limitations of the disabled are what cause people to be discriminative. This stands in stark contrast to the minority group position on disability, that discrimination is a product of the stereotyped notions about people with disabilities. More explicitly, it implies that employers discriminate against people with disabilities because they do not believe that they can perform certain job functions, and not because they hold negative stigmatised beliefs about what it would be like to work around people with disabilities or how they think their customers will react to them (Hahn, 1994). Minority group disability theorists adamantly insist that discrimination occurs as the result of prejudice. Allowing the individualised notion of disability to prevail allows policymakers and employers to conceptualise disability as a misfortune that some people encounter, which legally only requires them to compensate by extending the reach of their services. It shows no recognition of the disability activists' contention that civil rights are being breached due to negative ideas and images that the non-disabled have about people with disabilities, nor does it show an understanding of the institutionalised nature of discrimination against people with disabilities.

Another troubling issue is found in the fact that only 'reasonable accommodations' are necessary and that employers should not have to suffer 'undue hardship'. The Equal Employment Opportunity Commission, the United States government's main institution for civil rights prosecution, has been delegated the authority to handle lawsuits, seek settlements and provide the public with information on Title I (Employment) of the Americans With Disabilities Act. Although the commission has the responsibility to set forth interpretive guidelines for the enforcement of the law, it effectually shares its power with the federal courts that make the ultimate decisions on cases that proceed through litigation. Since the inception of the Americans With Disabilities Act, the commission has made available a number of publications that describe its position on acceptable practices and procedures under the law. A recent guidance (EEOC, 1999) on the 'reasonable accommodations' and 'undue hardship' clauses, clears up some of the debate that has surrounded the circumstances under which an employer can avoid providing an accommodation to a person with a disability. In an apparent sign that people with disabilities will be granted accommodations despite the cost to employers, the document states that the test for 'reasonableness' does not allow for a consideration to be made for economic difficulties that may be incurred by the employer. Yet in its clarification on 'undue hardship', the guidance states that financial difficulties, major structural changes and other employer concerns may indeed be used as a defense. The guidance does make it clear, however, that it is the responsibility of employers to ensure accessibility. In fact, the document expresses the commission's staunch disagreement with the decisions made by federal judges that do not go hard enough on businesses. Yet it would seem that employers must make a decision to either follow the stricter guidance set forth by the commission, or pursue a costly disagreement in the federal courts (Janero & Ketay, 1999).

As a point of comparison, perhaps we should consider how the Civil Rights Act of 1964 would have been received by women and African Americans if it allowed employers to discriminate in cases where it may cause them undue harm otherwise. Many writers, in fact, have pointed out this glaring disparity between the civil rights that were won for African Americans, and those that were achieved for people with disabilities (Alston *et al.*, 1994; Johnson & Baldwin, 1994). Clearly, African Americans and women were granted unconditional civil rights protection, whereas people with disabilities seem to have only won civil rights to the extent that they are not given at too great of an expense to their oppressors. From this perspective, the Civil Rights Act and the Americans With Disabilities Act have much less in common than it may appear at first glance. In order to understand why the Americans With Disabilities Act was embraced by activists despite these limitations, an analysis of the strengths and weaknesses of the ideological basis of the minority group model is necessary.

Limitations of the Minority Group Paradigm

In an effort to debunk the entrenched authority of the medical model, a social constructionist paradigm has been adopted by many disability theorists and activists. They have suggested that society normally creates a negative social identity for people with disabilities (Gergen, 1985; Fine & Asch, 1988; Scotch, 1988; Brzuzy, 1997). Through the construction of this identity, which is typically characterised by deviant or abnormal behaviour, the non-disabled majority is granted a legitimate means to exclude and isolate people with disabilities. As removed members of society, their contributions are often discredited and their successes are treated as aberrations. Likewise, the expectations of people with disabilities are chronically low, and there is an ever-present suggestion that their lives are not necessarily worth living. This identity has been argued to derive from the medical model, which defines a disability as a deficiency that restricts one's ability to perform normal life activities. By adopting the social constructionist viewpoint, theorists and activists have contended that society has created disability by choosing not to remove structural constraints that would enable more people to participate and gain access to social resources. The social constructionist approach was an effective ideological rejoinder to the established medical model. Yet the question of how to convince the non-disabled majority that society has disabled certain individuals has not been adequately resolved. The activists attempted to adopt the social constructionist theory as a basis for a minority group model of disability. They would use this model to support a plea for action to people with disabilities as a mechanism to overcome the oppression being inflicted upon them by the non-disabled majority.

While it is clear that such a transformation of the definition of disability among academics and disability activists has clearly taken hold, the disability movement appears to have achieved only limited success in changing the views of the non-disabled majority. By accepting the reward of civil rights protection without insisting that the medical model be publicly dismantled, the hopes of the disability activists to change the views of the broader public may have been sacrificed. The

willingness to make this concession may have stemmed from the belief among social constructionist theorists that society will change its perception of disability if it is merely demonstrated that the prior notion has been made unjustly. From a structural point of view, it would seem to take much more to convince a dominant group in society that it needs to redistribute power and access to its treasured resources. The more desirable arrangement to the non-disabled majority is one that maintains the superiority of people with 'normal' abilities. As a result, the disabled are typically described as dysfunctional and are often perceived to be incapable of understanding the world in the same way that 'normal' people do. Although social constructionists argue that such judgements regarding how people should be able to think or act are subjective notions that stem from dominant social ideologies, they may be said to underestimate the extent to which those ideologies are created and legitimated by the non-disabled majority because they best serve their interests.

Similar conclusions may be drawn from the social constructionist view on the formation of the disability identity. Berger and Luckmann (1966) refer to identity as a social phenomenon created by the theoretical interaction between language, the social structure and individual consciousness. The melding of these social dynamics creates a dialect of communication for reference to a type of person. That dialect, in turn, serves to reinforce the ideas and images present in its creation, onto the actual person and further perpetuate its reality. Berger and Luckmann do not, however, see it as a pre-determined outcome, i.e. their inclusion of the role of individual consciousness. Instead, they see identity maintaining a constant state of flux, which can be affected by the individual as well as external factors. While it may be said that at its core the dominant perception of identity consists of a discourse between language and the social structure, the social constructionist theory maintains the optimistic viewpoint that the individual is capable of choosing to resist that image or take on the ascribed role. It is evident that the disability activists embraced this notion in their very public struggle for civil rights that was so noted for its leaders who refused to accept the standard role of the disabled. Despite the apparent value that this method had in persuading American policymakers, it may be said to have perpetuated the notion that people with disabilities must take it upon themselves to defy the expectations of the non-disabled. Due to this belief, the minority group model theorists may have compromised their position that society has been exclusively to blame for the unequal position of people with disabilities. To the contrary, the absence of such an uprising of people with disabilities in the past could just have easily been blamed for the unequal status of the disabled. This is an important element of the social constructionist theory that seems to have weakened the bargaining power of the disability activists and also led to a costly similarity to the medical model, in the view that an individual alone may have the capability to overcome disadvantage. Had the disability activists focused more on their core position that language and the social structure form a dialect that is largely reflective of the broader society's values, morals and interests, they may have considered more radical measures that would have made them reluctant to accept civil rights at the expense of a compromise on the definition of disability.

Another problematic aspect of the minority group paradigm is its assertion that people with disabilities actually redefined themselves, and that the movement really stemmed from the 'community' of people with disabilities. Scotch (1989) cites the wide geographical distribution of people with disabilities across the country; the lack of shared characteristics among the activists (aside from their disabilities); and the differences between the accommodations they require specific to their disabilities; all of which likely contributed to a less than uniform effort among disabled individuals seeking a new public perception. Zola (1982) has further pointed out that many people with disabilities are isolated from the outside world, making it difficult for them to participate in such a movement. This inevitably raises the question of whether the social constructionist paradigm allows for the redefinition of a group of people through the actions of a few. This may be a point of inconsistency between the minority group model and the social constructionist theory. Clearly, the minority group approach must hold that a social movement is capable of achieving group redefinition, but it is not quite clear that the traditional view of social constructionism would consider that new definition to be equal among the competing identities that derive from language and the social structure.

Finally, the debate between the medical model and the minority group model is essentially a struggle for legitimacy. The long standing, unequal position of the disabled has been adequately shown by the social constructionists to rest upon the hegemony of the medical model. In order to alleviate that inequality, a transformation of the ideological basis of legitimacy needs to take place. Consider the traditional social constructionist view on legitimation:

Legitimation produces new meanings that serve to integrate the meanings already attached to disparate institutional processes. The function of legitimation is to make objectively available and subjectively plausible the 'first-order' objectivations that have been institutionalized ... Legitimation 'explains' the institutional order by ascribing cognitive validity to its objectivated meanings. (Berger & Luckmann, 1966, pp. 92, 93)

The 'meanings already attached' are those negative images that come with the label of disability. Perpetuated by the media, culture and popular literature, these meanings are the sources of misconceptions and stigmatisation. The 'new meanings' adapt the nature of these ideas and crystallise the common ideology of disability. This ideology is then called upon in common conversation and behaviour in society, strengthening the notion and increasing its acceptance. It is then not only commonly accepted, but also entirely plausible in the minds of those that incorporate it. At the point in which the notion has become fully legitimated, it becomes a strong ideological force that cannot be easily transformed. The reign of the medical model definition of disability has been predicated on its ownership of this legitimacy. As the social constructionist theory predicts, language and the social structure operate to define identify and meaning. This would lead to the conclusion, therefore, that the social constructionist paradigm will only gain wider acceptance if it is able to transform the ideological basis of legitimacy on the definition of disability.

Conclusion

The medical model of disability has been the legitimate conceptual paradigm for understanding disability throughout the history of modernity in America. The attempt to replace it with a definition of disability based on a social constructionist interpretation known as the minority group model, does not appear to have been completely successful. Despite the passage of the Americans With Disabilities Act of 1990, it remains unclear whether the movement has earned legal civil rights protection alone, or if it has accomplished an ideological transformation of the established disability identity. This paper has argued the position that the Americans With Disabilities Act granted legitimacy only to the claim that people with disabilities deserve civil rights protection. Due to its failure to reject the medical model definition of disability, it has essentially provided a benefit to people with disabilities under the condition that they continue to be defined as abnormal members of society. This is illustrated by the criteria that the Americans With Disabilities Act sets to define people with disabilities. According to the legislation, the disabled are those who are incapable of performing normal life activities. This definition is perfectly consistent with the medical model, which has been said to individualise the nature of disability. In addition, the Americans With Disabilities Act fails to provide unqualified civil rights protection to people with disabilities. This is in notable contrast with prior civil rights acts that granted such freedoms for other disadvantaged members of society. It was further argued that this unequal compromise was struck between the disability activists and policymakers, due to a number of different weaknesses in the ideological basis of the minority group model. Key among its deficiencies is the potentially idealistic notion that the non-disabled majority will not resist a redefinition of disability at the cost of its own power and dominance. Inconsistencies between the minority group paradigm and the social constructionist theory on the role of the individual, were also cited as possible reasons why the disability activists may have settled for a qualified victory.

In conclusion, it would appear as though the work of the disability movement has not yet been completed. In order to achieve the transformation of the disability identity from one that invokes notions of personal tragedy to one that reflects a history of prejudice and oppression, a visible shift in the ideological basis of the legitimate definition of disability must be achieved. While recent history may suggest that this transition cannot be accomplished due to the strength of the resistance to such a change, a future social movement may be capable of achieving success. The findings of this analysis would suggest that such a movement would need to develop a strategy that incorporates a viable response to structural resistance. It would further need to define success only upon validation of a new and legitimate definition of disability. Accepting a partial victory may be tantamount to a sacrifice that would undermine its mission.

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