

The (Mis)interpretation of Disability: Why Quantitative Research May be Ineffective in American Politics

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Abstract

In America, there are widespread historical, cultural, epistemological, and ontological research conducted about the problems associated with racism, sexism, classism, and other types of prejudice; however, there is paucity on disablism. There has been insufficient research on disablism and typically, it has been researched as a health, economic, technical, or safety issue rather than prejudice. This paper focuses on aesthetic, ontological, epistemological, and ethical questions raised in research methods towards the politics of disability. More importantly, the paper will investigate the types of knowledge and paradigms that construct disability policy stemmed from the ostensible research methods on disability. The viewpoint of research methodology in constructing an identity politics of disability has continued to be rooted in a narrow medical paradigm and continues to perpetuate prejudice (unintended) towards people with disabilities. Lastly, this paper will discuss the use of testimony and case studies as possible research strategies that would promote a positive and diverse approach and discipline of human understanding towards people with disabilities in America.

Introduction

There are more than 50 million Americans with a disability, yet disablism¹ is still one of the oldest forms of discrimination and one of the most difficult issues to tackle in American policy. Disability policy in America “remains fragmented...millions of dollars are being spent on social welfare, vocational rehabilitation and employment programs that virtually all observers agree have done little to better the lives of the disabled” (Switzer, 2003). ‘Progressive’ policies in the last 25 years have attempted to eradicate disablism; however, disability policy continues to be addressed in a narrow ontological research framework of what the problems/solutions are in the politics of disability with neglect to sociocultural¹ context (Pugach, 2001). The major quandary is that most instrumental disability policies such as the Americans with Disabilities Act of 1990 (ADA) is written and researched from a specific interpretation utilizing a medical

¹ This paper defines disablism as a social phenomenon and a form of societal oppression towards disability using *impairment* as a negative ontology to define what it means to be disabled in society. For more information on disablism, please refer to Gillinson et al (2004). *Disablism*.

paradigm of how to provide ostensible accommodations by using an anthropocentricⁱⁱ framework of policy without including the voices of the people with disabilities.

It is, then, not surprising that “until the 1980’s, historical assessment of disability came almost exclusively from outsiders: educators, doctors, and policy makers” (Burch et al 2006:128). This means that for nearly more than 200 years, the politics of disability has become an archaeology of knowledge researched by non-disabled people from a closed-system approach where disability “is not just a tool of analysis, but part of the object of study” as an ostensible ‘value-free’ perspective on the politics of disability (Sayer 1992:178). American policy has resorted to a medical paradigm as an objective “search for translation, convertibility, mobility of meanings, and universality...when one language (guess whose?) [sic] must be enforced as the standard for all translations and conversions” (Haraway, 2003:26) especially since non-disabled researchers excluded the voices of the disabled person in order to write policy that would determine lives of others. This approach has been ineffective in the politics of disability as it continues to “present a partial and to a certain flawed understanding of the relation between impairment, disability, and society” (Terzi, 2004).

Disability policy continues to limit its research framework by solely relying on quantitative methods and neglecting the individual’s emotive and cultural existence that have been oppressed or disenfranchised throughout history; thus also neglecting sociohistorical factors as well (Foster, 2001; Glickman 2003; Pugach, 2001; Zigmond, 2003). This paper argues that current policy, under a quantitative and medical/legal approach, remains ineffective and suggests that a redirection of policy by incorporating qualitative studies may be the missing link. The early efforts to study disability issues in a

qualitative avenue are inspired by impressive scholars such as Guba, Brice, Metz, and Peshkin. The effectiveness in using the qualitative model of research is also reinforced by current scholars who have confidently taken the road of sociological analysis on disability studies with profound success (Ayres, 2002; Glickman, 2003; Hall, 2002; Harris, 2003; Pugach, 2001; Knotek, S., 2003; O'Day, 2002) while other scholars criticize the usage of quantitative data in disability studies (Tindal, 2003). This paper focus towards the social construction of disability and its emphasis on the qualitative approach specifically testimonies and case studies rather than quantitatively in pursuit to consider the broader sociocultural contexts within which disability exists because rarely have these studies been extended to these areas of exploration (Pugach, 2001).

Discourse on Disability

“Nothing about us, without us.”

-The theme of International Day of Disabled Persons of 1994

This paper originates because policymakers continue to abandon the sociohistorical and sociocultural implication of disability by continuing to focus on the medical approach as the most *effective* way of researching in determining the framework of disability policy. This working paper targets aesthetic, ontological, epistemological, and ethical questions raised in research methods towards disability. More importantly, the paper investigates the types of knowledge and paradigms produced by the ostensible research methods in creating public policy with respect to the politics of disability. This paper will use the ADA as a primary example because it has been considered the “most progressive and aggressive piece of legislation...and affects the lives of 43 million persons at the time of the passage;” thus, the ADA has a huge (if not the most) impact on the lives of people with disabilities in society (Mezey, 2005:1).

Historically, disabled people are defined and treated as a homogenous group of people, which is a critical problem with current legislation and the implementation of laws and policies (Martin, 2002). The ADA are anthropocentric in a sense that the law originates from a calculated analytical research process called *rationalized* legal reasoning that results in “the lack of required, legally, correct rules, methodologies, or results...[and] is in part of a function of the limits of language and interpretation which are subjective” (Kairys, 1998:5; also See Jain, 2004). United States policy has consistently ignored diversity and has attempted to homogenize it ‘objectively’ by a number of “perceived attributes of the legal-decision making process including judicial subservience to the constitution, statutes, and precedent; the quasi-scientific, objectives nature of legal analysis” (Kairys, 1998:2).

Research in disability also stem from the ostensible use of writing as scientific inquiry to modernize and normalize the socio-historical identities and diversity of disability. Consider the apparatus of writing by non-disabled scholars as a scientific language/research and its reconstruction of the “historical, archaeological, ethological, and philosophical wealth of information” to shape disability objectively with no respect to diversity (Derrida, 1974:28). While language and writing (as research) are two distinct systems of signs, the latter’s purpose is to represent and regulate the former. Further, writing as research is the exterior representation of language and the problem of language through writing has “invaded the global horizon of the most diverse *researches* and the most heterogeneous discourses, diverse and heterogeneous in their intention, method, and ideology” (Derrida, 1974: 6, *emphasis added*). In this respect, Derrida also reveals how

the apparatus of writing (and specific types of research) can be a form of degradation and oppression, it:

commands our entire culture and our entire science, and it is certainly not just one fact among others. Nevertheless, it does not respond to any necessity of an absolute and universal essence (1974:30).ⁱⁱⁱ

And Foucault (1977:192) adds that:

the examination opened up two correlative possibilities: firstly, the constitution of the individual as a describable, analyzable object not in order to reduce him to specific features...but in order to maintain him in his individual features, in his particular evolution, in his own aptitudes or abilities, under the gaze of a permanent corpus of knowledge...

Thus, disability policy, through a specific apparatus of research (or examination), historically has shaped the construction of disability; a tool used by scientific technicians as a regulation and exploitation of knowledge and power (Derrida, 1974, p. 125; Foucault, 1977:27; Jones, 2002; Tremain, 2005:13). This is done through the various court case decisions and disability policies such as the ADA.^{iv} Paul Longmore, a prominent Disabled historian points out that “[s]ome 50 acts of Congress passed between 1968-1990 represented a major departure in lawmaking and policymaking regarding persons with disabilities. This body of legislation did not propose to provide more ‘help’ to persons regarded as disadvantaged by disability. Instead, it reflected and sought to implement a fundamental redefinition of what disability is, of what it means to be disabled in American society” (Longmore & Umansky, 2001, p. 10).

In *Disabling Interpretations*, Susan Mezey (2005) uses three important court cases known as the ‘Sutton Trilogy,’ that narrowly shaped what it meant to be disabled. Specifically, the Supreme Court contended that if an “impairment was correctable, they were not substantially limited in any major life activity and thus did not meet the definition of disability” (Mezey, 2005). In other words, the Supreme Court determined objectively that once an impairment is (and I add, ostensibly) ‘corrected’ then they were

not limited in any life activity, but the Court failed to consider the cultural implications of the correctiveness including potential discrimination towards the individual; however, because the plaintiffs did not meet the definition of disability, they were not applicable to the protection under the ADA (National Council on Disability, 2004:46). This takes out the power and privilege from the person with disability to the Courts to determine their status as a wage worker in today's society, their economical status, and ultimately their livelihood when discussing what it means to have a life activity in accordance to the Courts.

In the ADA, the objective term 'disability' means an individual with "a physically or mental impairment that *substantially* limits one or more of the major life activities of such individual" and a qualified individual with a disability is "an individual who with or without *reasonable accommodation*, can perform the *essential* functions of the employment position that such individual holds or desires" (Department of Justice, 28 CFR 35.104). 'Reasonable accommodations' and 'substantially' are one of the numerous ostensible empirical terms that are derived from previous court cases decisions to shape the politics of disability. The employers (non-disabled people) are given the authority to determine what the measurement of what is 'substantial' and what is 'reasonable' under the ADA rather than the employee (person with disability). Unfortunately, these terms are measured and researched through a narrow medical model and documented through the apparatus of writing by non-disabled people. The term of 'social inauthenticity' presents the dangers of writing in neglecting historical and cultural diversity by being "no longer linked to our past by an oral tradition that implies direct contact with others, but by books amassed in libraries...books from which criticism endeavors with extreme

difficult to form a picture of their authors” (Rousseau in Derrida, 1974:136-7). This relationship between the disability and policy/medical professions/research community are divided by the apparatus of writing as:

the power of writing in the hands of small number, caste, or class, is always contemporaneous with hierarchization...it is at the same time distinction into groups, classes, and levels of economico-politico-technical power, and delegation of authority, power deferred and abandoned to an organ of capitalization (Derrida, 1974:130).

“When others speak for you, you lose.”

-Ed Roberts, 1993 First National Assembly Disabled Peoples' International

The ability of social agents such as courts and policy-makers to ‘speak,’ regulate, and normalize diversity through research is similar to the efficiency and authority to define disability as a form of social power (Conrad & Schneider, 1992:268; Lauderdale, 2003:224). Also, the medical authority is evident by the medical profession to individualize disability as a pathological condition in need of medical intervention without considering the broader aspects of disability as prejudice. For instance, in order to receive services under the ADA, one must subsequently consent to having a disability in a specific medical criterion and norm to policy-makers’ definition of what disability is. It is, then, not surprising that many people including Ed Roberts has affirmed that once you let them [outsiders] speak for you, you lose. Disabled people lose a significant cultural and historical importance of their own identity by allowing policy-makers to place them in a category that can be researched upon.

The exclusion of sociocultural factors in diverse subjects is regulated when medical definitions and intervention as social control “seeks to limit, modify, regulate, isolate, or eliminate deviant behavior with medical means and in the name of health” (Conrad & Schneider, 1992, p. 29). The subject is researched through audiologists, counselors, employers, teachers, court-case decisions, and policy-makers as technical

objects of power to achieve political consequences that are totally unrelated to the individual (Lane, 1999). These social agents of power are able to codify and normalize diversity through a 'medical' language in order to "increase mystification and decrease the accessibility of public debate" (Conrad & Schneider, 1992, p. 249).

If the current research paradigm continues under the medical framework, then, public policy will continue to regulate and normalize diversity in disability and continue to be the "legitimate conceptual paradigm for understanding disability throughout the history of modernity in America" (Donoghue, 2003). The medical language, as the power to name bodily dysfunctions, researches the disabled person by disciplinary techniques of bio-power which structure produce and optimize the capabilities of the body developing its economic utility and ensuring its political docility (Hughes, 1997). Further, the medical language used in research on disability has been historically dominated by those who regulate the knowledge as power and it is difficult to grasp the "confinement" or 'mind colonization' as Nader (2002:127) would inquire especially if it happens "slowly and incrementally over many years."

In line with Hughes and Nader, they explain that using disciplinary techniques of bio-power as scientific research to examine the body, it is devoid of history and culture. The biological and cultural identity of being Disabled is pulled apart; thus, the body as a social and historical construct is oblivious and docile. Nader (2002) explains in discreet terms that "law is a science of connections" and that public policy like the ADA is being applied as a legal concept as if they were universal, homogenous, and normalized without respect to the local context. Campos (1998:186) reaffirms this notion by explaining that:

Law is manifesting in a kind of cultural madness, where hyper rational modes of decision making are employed in a vain attempt to solve rationally what are rationally irresolvable moral and political conflicts.

Campos is on target when he explains that American Law, namely the ADA, is a result of trying to formally examine the legal system while attempting to research accurate empirical and scientific conclusions without anything like the necessary data, thus, resulting in a ritualistic elaboration of abstract rationalization.

The ADA may have accomplished an “important legal victory, but lost in its broader effort to transform the way in which most people conceptualize disability” (Donoghue 2003). Also, research policy like the ADA has dangerously assimilated the fundamental identities of a myriad of disabilities into one homogenous identity: the Disabled person. Identity politics criticize the risky research process of American policy in creating a caldron in which “inequalities of class, gender, race, age, and disability are brewed into a lethal cocktail” (Humphrey, 1999). The ADA has failed to recognize the historical timeline^v in which Disability has been modified and does not incorporate cultural indigenous values as substance; thus, it “fails to recognize the distinction between these levels” and results in the “fallacy of misplaced concreteness” (Lauderdale et al, 1983:321). By being anthrocentric, the ADA does not regard its historical praxis of hegemony and power relations as a factor in disablism. Therefore, disability needs to be addressed both historically and culturally if it wants to research and understand the “dynamics and change in the government of disability and in the process of economics and power” (Jolly, 2003). We need to research how power, knowledge, and economics are historically instrumental in the praxis of government and how they shape disablism in our society.

The narrow legal, social and medical classifications of disability identity and the anthrocentric language of medical and legal experts through research can be examined as

an ideological system that allows the ambiguous social creation of disability and its problematic policy agendas in addressing disablism. Disability remains a social construction and that in order to understand disability and to prevent bias; it is necessary to be open to the full context and experience of the sociological lives of individuals with disabilities. O'Day & Killeen (2002:13) affirms this when she explains that the ability to engage in qualitative disability studies will open locked doors of disability experience; thus, provide “a powerful means both for understanding participants perceptions and for developing action strategies that will address the problems they face” with a futuristic hope that ADA will exit from the medical model into a sociocultural paradigm to better serve the needs and expectations for the future generation. This paper turns into possible research strategies that would promote a positive and diverse approach and discipline of human understanding towards people with disabilities in America.

Future Study

“[A] politics of liberation must always begin with the perspectives, desires, and dreams of those individuals and groups who have been oppressed by the larger ideological, economic and political forces of a society....”

-Norman Denzin (1994) in K. Plummer *Document of Life 2* (2001)

If the publication of my case is dangerous, so is likewise silence.

-William Belcher (1796) in Reaume's (2006) *Mad People's History*

The use of testimonials as a critical discourse analysis in a qualitative approach provides a possible strategy in bringing “to the surface stories of those whose voices have not been heard, those who have been oppressed or disenfranchised...” (Pugach 2001).

This paper has to give due credit from feminist scholarship on the “epistemological and political significance of taking the lived ‘experiences’ of disabled people seriously” (Thomas et al, 2002:19). Using testimony as a part of disability studies would be a

possible retreat from the medical paradigm and escaping the “chains of an epistemological world in which medical dominance and the prominence of bio-psychological thought was evident” (Hughes et al 1997). In order to discuss disability, one must include the sociohistorical implications that have transpired throughout American public policy including the “way social power, abuse, dominance, and inequality are enacted, reproduced, and resisted by text and talk in the social and political context” (van Dijk, 2003:352). Testimony may provide a way how a particular experience and presence of the ‘author’ has been impacted by objective policies. Rather than abiding to the policy and texts written by non-disabled people, testimonio is framed as an “affirmation of the authority of personal experience” and way of life that supersedes the medical/legal authority of determining others’ way of life (Beverly, 2003).

It is not surprising that more and more academic scholarly articles and books rely on the use of testimony as personal narrative stories to reveal the deep rooted emotive and alienated minds of people with disabilities that have been impacted by society (Adams et al 2006; Corker & Shakespeare 2002; Longmore & Umansky 2001; Meade, T. & Serlin, D. 2006). These works uncover similar patterns of human interaction, cultural attitudes, institutional oppression, and biological stigmatization resulted from public policies. This type of research “uncovers realities that are missed in quantitative approaches” in which it is these realities that is fundamental in understanding disability (O’Day et al 2002). For too long, disability has been studied as a ‘measurement’ in the medical and legal realm, testimony as a qualitative approach is not designed to measure a phenomena, but rather it is to reveal the complexities in the disability experience. The power of testimony shifts the power to the victims so they can express the social and

political tribulations of disablism. It is their voice that serves as a starting point in determining the most effective avenue in addressing disability in public policy because it is “often the stories that stay with us as the kernel of our commitments to action” (Pugach, 2001). Possible approaches of obtaining testimony from people with disabilities can be found through (but not limited to): 1) poetry that signify the ongoing issues and frustrations from disabled people, 2) narratives as testimony that are often found in many current academic books/journals written by people with disabilities, and 3) grassroots magazines that are the ‘voice of the disability nation’ including Mouth Magazine and Ragged Edge and 4) conferences that focus on disability issues.

This paper deconstructs disability in a sense that disability is much more than just the biological impairment and to resort to scientific ontology as a basis of research for policy is ineffective. There cannot be an “objective viewpoint when the questions being dealt are about human experience and social problems” and once policy acknowledges that, the sooner they are able to focus on possible strategies in understanding disability (Gillinson et al, 2004:33). It is also important to acknowledge that “so few policy scholars have investigated policy outcomes that political scientists do not know what difference policy make on the lives of people with disabilities” (Hinton 2003). Zigmond (2003) suggests that we need to “explore new research designs and new data analysis techniques that will help us bridge the gap between efficacy findings and decision making on placements” for people with disabilities.

While it is unfeasible to include *all* ‘types’ of disabled people in a case-studies paradigm, the case-study approach offers a strong realization that there is much more to be understood when discussing disability in “dictating the legitimate definition of what it

means to be disabled and how disability arises” (Donoghue, 2003). For example, American Disabled for Attendant Programs Today (ADAPT) hosted a conference on March 19, 2006 where it was able to organize live testimonies from more than 64 people with different disabilities. These testimonies were given in front of a panel of individuals who were instrumental to disability policy including; 1) John Lancaster, Executive Director for National Council on Independent Living (NCIL), 2) Andy Imparato, President of American Association of People with Disabilities (AAPD) and Advisory Panel for the Social Security Administration, 3) Gwen Gillenwater, Senior Director for American Association of People with Disabilities, 4) Dr. Margaret Giannini, Director of the Office on Disabilities and physician, 5) Jim Ward, President of the ADA Watch and National Coalition for Disability Rights, and 6) Carol Novak, representing the National Council on Disability (NCD). These people with disabilities expressed frustrations ranging from abuse, institutional confinement, employment discrimination, and a loss of dignity from society. This provided opportunity for the policy-makers and critical role players in disability studies to examine potential patterns of prejudice and what their key concerns are in the politics of disability. Burch et al (2006) contends that “case studies of specific populations of the disabled have been the bedrock of disability history” possibly because this type of research framework will provide a sociohistorical perspective of specific populations of the disabled that may not be readily identified during testimony when discussing disability history.

This paper does not necessarily reject the quantitative approach, but rather, suggests policy-makers and researchers on disability to reconsider their research strategies including the effort to use qualitative methods or perhaps finding ways to

integrate both quantitative and qualitative methods in addressing disablism; however, the “difficulty in using these results to select ‘best practice’ sites for study is the lack of consistency....” (Smits 2004:654-5). Thus, to avoid inconsistency in mixing qualitative/quantitative research and to prevent repeated failure of policy by resorting into quantitative means in addressing disability, this paper calls for a shift of research methods by using testimony case studies as a promising vantage point in positioning our study on disability.

The qualitative approach suggests that it “can keep us focused upon the reality of the disability experience and provide a powerful means both for understanding participants’ perceptions and for developing action strategies that will address the problems they face... whereas quantitative research could not have revealed that data. Thus, it can open doors for new discoveries and unanticipated findings” (O’Day et al 2002). This paper has shown that a possible shift in research methods may disentangle the sociohistorical and sociocultural implications of disability and provide opportunity for a better overall understanding on humankind.

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ⁱ This paper refers sociocultural context as a constructivist approach of reflexivity by granting people with disabilities their rights to an identity. These symbolic patterns allow themselves to be reflective in a society to form their own specific identities, attitudes, opinions, behaviors, and knowledge as a system of values institutionalized in social systems and internalized in personalities as important fundamental identities and culture of people with disabilities (Rusu, 2002).

ⁱⁱ Laura Nader in *The Life of the Law* refers anthropocentric as the culturally biased approach of gathering information by not incorporating cultural values and ignoring millions of years of evolutionary history.

ⁱⁱⁱ Derrida comprehensively discusses human's exploitation by the apparatus of writing and uses the Nambikwara Tribe to portray the innocence of the tribe and their exploitation by Man in Chapter 1: Part II. In this section, Derrida explicates speech to writing "as a *leap*, as the instantaneous crossing of a line of discontinuity: passage from a fully oral language, pure of all writing-*pure* innocent-to a language appending to itself graphic "representation" as an accessory signifier of a new type, opening a technique of oppression" (Derrida, 1974: 120).

^{iv} Along with legal policies, it is equally as important to include educational and medical policies that are sister to the ADA including the Individuals with Disabilities Educational Act (IDEA) and Title XIX (Medicaid). Like the ADA, IDEA "reflects on the medical/public health sub model and reflects the psychological sub model in its requirements for a nondiscriminatory evaluation of the student" (Turnbull et al, 2001). The medical policies under the medical model was the "bedrock for Title XIX (Medicaid) of the Social Security Act that allot federal funds to states so that these funds may be used to maintain acceptable standards of habilitation and treatment" (Turnbull et al, 2001:199).

^v The history of disability can be traced back to 2500 B.C, as documented in the Rig-Vedas, an ancient sacred poem of India. Throughout the centuries, there have been a myriad of social perception of what it means to be Disabled and historical social processes shaped by social movements, legislative, and institutional reform.