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Intersections of disability studies and oral history.

In my essay, I want to talk about the intersections of disability studies and oral history from a theoretical perspective. First, I am going to provide background information regarding possible research paradigms regarding disability, with an emphasis on the social model of disability research. Drawing on the critiques of the social disability model, I will analyze Karen Hirsch's article and discuss the implications, as well as some of the illusions of her understanding of the role of oral history within disability studies. Throughout the text, she postulates the need to include disability issues as an analytic category in historical scholarship; and examine the role of oral history in the development of disability studies and disability history. She contemplates essential aspects of disability history and, most importantly, the implications of thinking about people with disabilities as a group.

FRAMING DISABILITY RESEARCH

The dominant representation of disability, both within sociology and culture conceptualizes disablement in terms of tragedy, the impaired body and otherness, consistently locating "the problem" within the body rather than oppressive society. Disabled people and disability theorists have sought to identify a new methodology that would provide amore accurate tool in their fight against social oppression of disabled individuals. At the same time, they strove to describe and point out some of the shortcomings of the traditional research model (Stone and Priestley 1996, p.699).

The way of framing research and policy questions is related to the theoretical paradigm from which the researcher begins (Rioux 1997). Another important aspect is the degree of social responsibility the researcher towards people with disabilities as a group, which influences the treatment, diagnosis and perception of disability, both scientifically and socially (Rioux 1997).

My aim in this section is to present four social and scientific formulations of disability that are reflected in the treatment of persons with disabilities in law, policy and research agendas, outlined in Marsha Rioux's article "When Myths Masquerade as Science..." Two of those formulations stem from theories of disability as a consequence of individual pathology and another two derive from the concept of disability as a consequence of social pathology. As Rioux emphasizes, those assumptions are neither mutually exclusive nor have they evolved in chronological order (Rioux 1997).

Rioux defines two broad approaches within the context of disability as an individual pathology, namely the bio-medial approach and the functional approach, elaborating on their shared characteristics. To start with, both follow the positivist research paradigm and approach disability as a field of professional expertise, where the unit of analysis is the individual. Both focus on prevention, including biological and environmental conditions. The disabled individual becomes the point of intervention; while his/her incapacity is established in relation to non-disabled persons. Disability is perceived not only as an anomaly, but also as a costly social burden. Finally, the inclusion of people with disabilities is relegated to the private sphere, rather than conceptualized as a public responsibility.

As for finer distinctions between the two approaches, within the bio-medical framework disability is caused by a mental or physical condition that can be prevented or ameliorated through medical, biological or genetic intervention. The aim of the researcher, therefore, is to decrease the prevalence of the condition in general population. The disabled individual, viewed through the lenses of bio-medical research perspective, is perceived as sick, injured or afflicted and research is directed to the cure. Within the functional approach, the problems that persons with disabilities experience are interpreted as a result of functional incapacity resulting from individual impairment. In order to enable the individual to become as socially functional as possible, day centers, rehabilitation centers and similar services should be made available.

Environmental approach and rights outcome approach constitute the two paradigms that define disability as social pathology. They start from a perspective which assumes that disability is not inherent to the individual; instead, they assume that disability as such is inherent to social structure. Both approaches share the belief that disability is neither inherent to the individual, nor independent of the social structure. Disability is viewed in terms of interaction between the individual and the society and recognized as difference rather than anomaly. While the social system becomes the unit of analysis, the point of intervention is located within the social, environmental and economic systems. A final comment, following from the above mentioned characteristics, is the claim that the inclusion of people with disabilities should be seen as a public responsibility.

As Rioux comments, environmental-based research is increasingly showing that the impact of disability can be lessened through creating accessible environments, adapted to enable full participation of disabled individuals. The rights-outcome approach concentrates on an analysis of how society marginalizes people with disabilities. This approach focuses on empowering disabled individuals and responding more effectively to their needs. Research based on this approach is interdisciplinary in methodology, and frames disability issues through the lens of human rights principles (Rioux 1997). The rights-outcome approach is more widely known as “disability as social construction approach” in which disability has social causes and is a consequence of how the society is organized (Oliver 1990).

As Rioux suggests, the four above mentioned approaches can be evaluated “on the degree of myopia of the disciplinary limits from which they approach disability” and argues that none of them is inherently wrong. Nevertheless, as she points out, problems begin when one particular discipline lays claims to the field of disability as its exclusive domain. She postulates that regardless of the approach used, researchers should always address the fundamental issues of disenfranchisement of disabled individuals, as well as enquire about potential directions in the battle for disability equality (Rioux 1997).

All throughout her article, Rioux expresses her strongest support for research based on the social model of disability, and views the increased interest in disability activism with hopes that the movement will “guide research community to questions worth asking” (Rioux 1997). Therefore, in the next section, I am going to devote more space to the development of social model of disability.

The social model of disability was developed in the 1970s by the activists in the Union of Physically Impaired Against Segregation (UPIAS). The model acquired academic credibility via the academic work of Vic Finkelstein, Colin Barnes and Mike Oliver. The social model is now being used by the disabled people’s movement

to distinguish between organizations, policies, laws and ideas which are progressive and those which are inadequate (Shakespeare 2002).

The core definition of the social movement can be found in the UPIAS document:

In our view, it is society which disabled physically impaired people. (...)Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation called “disability” of people with such impairment. (Oliver 1990)

The social model was of utmost importance for the British disability movement. First of all, it enabled the activists to identify a political strategy, namely the removal of barriers imposed by the society; while also giving them an impulse to pursue a strategy of social and legal change. Secondly, the social model had a huge impact on disabled people themselves; as it empowered them to mobilize, organize and work for equal citizenship and provided liberating strategies for activism (Shakespeare 2002).

The key concept, therefore, in the British model is the distinction between the impairment that people have and the oppression which they experience. Within this framework, disability is defined by activists and researchers as social oppression and not form of impairment (Shakespeare 2002). The North American approach, which provides the main frame of reference for Karen Hirsch’s article, borrows from the British approach in that it has mainly developed the concept of people with disabilities as a minority group, without redefining ‘disability’ as social oppression (Shakespeare 2002).

INTERSECTIONS OF DISABILITY STUDIES AND ORAL HISTORY

In her article, ‘Culture and Disability: The Role of Oral History’, Karen Hirsch discusses oral history’s role and relation to disability studies. She starts out with analyzing the impact of Black movement and women’s movement on historical scholarship, and points out the lack of parallel relationship between the disability rights movement and historians. She claims that people with disabilities constitute one of the “most powerless individuals in any society” and therefore it should not be surprising that disability issues have not been broadly dealt with in historical writings (Hirsch 1995). She suggests that the use of oral history methodology in disability studies could allow yet another group to ‘find a voice’, a motif definitely not uncommon in feminist interpretations of oral history. According to Paul Thompson, even though oral history per se is “not an instrument of change” it can lead to a shift of focus through which the socially marginalized groups get a chance to express themselves (Thompson 1988).

Furthermore, the introduction of the disabled/non-disabled dimension in historical studies could bring to light new issues that for the most part do not fall within the scope of research questions centered on such categories as gender, class, race, age or sexuality. Hirsch also suggests that the introduction of disability issues perspective within the research agenda might lead us to reformulate some of the findings of scholars in fields of medicine, rehabilitation, public health, special education. Scholars who treat disability as an illness, tend to focus on disability as individual pathology. Understandably, producing disability history does not usually fall within their research interests, though the knowledge they produce might provide relevant background information.

It is only recently, Hirsch claims, that the need for a broader cultural and historical approach to disability studies has been recognized. The process of recognition is closely intertwined with disability rights movement, which in turn is reflected in scholarship. Overall, medical historians have generally failed to account for the voices of the patients, service users or residents of nursing homes and treatment facilities:

(...) while there are many oral history projects that need to be done, the most important ones are those that deal with disability experiences as they have been lived by disabled people, and that can give voice and interpretive authority to people with disabilities themselves (Hirsch 1995)

Hirsch is not in favor, however, of a merely mechanical inclusion of persons with disabilities as objects of research without developing a broader perspective of disability history that would focus on everyday life experiences of people with disabilities and the meaning of a lived disability experience. If the researchers fail to do that and will choose to remain within the paradigm of the “sick role” of the disabled individual, then in Hirsch’s view this situation would be tantamount to “confusing gynecology with the study of women in the society or dermatology with the study of racism” (Eisenberg 1982).

Oral history interviews add a previously ignored viewpoint, since it was assumed that disabled people do not have an articulate view of their experiences that differs from the mainstream and/or medical view. Hirsch claims that scholars in the humanities are discovering that disabled people have a unique perspective on life informed by their disability experiences (Hirsch 1995). Among pertinent questions to be asked, the most salient one seems to be whether one can talk of disability culture. Hirsch also lists the following questions: What are the aspects of lived disability experience? What is the effect of social policies on disabled individuals? What is the cultural meaning of disability experiences? How are disabled individuals integrated into various cultural contexts? She relates the answers to those questions closely to disability advocacy and the efforts of scholars and activists to acknowledge persons with disabilities as a minority with a legal status, not individuals with private problems.

CRITIQUE

I am going to devote the last section of my essay to a critique of Hirsch’s project. I will concentrate in particular on problematizing the notion of experience upon which she bases her project and as well as her assumption that disabled individuals constitute a group that shares a common identity. Oral historians, such as Karen Hirsch, set out to find clues as to the meaning of a lived disability experience. Hirsch’s project consists in documenting the lives of those omitted or overlooked in the accounts of the past, challenging evidence produced by mainstream history. This challenge, as Scott puts it, rests its claim to legitimacy on the authority of experience (Scott 1992) and indeed, Hirsch defines the main focus of disability history as “the experience, individual and social of living with a disability” (Hirsch 1995) Hirsch never stops, however, to reflect on issues connected with privileging and essentializing experience by historians of difference like herself. As Joan Scott puts it,

the project of making experience visible precludes critical examination of the workings of the ideological system itself, its categories of representation (...), its premises about what these categories mean and how they operate, its notions of subjects, origin and cause. (...) [it] precludes analysis of the workings of this system and of its historicity; instead it reproduces its terms (Scott 1992, p. 25).

Furthermore, when Hirsch poses the question whether persons with disabilities form a group with shared experiences, by implication, she assumes the existence of this group *a priori* (Hirsch 1995). Will oral history interviews, though, reveal a group identity among such a diverse and random collection of people with disabilities? As Shakespeare points out, currently, the disability studies share the assumption “that we know who the disabled subject is, yet this cannot be taken for granted”. (Shakespeare 2002). Neither can the shared characteristics of the disability experience be taken for granted. Different impairments influence the individual in different ways; they have different implications for health and capacity but also generate different responses from the broadly defined social environment. For example, visible impairments trigger social responses while invisible impairments may not (Shakespeare 2002). Furthermore, as Mairs points out, the term "disability" is almost too broad to have useful meaning:

The realities of my life as a quadriplegic with advanced multiple sclerosis bear little resemblance to those of my 91-year-old mother-in-law, still physically robust but increasingly confused, or my 33-year-old niece who has no eyes, and none of the three of us has much in common with the African-American man mumbling and shambling down the street in front of my house. (Mairs 2004)

What is more, individuals might perceive, accept and cope with similar disabilities in different ways depending on the social and cultural context of each individual. One cannot assume that different social groups perceive or experience health, illness and disability in the same ways. Ideas and attitudes drawn from each person's social context influence the 'rules' and norms which govern how he or she perceives health and disability (Atkins 1991, p. 2).

Furthermore, the underlying assumption of disability politics, namely the disabled vs. non-disabled distinction, remains quite unproblematic for Hirsch. On the basis of the example of students who received a grant from their university to establish a Disabled Cultural Center on campus, she talks about “group solidarity waiting to be discovered”. In her opinion, this example is one of many to show that people with disabilities are becoming a more cohesive group than before - a minority group with shared political goals, similar educational experiences and some common emotional bonds and concerns (Hirsch 1995).

Shakespeare, however, points out the costs of such an understanding of identity politics. While the activists are willing to make the label into a badge, and transform their ghetto into an oppositional culture, he asks “what about those who wish to be ordinary, not different”? (Shakespeare 2002) He further mentions that many disabled people do not want to see themselves as disabled, either in terms of the social or medial model. They might downplay the significance of their impairments and seek access to a mainstream identity. They might lack a political identity because

they do not have any sentiments of belonging to the disability movement either. Their refusal to define oneself by impairment or disability, to “come out” as disabled has sometimes been seen as internalized oppression or lack of consciousness by radicals in the disability movement. The coming out analogy is, I believe, quite appropriate, since similar attitudes can be found in particular within the gay and lesbian community. Yet this attitude is clearly patronizing and can be oppressive, since people do have a choice as to how they identify, and, as Shakespeare points out, “identity politics can be a prison and a haven” (Shakespeare 2002).

What is more, the issue of multiple identities cannot be overlooked here. While some people resist identification as disabled because they want to see themselves as normal, others are more likely to identify in terms of alternative parts of their experience. Some might choose to prioritize those aspects of their identity related for example to ethnicity, sexuality, class or marital status. In his book on disabled gays and lesbians, Shakespeare claims that a substantial number of gay people identify first and foremost in terms of their sexual orientation and ignore their experience of impairment (Shakespeare *et al* 1996). Feminist researchers and activists emphasize that social model perspectives have not proved very effective or inclusive when it comes to issues of gender, race and/or sexuality (Morris 1991, Hillyer 1993). Most people are simultaneously situated in a range of subject positions. To assume that disability will always be a key to their identity is to repeat the error made by those from the medical model perspective who define individuals solely in terms of their impairment. Any individual person may strategically identify, at different times, as a person with a particular impairment, as a disabled person, or by their particular gender, religion, ethnicity, sexuality and education (Shakespeare 2002).

At one point in the article, Karen Hirsch goes as far as to say that the growing trend towards the rejection of the “disability-as-stigma” concept might be associated with the growth of the disability history, and therefore disability activists should advocate for oral history projects and collaborate with the researchers towards developing the history of the disability movement and community. Her support for the inclusion of oral history within disability studies leaves an even more fundamental question, unasked: does the experience of disability always influence the life story of a given individual in a meaningful way? Overall, Hirsch’s project is very much consistent with the outline of feminist oral history; the author herself makes repeated references to parallels between reclaiming disability history and the efforts of feminist historians recording women’s stories. Maybe feminist research should also be a starting point for the critique of some of the illusions inscribed in Hirsch’s article, which I tried to present in my essay. After all, it was feminist researchers such as Reinharz who talked about the phenomenon of righting historical injustice through enabling women to “tell their stories” and “speak for themselves” (Reinharz 1992). It is also Reinharz, who urges the researchers to analyze the conditions under which the voices are speaking, as well as pay careful attention as to whose voice is really coming through.

BIBLIOGRAPHY

Atkin, Karl. "Health, Illness, Disability and Black Minorities: a Speculative Critique of Present Day Discourse" *Disability, Handicap & Society*, Vol. 6, No. 1, 1991/37, p. 2

Eisenberg, Myron G., Cynthia Griggins, and Richard J. Duval. *Disabled People as Second Class Citizens*. New York: Springer Publishing Company, 1982

Hillyer, Barbara. *Feminism and Disability*. Oklahoma: University of Oklahoma Press, 1993

Hirsch, Karen. "Culture and disability: The role of oral history." *Oral History Review*; Summer 95, Vol. 22 Issue 1, pp. 1-27

Mairs, Nancy. "Disability/gender bifocals". *Women's Review of Books*; June 2004, Vol. 21 Issue 9, p. 16.

Morris, Jenny. *Pride Against Prejudice: Transforming Attitudes to Disability*. London: The Women's Press, 1991.

Oliver, M. *The politics of disablement*. Basingstoke: Macmillan, 1990.
Reinharz, Shulamit. *Feminist Methods in Social Research*. New York: 1992.

Rioux, Marcia H. "When Myths Masquerade as Science: Disability Research from an Equality-Rights Perspective." [in] Barton and Mike Oliver (eds.) *Disability Studies. Past, Present and Future*. Leeds: The Disability Press, 1997

Scott, Joan W. "Experience" [in] *Feminists Theorize the Political*. New York: Routledge, 1992, pp. 22-40.

Shakespeare, Tom, Kath Gillespie-Sells and David Davies. *The Sexual Politics of Disability: Untold Desires*. London: Cassell, 1996.

Shakespeare, Tom, Nicholas Watson. "The social model of disability: an outdated ideology?" *Journal of Research in Social Science and Disability*. Volume 2, pp.9-28, 2002.

Stone, Emma and Mark Priestley. "Parasites, Pawns and partners: disability research and the role of non-disabled researchers." *British Journal of Sociology*, Volume 47, Issue 4, pp. 699-716, 1996.

Thompson, Paul. *The Voice of the Past: Oral History*. Oxford: University Press, 1988.