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Paradigms of American Social Research on Disability: What's New?

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Abstract

In this paper, I discuss aspects of the recent history of disability research in the United States, particularly in the social sciences, that reflect the evolving nature of disability politics and corresponding public policies and programs. Current movements in research are discussed in the context of the social organization of professional and scientific research on disability and rehabilitation.

Introduction

The goal of social research is to explain (and perhaps predict) the relationships among the facts of social life - how the circumstances of individual lives and events are shaped by larger social forces. C. Wright Mills (1961) called this the intersection of history and biography. For those of us who assume that we live in a social, political, and economic world that follows rules and exhibits certain consistent patterns, the challenge of research is to discern those rules and patterns within what William James called the blooming, buzzing confusion of social life.

We can recognize generic methodologies, procedures, assumptions, and concerns that underlie social research. At the same time, various social science disciplines look to different institutions, to the economy, the polity, or kinship and religious systems, for the foundations of causality. They also rely on different theoretical assumptions about the nature of human choice or social action, and employ different methodological strategies for learning about what is going on in the world. (Of course, to true postmoderns, the world is unknowable, and research is largely a matter of opinion based on personal experience and good research depends on the authenticity of the researcher. (Turner, 2001, 257-258))

Historical and Conceptual Roots: the Sociology of Disability Knowledge

In the past few decades, there have been tremendous advances in social science research on disability, often in association with the evolution of public policy on disability. Some of the recent work has been the result of increased funding for disability research from the federal government and much of such funding has been focused on topics that were supportive of major federal disability programs. For example, over its history the National Institute for Disability and Rehabilitation Research has tended to fund applied research in professional rehabilitation practice and rehabilitation engineering that was related to the federal-state vocational rehabilitation (VR) program. Of course, disability experience and disability policy are not unrelated. As a society our concepts of disability are significantly related to the implicit and explicit assumptions about disability built in to public policy. (Scotch, 1984) Harlan Hahn (1987, 182) has written of "the fundamental fact that disability is ultimately defined by government policy. In other words, disability is essentially whatever public laws and programs say it is."

Forty years ago, American disability research largely relied on concepts and models from medical and vocational rehabilitation which typically viewed disability from a medical model rooted in the perspective of the provider of health and rehabilitative services and/or an economic model which associates disability with incapacity as measured by the ability to work and the related need for public support and benefits (Hahn, 1985). Since much of the research was done in relation to diagnosis and treatment in the course of service provision or eligibility for services and/or benefits, we knew very little about the characteristics and experiences of people with disabilities in their everyday lives, outside of their roles as patients or clients, in which their impairments were usually the central focus.

The limited focus of much disability research was exacerbated by the personal and social separation between researchers and clients. Most of those conducting the research did not themselves have significant impairments, while most people with disabilities found it difficult to obtain the educational and training credentials to join the professional ranks of researchers.

Although the experience of disability was not a major factor in setting the agenda or providing a conceptual context for disability research, a very important factor was the growing availability of funding for research that flowed from the evolving federal-state vocational rehabilitation (VR) program. Changes in that program typically have been driven by the priorities of a network of disability policy entrepreneurs (Percy, 1989, 24-29) that included the senior leadership of the executive branch agency that administered the VR program, the Rehabilitative Services Administration; the legislative staff of key Congressional committees; and outside advocates who, until the late 1970s, primarily were representatives of disability service providers and professional associations such as the National Rehabilitation Association. (Scotch, 1984)

Saad Nagi (1991), long a key figure in disability research, writes, "Early attempts at conceptualizing disability and its dimensions were prompted by influences from several sources. Three are particularly important: rehabilitation, chronic diseases, and compensation and insurance benefits." Nagi goes on to describe the key role of funding for disability research provided under the various iterations of the federal VR Acts. Research supported through the VR program included surveys whose purpose was to estimate the prevalence of "illness and disability resulting from chronic disease by diagnosis, degree and duration of disability" (quoted in Nagi, 1991, p. 312). These surveys used measures that were based on limitations in the ability to perform activities of daily living, limitations in overall functional capacity, and limitations on the ability to work, keep house, or attend school.

Such measures built incapacity into the basic concept of disability and often led to overly determined models in which for people with disabilities, their impairment was the central aspect of their lives. For example, in 1980 the World Health Organization (WHO) published an international classification scheme for impairment, disability, and handicap (ICIDH) that primarily utilized medical/functional concepts associated with impairment. Although the scheme did incorporate considerations of social and economic disadvantage, these were interpreted as linked to impairment rather than environment. (Fujiura and Rutkowski-Kmitta, 2001)

Adrienne Asch and Michelle Fine (1988, 8-12) have summarized the assumptions built into much of disability research in social psychology and these assumptions might be seen as representative of how disability was conceptualized in other disciplines as well:

1. It is often assumed that disability is located solely in biology, and thus disability is accepted uncritically as an independent variable;
2. When a disabled person faces problems, it is assumed that the impairment causes them;
3. It is assumed that the disabled person is a "victim";
4. It is assumed that disability is central to the disabled person's self-concept, self-definition, social comparisons, and reference groups; and
5. It is assumed that having a disability is synonymous with needing help and social support.

A similar inclination toward medical models of disability may be found in traditional rehabilitation research. To some extent this is a natural extension of the inherent professional perspective of behavioral science with which rehabilitation researchers typically identify, but the marginal academic and scientific status of the field of rehabilitation compared to more established scientific fields may reinforce the field's adherence to the language and culture of natural science. Nathan Glazer (1974) has noted that aspiring developed occupational groups (which he refers to as the "minor professions") seek legitimacy by adhering closely to the approaches and procedures of high status fields such as medicine.

In 1985, Joseph Stubbins wrote that

> The academic and research underpinning of psychosocial and vocational rehabilitation is largely empirical, atomistic, and meagerly informed by theory. ... there is little that

> binds the pieces together to provide definition and direction to rehabilitation as a field of study. As a consequence, the academic literature reflects little awareness of developments in the philosophy of science that have been stirring in the social sciences and more significantly, how its own epistemology has influenced the content of its research. (392-3)

He continued, writing that "as [rehabilitation] researchers and counselors, they would like to be viewed in the mold of natural science. So long as they evade the social, economic, and political setting of their subject matter, they could succeed in sustaining an image of neutrality." (393)

The Growth of a Sociopolitical Model for Disability Research

While the medical model of disability and the perspective of service providers dominated disability research for many years, a more conceptually important component of the growing body of disability research has been stimulated by the emergence of new research paradigms that flow from the personal (and political) experience of having a disability and by the evolving field of disability studies. Alternative views to the medical model always have been present, particularly among people with disabilities themselves.

Asch and Fine (1988) note that in 1948, Roger Barker wrote about disability in minority group terms and Alan Meyerson commented on the importance of social and psychological factors in the "problems of the handicapped" (both cited on pp. 6-7). In 1964, for a study of decision-making in the Social Security Disability Insurance program (SSDI), Saad Nagi developed a framework that distinguished impairments and functional limitations from disability. The latter concept, to Nagi, incorporated aspects of the environment into the concept of disability including how the individual with an impairment and his or her significant others defined the impairment and how expectations for the individual were affected by it as well as characteristics of the environment, including physical and sociocultural barriers (Nagi, 1991, 315).

A more widespread paradigm shift in conceptualizing disability occurred in disability research began in the late 1970s and early 1980s. The new paradigm was referred to as a minority group model, a sociopolitical model, or a disability studies perspective. Similar research directions in the United Kingdom came to be called the social model of disability. All versions shared a set of conceptual assumptions that disability was (at least) jointly determined by the environment as well as the impairment and that people with disabilities constituted a minority group that was politically and socially oppressed. Associated with this perspective was the conviction that most problems associated with disability could best be addressed through self-advocacy and the removal of disabling environmental barriers such as cultural beliefs that stigmatized, public policies that provided perverse incentives that made it difficult to live independently and technology and physical structures that effectively excluded people with disabilities.

Since the experience of disability was at the conceptual core of the emerging model, supplanting observation by professional service providers, more subjective methodologies were necessarily involved as was the formal participation of people with disabilities in research as informants and consultants (Brown, 2001). Investigators with disabilities assumed more central roles in research activities and approaches such as participatory action research (PAR) were adopted to involve people with disabilities in all phases of the research process (Whyte, 1991).

In many instances, qualitative approaches were employed to examine the perspective of people with disabilities in the definition of concepts, the identification of problems, and the evaluation of service and policy options. Because there is no single experience of disability in general, or even of any single type of impairment, in qualitative research the significance of disability varies according to how each individual constructs meaning for her impairment and examining that meaning requires a sense of rapport that Max Weber called "verstehen" (Ferguson, Ferguson, and Taylor, 1992). Ironically, incorporating the perspective of many people with disabilities has often refocused attention on barriers and opportunities located in the environment rather than on impairment alone. For example, in the landmark survey of people with disabilities conducted by Louis Harris and Associates in 1985, many people with disabilities cited discrimination as a major explanation for the unemployment or under employment (Louis Harris and Associates, 1986).

As the focus shifted from the impairment and the individual to the social context of the individual, there was increased investigation of environmental barriers, cultural depictions, policy constraints, and the social and political movements that emanated from the disability community. This work often involved an array of empirical techniques, including more open-ended personal interviews, ethnographic observation, institutional and legal analysis, and archival and historical research. Quantitative research was affected by the developing sociopolitical model as well as survey instruments were developed to better reflect the expressed concerns of people with disabilities in non-medical arenas of everyday life in the community (Altman, 2001).

The development of this paradigm was led by a number of disability scholars outside of the rehabilitation establishment. Most of the leading figures involved with this shift were largely independent of the rehabilitation field. Many were scholars who themselves had disabilities and who had been active in the growing social movements for independent living and disability rights. For example, political scientist Harlan Hahn proposed a sociopolitical definition of disability and examined how public policy was inextricably linked to our understanding of disability (Hahn, 1985). David Pfeiffer contributed analyses that built on his experiences as a political scientist and a community activist (Pfeiffer, 1977). Irving Kenneth Zola, whose work in medical sociology already had examined medical practice from the perspective of the patient, wrote about the social and political construction of disability while reexamining his own experience as a polio survivor and a participant with the self-help movement in health (Zola, 1982), and anthropologists such as Nora Groce and Jessica Scheer examined the varying roles played by people with disabilities in community life. (Groce, 1985; Scheer and Groce, 1988) Historian Paul Longmore helped to reveal the little known history of political activism among people with disabilities (Longmore and Umansky, 2001), while psychologist Adrienne Asch has explored the relationship between disability and social science (Asch and Fine, 1988a), gender (Asch and Fine, 1988b), and medical ethics (Asch and Parens, 2000).

By the late 1980s, researchers from across the social sciences and humanities were reexamining disability through the lenses of their own disciplines and lending support to socially and politically oriented concepts of disability organized around the subjective experience of people with disabilities. It was frequently difficult for researchers adopting the emerging social/sociopolitical perspective to publish in established rehabilitation journals whose peer review processes favored more traditional research paradigms, yet a number of cross-disciplinary journals, including several with public policy orientations, published special issues in the mid-1980s that presented compilations of research that incorporated the perspective of people with disabilities.

Within this network of established and emerging scholars, disability research frequently was linked more closely to political advocacy and independent living movements than it was to the provision of rehabilitative or health services by professionals. In the San Francisco Bay area, the World Institute on Disability (WID) was founded in the late 1980s by movement activist leaders Ed Roberts and Judy Heumann. WID-affiliated researchers such as Simi Litvak and Devva Kasnitz conducted important studies of issues of concern to the movement such as personal assistance services and independent living.

Institutional focal points for sharing these new research initiatives developed as well. A group of sociologists from the western United States created an interest group on chronic illness, impairment, and disability in the early 1980s whose meetings brought together scholars from a variety of social science disciplines from across the U.S. This group reformed as a national research society which ultimately became the Society for Disability Studies (SDS) whose membership grew to include a great many scholars from the humanities and the arts. There long had been humanists and artists who had explored the experience and cultural meanings associated with disability. A significant number of these scholars and artists had strong ties to disability activist movements and presented their work in movement publications as well as more traditional venues. Some were affiliated with academic institutions while others worked independently or created new institutional forums for their work and for networking with their peers.

A disability research newsletter founded by Irving Kenneth Zola in the early 1980s evolved into the research journal Disability Studies Quarterly (DSQ) which attracted an international and interdisciplinary audience. Following Zola's death in 1994, David Pfeiffer assumed the position of DSQ editor and the publication became formally affiliated with SDS. In the following years, the publication changed its format, attaining the appearance of an established academic journal, while retaining its links to political advocacy and to examining the experience of disability from a consciously diverse set of approaches. Like SDS, DSQ included research and creative expression from humanists, disability activists, and creative artists.

As DSQ was developing in the U.S., the British journal Disability and Society developed in similar directions although in a format that was more like a traditional scholarly publication. The journal has published a great deal of research by disability scholars from around the world, primarily from the perspective of the social model of disability that was supportive of the aims of the movements for independence and disability rights. (The large and important body of disability theory contributed by British and other non-American scholars of disability is not addressed in this paper.)

There have been numerous instances of overlap between the two worlds of disability research and these have grown substantially in the past decade. In Washington, DC, the National Rehabilitation Hospital has served as a center of policy-oriented research on the experience of disability while retaining strong ties to the rehabilitation community. At the University of Arkansas' Department of Rehabilitation, then research director Kay Schriner founded the Journal of Disability Policy Studies (JDPS) which has featured policy-oriented research of interest to both consumers and providers of services. In the late 1990s, JDPS became a publication of Pro-Ed, a publisher of journals for special education researchers and providers and its editorship passed to two professors of special education. Although affiliated with institutions associated with more traditional research paradigms, JDPS appears to have retained its eclectic perspective. The ICIDH classification scheme that had been developed in a largely medical model in 1980 was revised in 1999 to expand consideration of restrictions on social participation (Fujiura and Rutkowski-Kmitta, 2001) although these revisions have remained unsatisfactory to a number of critics working from the perspective of disability studies. (See, for example, Pfeiffer, 1998.)

Rehabilitation Research Redux

Despite increasing recognition of the sociopolitical perspective by researchers in rehabilitation in recent years, a significant proportion of the studies conducted over the past decade in academic research and training centers and being funded by federal research agencies such as the National Institute of Disability and Rehabilitation Research (NIDRR) has continued to draw on a more traditional model of disability research. While such work has led to significant advances in the lives of many people with disabilities (National Institute of Disability and Rehabilitation Research, 2001, 4), the body of empirical research on disabling environments within the field of rehabilitation has been far slower to develop relative to research being conducted in the social sciences and public policy studies. Thus research on the environment of disability has been referred to in current NIDRR publications as the "new" paradigm of disability, despite the decades of work by scholars holding a sociopolitical perspective noted earlier in this paper.

Further, since much of the published research in disability studies that has focused on environmental factors has been conceptual and/or anecdotal, concerns persist among research gatekeepers such as peer reviewers and research administrators about the rigor of such endeavors.

These concerns may be reinforced by disconnects in professional training. While the research tradition in rehabilitation has consciously borrowed methodological and epistemological approaches from the fields of medicine, clinical psychology, education, and engineering, research on broader contextual effects in these fields has often been marginalized compared to such work in the social sciences. Observations and research methodologies that are well accepted and considered quite rigorous to a sociologist, anthropologist, or political scientist may appear fuzzy, subjective, or unscientific to someone trained in clinical or experimental research methods. Yet the significance of complex and often subjectively charged concepts such as disability, equity, oppression, or reasonableness must be addressed to understand how environments constrain or empower individuals with disabilities and that significance may only be understood through the study of meaning, identity, and culture as it operates in the world experienced by people with disabilities. In numerous instances, established rehabilitation researchers have struggled to develop reliable and rigorous environmental measures without drawing on the work of scholars in the social sciences and disability studies.

One ongoing study that demonstrates what can be gained from the appreciation of complexity and attention to prior work in disability studies is the Meaning of Disability Study being conducted by investigators at the Disability Statistics Center at the University of California, San Francisco (Mullan et al., 2001). The goal of the study is to develop more appropriate and complex measures that identify people with disabilities and examine their experiences for use in survey research. Drawing on key concepts from researchers in disability studies, the investigators conducted a series of 14 focus groups with a variety of people who self-identify as having disabilities and have analyzed the discussion in terms of a number of themes identified as important by participants, including problematic social interactions with others, management strategies for solving problems associated with participation in everyday life, and ways of "doing things differently" to attain daily objectives. These findings will ultimately used to construct survey items that identify aspects of disability in more appropriate ways than those currently in use in major federal studies.

Conclusion

Disability research is at an opportune moment where many of the ideological tensions within the broader research community are waning. Long-time critics of traditional approaches have had new opportunities to contribute to changes in the research establishment. It would be naive to expect a heterodox consensus in the foreseeable future, but more diverse dialogues about what constitutes conceptually and methodologically sound research are taking place than has ever been the case. All of us can learn from these discussions by sharpening our own points and considering the perspective of others. The knowledge that is gained from the host of research that has been initiated in recent years should have lasting consequences for the research community, for more appropriate public policy initiatives, and for the lives of many people with disabilities.

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