

**SOCIOLOGY LOOKING
AT DISABILITY:
WHAT DID WE KNOW AND WHEN
DID WE KNOW IT**

RESEARCH IN SOCIAL SCIENCE AND DISABILITY

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VOLUME 9

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FOREWORD

...like all human achievement, getting from “there” to “here” in social science research is fraught with difficulties. (Lofland, 2007, p. 474)

This volume is a self-reflective examination of both the damaging assumptions and the glimmers of hope to be found in early sociological literature on disability. In particular, it is an exploration of early work that helped sociology move along the difficult path from a “there” in which some sociologists tacitly, and sometimes not so tacitly, supported the eugenics movement to a “here” in which disability is increasingly viewed as a theoretically important socially constructed category of human experience. While we have titled this volume, *Sociology Looking at Disability: What Did We Know and When Did We Know It*, given the way the volume evolved from “there” to “here,” we might well have called it *American Sociologists Looking at Sociology Looking at Disability*. We intended for it to have international scope, but the US-centered focus of many of the papers in the volume is perhaps neither surprising nor inappropriate given the way in which the volume came about.

The editors of this volume, the authors of its papers, and the editors of the RSSD series are all members of the American Sociological Association (ASA). Most have held leadership roles in the ASA and have worked with its staff to enhance the inclusion of both disabled sociologists and disability scholarship within the ASA. Some authors are senior and emeritus scholars who are veterans of the struggle to claim a space for disability scholarship in sociology and for sociology in disability scholarship. Others are junior scholars or advanced doctoral students in the process of creating their own space within this contested area of the discipline. Some papers are collaborations between veterans and new voices in the sociology of disability. Many of the authors in this volume, though not all, have personal or family experience with disablement and know first-hand the struggles of living in a non-accommodating world. All are committed to building on the strengths of past work while critically interrogating its assumptions and helping to fill its gaps and lapses in order to move the sociological examination of disability from the margins to a more central place in the life of the discipline.

The idea for this volume grew out of the work of the ASA Status Committee on Persons with Disabilities in Sociology. This committee was established in 1981 after many years of advocacy work by individual sociologists including some of the authors and subjects of papers in this volume and was formalized as a standing committee in the association's governance structure in 1987. In 1999, the status committee was charged with the following responsibilities: "To ensure the full participation of sociologists with disabilities in the life of the Association and to encourage sociological scholarship on disability issues" (Howery, 2007). This was an important moment in the discipline of sociology in the United States. These formal committee charges represent an official recognition on the part of the discipline's national scholarly organization that there exists within US sociology the kind of dual marginalization of both disabled scholars and disability scholarship that is noted by UK disabled sociologist and disability scholar Michael Oliver:

As a sociologist, my own experience of marginalization has been more from the sociological community than from society at large. A sociologist having either a personal or a professional interest in disability will not find disability occupies a central or even a marginal place on the sociological agenda. And even where it does appear, sociology has done little except reproduce the medical approach to this issue. (Oliver, 1990a, 1990b, pp. x–xi)

This dual disablement is, of course, not limited to the United States and the United Kingdom. Canadian sociologist Tanya Titchkosky, says, for example, "Like the normal who are full of pity and avoidance, sociology, too, often avoids disability as a phenomenon in its own right. Such a hegemonic presentation of disability is a sign of the kind of tyranny that surrounds disability as a sociological topic" (2000, p. 211).

While much remains to be done to improve the positionality of disabled scholars and disability scholarship in the discipline of sociology around the world, some encouraging progress has been made within the ASA over the last few years. As Sharon Barnartt notes in the introductory paper for this volume, the ASA Section on Disability and Society was formally accepted into the association in 2010. This was another landmark moment because the existence of this section guarantees a place for disability scholarship in the annual conference program and provides a formal mechanism for mentoring and networking among disability scholars. The section and status committee both continue to advocate for changes that enhance inclusion of scholars with disabilities and disability scholarship throughout the discipline. In the last few years, the Section on Disability and Society has been

building bridges with the much larger and older sections Aging and the Life Course and Medical Sociology. Many of the authors of papers in this volume are active in more than one of these sections. Over the last few years, the sections have jointly sponsored several conference sessions – including a session honoring the work of the late Irving Kenneth Zola who is the subject of papers in this volume.

When Tom Gerschick and I were asked to become co-chairs of the status committee in 2013 and began to gather ideas about what the committee should accomplish during our term, we quickly discovered that many of the action items suggested by new committee and section members had already been suggested in the past. In fact, we learned from Margaret Vitullo (ASA Director of Academic and Professional Affairs and the staff liaison for the status committee) that in some cases, the suggestions had already been acted upon by ASA. In conversations with past status committee chairs, we concluded that there was a need for the status committee to reflect more systematically on our discipline's history related to disability in at least two areas: the effectiveness (or lack thereof) of the status committee as an agent of social change within the national association and the history of sociological scholarship on disability. Sharon Barnartt and Barbara Altman suggested that we make the latter the focus of Volume 9 in the RSSD series and Emerald agreed. We also decided that both the status committee and the section should take a more active mentoring role to support and encourage both disabled graduate students and junior scholars and those who take the risk of focusing on this underappreciated area within the discipline. This volume represents one step in that mentoring effort.

In putting this volume together, Sharon and I were not only interested in reiterating the well-documented and lamentable dearth of mainstream sociological work in which disability is interrogated as more than an individual medical issue, but also in highlighting the early scholarship that bucked this trend. Titchkosky has said:

The prevalence of the sociological representation of disability as a mere spectacle in service of normalcy, stripped of any understanding of its social production, is certainly open to debate. What is not open to debate is that this is *one* way that academics produce disability-knowledge. It is also beyond question that since the category “the disabled” entered Western culture, *there have been researchers and theorists that have resisted conformity to the dominant ideologies of their day ...* and, of course, others who have not [emphasis added]. (Titchkosky, 2000, p. 211)

Sociologists and disability scholars in other disciplines have sometimes neglected to recognize “the researchers and theorists that have resisted

conformity” by using a broad brush to characterize that larger group of “others who have not.” This is, of course, quite understandable and even necessary in an area of scholarship that has experienced neglect and abuse and had its legitimacy contested within the discipline. Leonard Davis, for example, argues in his introduction to the *Disability Studies Reader*: “As with any new discourse, disability studies must claim space in a contested area, trace its continuities and discontinuities, argue for its existence, and justify its assertions” (Davis, 1997, p. 1). The same can be said of non-medicalized approaches to the sociology of disability. There has been a very real struggle to claim space within a resistant discipline.

Territorial claims making, however, can lead to uninformed disdain for all past work and loss of important insights and glimmers of hope offered by early work that anticipated and contributed to more current perspectives, even if imperfectly. In her contribution to a special memorial edition of *Symbolic Interaction*, Lyn Lofland says of the work of my friend and colleague the late Spencer Cahill (whose disability scholarship Titchkosky places in the resistor category):

... much work in sociology evinces two characteristics that the rest of us would do well to jettison: sociological illiteracy or intellectual isolationism, on the one hand, and easy dismissal of the literature, on the other The second characteristic is one all too familiar to most of us: a disdain for past work To say that Spencer’s work displays neither of these characteristics but instead demonstrates an *appreciative knowledge* of the literature is by no means to suggest that he avoids critical assessment. What I am arguing, rather, is that his critiques rarely, if ever, take on the character of all-out assaults. They are always based on a close reading of whatever work is in question (i.e., they are “knowledgeable”), but they are also measured, pointing to gaps or lapses or unexamined assumptions but recognizing how hard-won are the filling in of those gaps or the corrections of those lapses or the examining of those assumptions (i.e., they are appreciative) [emphasis in original]. (Lofland, 2007, p. 474)

It has been our goal in producing this volume to provide future researchers with an *appreciative knowledge* of some of the early scholarship in the sociology of disability that resisted the tendency of the discipline to equate disability entirely with individual bodily impairment and necessarily tragic consequences. Authors of the papers in this volume critically examine both the value and the gaps, lapses, and assumptions in early work on disability in sociology and related disciplines. They also point to gaps and lapses in current knowledge and suggest avenues for future research that are suggested by their reviews. We hope that this volume will prove to be a useful reference tool as our discipline makes its way slowly along the path, ever fraught with difficulties, from a “there” in which disability was viewed as

always and only an individual tragedy to a brighter “here” in which disability is valued as a socially constructed category that is worthy in its own right of sustained theoretical interest and meaningful political action, within sociology and beyond.

Sara E. Green
Editor

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INTRODUCTION: AN HISTORICAL OVERVIEW OF SOCIOLOGY LOOKING AT DISABILITY: WHAT DID WE KNOW AND WHEN DID WE KNOW IT?

This volume looks at how the field of sociology, and especially sociological theorists, have treated disability throughout the years. This paper sets the historical and sociological context for that examination. It begins with an examination of early theoretical work which could have been, but tended not to be, applied to disability (with a few exceptions). It then discusses the main sociological concepts which were applied to disability from the 1950s to 1970s; some of which have become unpalatable to sociologists studying disability. Finally it looks at concepts and theories through which disability has been analyzed since the 1980s.

In its attempt to provide a context for the papers which follow, this introduction does not just review the papers which comprise the volume. Instead, it is presenting an historical and conceptual context. It should not be read as a comprehensive history of sociological theory nor can it be read as a complete critical analysis of conceptions of all of the conceptions of disability which have been considered within the history of Sociology. It presents a beginning, a big-picture view, and the papers which comprise the bulk of this volume provide more clarification and in-depth analysis of the area or theory they are focusing on.

EARLY SOCIOLOGICAL CONCEPTIONS OF DISABILITY – OR THE LACK THEREOF

Most sociologists ignored the phenomenon of disability until recently. It was only in 2010 that the American Sociological Association (ASA) formed

a section on Disability and Society; this became possible only when the organizers could show that enough people were interested in disability from a non-medical framework.¹ Prior to this, most sociological work on disability appeared in the Medical Sociology Section of the ASA. Despite its title, that section gave a section award to Irving Kenneth Zola, one of the early sociologists to write about disability from a non-medical point of view.

None of those considered to be the top classical sociological theorists (Marx, Weber, Durkheim, Mead, and Cooley) addressed the issue, even obliquely. One exception among the work of early theorists can be seen in the writings of Harriet Martineau. She was an early sociological theorist who lived from 1802 to 1876. Little attention was paid to her until recently, although she was a social analyst who wrote on many subjects. Because she was also deaf, she wrote about deafness in theoretical terms, particularly in her “Letter to the Deaf” (Deegan, 2002, 2014). In this article she focused on interactions between deaf and hearing people. Although some of her observations were on track, others (even her use of the term “the deaf” in her title) are not accepted in sociology now, either empirically or prescriptively.

Mauldin and Fannon (see the paper “The Sociology of Deafness: A Literature Review of the Disciplinary History”) point out that, in the 1920s, Georg Simmel did write about deafness and how the interactions of deaf people might have changed and become problematic with the growth of urbanization. He was contrasting deaf people to blind people and not focusing on disability as a general characteristic. His overall conceptualization of deafness was as a problem to be pitied.

If early sociological theorists did not use the words “disabled” or “disability,” which are actually rather modern words, there was in fact discussion by early sociologists of conditions which might be disabling. Kirchner (2010) reviewed the work of several early sociologists and found a definite tendency to divide the world into categories which could be interpreted by us – or which were interpreted by the authors themselves – to approximate those of “disabled” and “non-disabled.” One set of categories, “the efficient” and the “inefficient,” was originally put forth by a sociologist named Henry Hughes in 1854 (Kirchner, 2010, p. 133). Other terms used to refer to people with disabilities, as Gerschick and Stevens found in their analysis of 27 papers relevant to disability, presented between (1906 and 1915 at the annual meetings of the American Sociological Association, were “unfit, defective, diseased, cripple, patient, and feeble-minded” (see the paper “Invisibility, Visibility, Vilification,

and Near Silence: The Framing of Disability in the Early Years of the American Sociological Society”).

Discussions of theories of evolution on the physical and social level led to the use of terms such as “the fittest,” “the unfit,” and “degenerates” (Kirchner, 2010, p. 135). In the late 1800s and early 1900s, writers from many disciplines were involved in debating principles of eugenics, and sociologists were no exception. However, their terms for “disability,” such as “the fit” or “degeneration,” were more concerned with moral categorizations than with specifically disability-related categorizations or conceptualizations (Kirchner, 2010, pp. 136–138).

SOCIOLOGICAL CONCEPTIONS OF DISABILITY 1950–1970

During the period from 1950 to 1980, sociologists developed many concepts which could have relevance to disability, but in many cases they were not actually applied to disability. Relevant functionalist concepts about social structure, by sociologists such as Linton and Merton, included roles, statuses, role sets, and reference groups (Coser, 1975, p. 199; Coser & Rosenberg, 1976). Work identified with symbolic interactionism, such as that by Sarbin and Allen (1968), also discussed role theory and provided more general concepts such as role hierarchy and role salience. Discussions about identity by McCall and Simmons (1966), among others, expanded on the relationship between self, role and interaction. None of these theorists discussed disability, although they could have.

There were several areas of thinking which did produce a large amount of writing related to disability during this time period: what came to be called the medical model of disability, a spate of literature from the deviance perspective, a substantial empirical focus on rehabilitation, and articles on issues related to families with a child with a disability. (This literature will not be reviewed here because it is discussed quite thoroughly in the papers “Renaming the Wheel: Social Model Constructs in Older Sociological Literature,” “The Sibling Disability Experience: An Analysis of Studies Concerning Non-Impaired Siblings of Individuals with Disabilities from 1960 to 1990,” and “Struggles and Joys: A Review of Research on the Social Experience of Parenting Disabled Children”). Finally, in an era in which sociologists produced community studies such as *Small Town in Mass Society* (Vidich & Bensman, 1958) and *Caste and*

Class in a Southern Town (Dollard, 1957), there was one such study done of a deaf community in Fredrick, Maryland (Furfey & Harte, 1964).²

Disability: Medicalized and Sick

Parsons (1951) was the first well-known American sociological theorist whose work was relevant to disability in policy, theory, and practice, although Parsons did not actually address the concept of disability directly. Rather, his discussion of the sick role (1951, pp. 436–439) had a huge impact on sociological thinking about disability, but it is usually not referred to as such. Discussions within the disability community and in sociological thinking often refer to “the medical model of disability,” almost always without attribution. The medical model of disability is simply Parsons’ “sick role.”

The sick role expects child-like behaviors, passivity, isolation, and dependency. It carries with it implications of incapacity, inability, and disability. The sick role provides an acceptable excuse from involvement in everyday activities, and, in fact, the person is expected to be isolated from everyday places and activities. “He (sic) is in a condition that must be ‘taken care of’” (Parsons, 1951, p. 437).

Being sick is a deviant status which hurts society as well as the person in the role.³ As a particular type of deviant status, Parsons says that “... unlike hoboism, illness ... provides ... a point of ‘leverage’ for social control” (p. 285). However, it differs from other deviant roles because it is morally legitimate. That is, the sick person is not seen as being responsible for the status that places them in the sick role – unlike those in other types of deviant statuses, such as criminal statuses. Rather, the person is “unlucky” or “ill-fated.” It happened to them; they did not choose it, and they are not morally stained by it⁴ – but they are also not expected to like it. To be ill is to be in an unacceptable and “unfortunate” (p. 285) state. However, even though being sick is not their fault, sick people are expected to work to become well, by cooperating with medical personnel, because it is in the interest of society that illness become minimized (p. 430).

Despite being a social role, being sick is seen by Parsons and subsequent authors as being an individual problem which will be dealt with individually by responsible and qualified medical personnel. They are the personnel who are given control over this role by society, who – although Parsons doesn’t say this explicitly – have the power to release a person from the sick role or to provide excuse for a person to be released from any other,

unwanted role such as school or work. Hughes (1971, p. 287) calls this part of the mandate given to physicians.

Parsons' original conceptualization of the sick role was applicable only to acute illnesses, because he designated it as a temporary role (p. 438). But it took little to extend it to chronic illnesses and disabilities. For example, Erikson (1968) attempted to extend the sick role to a chronic impairment, that of mental illness.

This conceptualization of illness was as a social condition for which words which imply legitimacy, such as oppression, discrimination, or inequality, have no place (1951, p. 477). This is true even though, as a conception of disability, it was the basis for laws to fund vocational rehabilitation and training, which are based upon the notion that people want to become "well." When people with impairments are seen as being ill, they are seen as being involuntarily incapable of performing economic roles or social functions; they are also excused from other roles such as jury duty or military service. Such people are deemed worthy of public (i.e., monetary) support, because the "illness" is not their fault (Berkowitz, 1987; Liachowitz, 1988; Stone, 1984; Scotch, 1984).

As mentioned above, this conceptualization of the sick role served as the basis for what has been called "the medical model of disability." This will be discussed in many of the subsequent articles, especially the paper "A Messy Trajectory: From Medical Sociology to Crip Theory."

Disability: Deviant and Stigmatized

Symbolic interaction theory, whose proponents initially had ignored disability, eventually had a huge impact on the conceptualization of disability as deviant and stigmatized. The clearest specifically sociological mention of disability as a deviant state is found in Goffman's (1963) book *Stigma*, but his was not actually the first examination of disability from this point of view.

Goffman (1963) focused on issues related to persons who have stigmatized or "spoiled" identities. Having a disability meant that the person could have a spoiled ("discredited") identity, although if the person had non-visible impairments, their identity was seen as being "discreditable." He mentions many other types of spoiled identities which ranged from being black to being a criminal to being the daughter of an ex-convict (p. 30). (Examples such as the latter sometimes came from Ann Landers' columns.) However, Goffman neither separated out disability (or any

other) category for extended analysis nor discussed sociological reasons for why disability should be stigmatized.

He wrote about the identities themselves, but his focus was on interactions, specifically on impression management. It is important to remember that *The Presentation of Self in Everyday Life* was published in 1959; *Stigma* was a continuation of that book. Further discussion of Goffman's work can be found in the papers "How Erving Goffman Affected Perceptions of Disability within Sociology" and "Managing the Emotions of Reading Goffman: Erving Goffman and Spencer Cahill Looking at Disability" in this volume.

Goffman was not the only sociologist writing about disability from a deviance perspective. In fact, there were a large number of articles written from a symbolic interactionist point of view which equated disability with deviance – although many of these have been ignored or forgotten, perhaps because their places of publications were scattered. Some examples include Davis' (1964) work on Deviance Disavowal (which begins to sound a lot like Goffman's work on Stigma management); Dexter's article on stupidity (1964), by which he seems to mean retardation; Mercer's (1968) article on labeling the mentally retarded; Friedson's (1968) on disability as deviance; and Haber and Smith's (1971) article entitled "Disability and deviance: Normative adaptations of role behavior."

Goffman's work, or, perhaps the combined work of these and other scholars cited here, was temporally, if not causally, related to an increase in sociological interest in disability. Gordon and Rosenblum (2001, p. 15) indicate that the numbers of articles in *Sociological Abstracts* on disability-related topics increased from 24 in 1963 to 36 in 1973 to 103 in 1983 – although they also note that these numbers reflect a minuscule proportion of all articles published. As they noted, disability was usually *not* included in textbooks which focused on deviance and stigma.

A number of attempts by sociologists⁵ to push back specifically against the almost automatic application of the concepts of stigma and deviance to disability have appeared. Some were published almost 20 years after *Stigma* (Elliott, Ziegler, Altman, & Scott, 1982; Smith, 1980). Others were written more recently, by journalists, such as Shapiro (1993), while others were written by sociologists such as Scotch (1984) and Higgins (1992). In fact, one could say that quite a bit of subsequent sociological writings about disability was an attempt to push back against the idea of disability as deviant and stigmatized.

However, the power of the conceptualization persists. American sociologists tended, with only a few exceptions (Albrecht, 1976; Darling, 1979;

Safilios-Rothchild, 1970), to continue to view disability into the 1980s as either deviance – and therefore a stigmatized condition – or a medical phenomenon. We can see the deviance perspective, for example, in works by Schneider and Conrad (1983) and Charmaz (1991). Both books, which are extremely well-regarded in the field, were also at least partially focused on managing stigma – related in the former case, to epilepsy, and, in the latter case, to many types of chronic illness. In about 1999, this author was asked to write an article about disability to be included in the *Encyclopedia of Criminology and Deviant Behavior* (Bryant, 2000). Despite this author suggesting that it was inappropriate, the editors wanted the article, which was included in the publication (Barnartt, 2000). Even more recently, when this author was asked to write an article in *Sociology of Disability for Cambridge Handbook of Sociology* (Korgen, forthcoming), she discovered that it was to be included in the section on deviance (until she explained why this was not appropriate.)

TOWARD NEWER THEORETICAL MODELS

In the late 1960s, there were attempts to inspire sociological attention to disability within the American Sociological Association. A discussion group was begun by Richard Smith and Lawrence Haber; this group sponsored a special session within the Medical Sociology section of the ASA at its 1969 meeting. It also sponsored other meetings and workshops, including one in Puerto Rico (Litman, 1970). Even Litman's article, which was the Introduction to Safilios-Rothchild (1970)'s book, did not draw enough attention to the book or to the pleas for a changing perspective made within it.

During the 1970s, disability was most commonly discussed within the subfield of medical sociology, although Kirchner (2010, p. 139) notes that it was not actually included as a topic within Bloom's history of medical sociology. An additional irony is that it was also not discussed in medical sociology textbooks (Barnartt, 1990, 1995). Medical sociology, which locates itself both within and outside medicine, had primarily approached disability from a within-medicine perspective, as a medical condition which needed to be cured or rehabilitated. Sociologists holding this view focused on topics such as individuals' adjustments to a dependent status (Kelman, Muller, & Lowenthal, 1964) or levels of social support in the family and community (New, Ruscio, Priest, Petritsi, & George, 1968; Tolsdorf, 1976).

However, there were two scholars who had a strong impact on Sociology's scholarship on disability who were active at that time: Saad Nagi and Irving Kenneth Zola.

Saad Nagi

In 1965 there was a conference, sponsored by the American Sociological Association and the US Vocational Rehabilitation Administration on "Sociological Theory, Research and Rehabilitation," which attempted to analyze disability in terms other than the sick role or stigma. The "overriding consideration in developing the conference was the usefulness and applicability of current sociological theory and research to the field of rehabilitation" (Sussman, 1965, p. iii). The meeting, and the resulting publication, attempted to look at rehabilitation, and, to a lesser extent, disability, as social processes, amenable to analysis by sociologists who did not have a medical or a deviance perspective. The papers attempted to apply sociological theories and concepts — other than those from the perspective of medical sociology or medicine — to disability and rehabilitation. That book provided some of the earliest sociological analyses of disability⁶ using concepts from social class analysis, status attainment theory, organizational theory, and interactionist theory.

Saad Nagi, however, was been foundational in developing conceptions of disability as being a non-medical phenomenon. His distinctions between medical conditions, impairments, functional limitations, and disability (Nagi, 1965) have permitted a conceptualization of disability which is not static and which focuses on the interaction between person and environment (see the paper "Conceptual Issues in Disability: Saad Nagi's Contribution to the Disability Knowledge Base").

Irving Kenneth Zola

One important link between the older, mainline sociological theories, and a newer sociological focus on disability was provided by Zola (1982a, 1982b, 1983). As a sociologist and a man with a disability, in the late 1970s and 1980s he began to apply insights both from sociology and from the civil rights movement to his situation and, by extension, to those of other people with disabilities. His method of analysis often involved using himself or a small number of interviewees, including his students, as examples in order

to get at the larger processes operating in a situation. Trained as a medical sociologist, Zola's professional socialization initially led him to view disability as a medical issue and view the field of medicine as the primary social institution which could provide relief. His early critiques, including a 1972 article called "Medicine as an institution of social control" (reprinted in Zola, 1983, pp. 247–268) were of the institution of medicine itself. Zola came to reject the medical model of disability, as he discussed in an article called "The political coming-out of I.K.Z." (1983, pp. 243–246). In it, he described a consciousness-raising process akin to that used by the Women's Movement.

According to the medical model, relief from disability was only possible in the form of a cure or rehabilitation, if neither existed, so be it. Zola insisted that society as a whole could provide – if not a physical or mental cure – at least accessibility and other ameliorations. He made it possible to think that a "cure" was not necessary, if society could be changed. His later writings and presentations emphasized the ways in which society was "complicit" in shaping disability, beginning with the word itself, which he always pronounced "dis-ability." As a recipient of the section award from the Medical Sociology Section, as well as one of the early and influential participants in an organization called the Society for the Study of Chronic Illness, Impairment and Disability (SCIID), he increased the stature and awareness of a sociological view of disability as non-medical⁷ (see the papers "Back to the Future: Irving K. Zola's Contributions to the Sociology of Disability" and "Bringing Our Bodies and Our Selves Back In: Seeing Irving Kenneth Zola's Legacy").

SOCIOLOGICAL CONCEPTIONS OF DISABILITY DURING THE 1980s

There were a small number of studies on aspects of disability from a purely sociological point of view before or around 1980, including Scott (1969) and Higgins (1980). It was in the 1980s, however, that sociological analysis began to turn more generally away from its medical focus. (Perhaps this occurred as doubts about the efficacy of rehabilitation were being raised.) This turn was perhaps not as sharp or as swift as some would have hoped, but it did begin adding several types of conceptions which could supplant those based upon the medical model.

The Social Model of Disability

Beginning in the early 1980s in the United Kingdom, sociological and other theorists were more explicitly trying to incorporate social and environmental effects into a conceptual model of disability. This work came to be called “the social model of disability.” This conceptualization sought to ignore the individual’s functional limitations and focus totally on what was interpreted as an oppressive environment and social structure (Abberly, 1987; Barnes, Mercer, & Shakespeare, 1999; Oliver, 1990a, 1990b; and Shakespeare, 1998). For example, in an especially interesting essay, Oliver (1996) argued that, not only had most societies been set up for walkers, but that the assumption of walking as normal pervades our language and thought; he challenged us to try to think from the perspective of non-walkers. The social model built upon an explicitly Marxist framework, in a way which American sociological concepts of disability never did. However, even though it was a “social” model, Barnes (1998) noted that it was not a “sociological” model, because it was largely ignored by sociologists in the United Kingdom. (It was not ignored by activists or researchers in other fields, just by the field of sociology itself.) The social model is often presented as being opposed to the medical model, although it has also been criticized – by some of its own proponents as well as others – for disregarding the actual impairment in favor of a total focus on societal conditions, including social structure and culture (Shakespeare & Watson, 2001).

This model takes a more expansive view of disability than one can extract from Parsons’ sick role. Parsons embedded the concept of the sick role within the institution of medicine, while the UK version of the social model considered all aspects of society in its view of social structure and the environment.

Disability as a Minority Status

In the United States, the Architectural Barriers Act of 1968 (implicitly) and the Rehabilitation Act of 1973 (explicitly), used a civil rights perspective in their discussion of disability. In April, 1977, protests by people with disabilities, who demanded the promulgation of rules for the latter law, embodied this new perspective toward disability. The protesters said that people with disabilities were a minority group whose members experienced discrimination – and who could therefore conduct a protest instead of passively accepting their fate (Barnartt & Scotch, 2000). Around the time

of these protests, journalists (Holmes, 1990; Jaekle, 1981; Schultz, 1977) and others (Bogdan & Biklen, 1977; Bowe, 1978; Gleidman & Roth, 1980; Kleinfeld, 1977) had begun to describe people with disabilities as “the newest minority group.” (This followed by more than a decade discussions about whether women (Hacker, 1951) and “the aged” (Streib, 1963) were minority groups.)

It had been clear in the empirical literature for a long time that people with various types of (usually physical) impairments experienced disadvantages similar to those experienced by racial or ethnic minority groups, including prejudice and discrimination, lower average socio-economic status, and overall lower social status. There had been research done about occupational and educational statuses of deaf people, for example, as early as the 1930s (Martens, 1937) and the 1950s (Lunde & Bigman, 1959) which highlighted the disadvantages experienced by deaf people. There was information published about socio-economic and other characteristics of blind people by Kirchner (1985) and others in the late 1970s (Kirchner & Peterson, 1979, 1981).

Economists around that time had examined issues associated with disability benefits and employment which highlighted their economic disadvantages. See, for example, Berkowitz, 1973; Conley, 1965, 1973; Meer, 1979; Scheffler & Iden, 1974; Swisher, 1973; Yelin, 1980. However, even though some of their questions were sociological, the population of focus was narrower than that for sociologists, since it was very much tied to work status and the receipt of benefits such as SSDI.

These could have been sociological topics. However, sociologists did not pick up on these ideas until the early 1980s. In part, this was because of the dominance of the medical model of disability. In order to conceptualize people with disabilities as members of a minority group, sociologists had to perceive them as having a *group identity* and *group issues* (e.g., discrimination), rather than as being individuals with individual problems (Stroman, 1982). Other aspects of the medical model also had to be overcome, such as the idea that having a disability was a disaster which no one would want, that being disabled means being incapable, isolated, and dependent, and that medical practitioners have sole control over the lives of people with impairments.

Beginning in the early 1980s, there was a spate of articles by sociologists which examined people with disabilities as a group, or specific impairment subgroups, using the concept of minority group – or “the minority group model.” This included Altman (1985), Deegan (1981), Barnartt (1982); Scotch (1984), Christiansen and Barnartt (1987). They and other

sociologists, as well as activists and people writing from many other disciplinary points of view, attempted to reframe disability as being a condition characterized by lower socio-economic status and discrimination. There was an entire conference on “The Sociology of Deafness” in 1982, held at Gallaudet University, in Washington, DC, which examined some of these issues and at which Irving Zola was the keynote speaker. The conference was funded by a grant from the American Sociological Association, and it produced five self-published books – but otherwise it received very little attention within the discipline.

Since the late 1980s, the idea that disability status is a minority status has become one of the dominant sociological views of disability. Various authors have attempted to compare it to other ascribed minority statuses (Barnartt & Seelman, 1988; Deegan, 1981; Stroman, 1982) and found significant similarities.

Disability as a Socially Constructed Category

The publication of Berger and Luckman’s *The Social Construction of Reality* in 1966 eventually had an impact on the sociological study of disability (as it had on the study of almost every other topic within sociology). However, it was more than a decade and a half after the publication of their book before the phrase “the social construction of disability” was commonly used. But, after it was applied to disability in the mid-1980s, sociology has strongly endorsed a conceptualization of disability that incorporates social structural (including historical and political), cultural, and environmental factors as being important elements in creating and defining disability and societal reactions to it. Disability is now routinely seen by sociologists (and anthropologists) as being socially, rather than medically, constructed (Higgins, 1992; Ingstad & Whyte, 1995, 2007; Liachowitz, 1988).

HOW SOCIOLOGY HAS NOT CONCEPTUALIZED DISABILITY

There are several sociological conceptualizations which have not taken account of, or been applied to, disability. With a few exceptions (Barnartt, 2001; Lorber, 1999), sociologists have not viewed disability as a distinct

status with its own culturally shared role expectations. Role theory, with the many associated concepts mentioned above, is just beginning to be applied to disability (Barnartt, 2016).⁸

Intersectionality, defined as the intersection of statuses such as race, class, and gender and usually studying how that intersection affects a given dependent variable, has gained great deal of popularity in sociology in recent years. However, despite the fact that many disability scholars accept the minority group model of disability, intersectionality theorists almost never mention disability in the context of intersectionality (Barnartt, 2013).

Status-attainment theory has been used extensively to discuss factors in status attainment and social mobility among white men (Blau & Duncan, 1967; Duncan, Featherman, & Duncan, 1972), women (Perrucci, 1978), and minorities (Duncan & Duncan, 1968; Hirschman & Wong, 1984). The effects of variables such as education, parental education, work status, and marital status, among others, have been extensively evaluated for their contributions to outcomes such as occupational status or income. Although a number of dissertations were done which focused on deaf workers or deaf graduates from one college (Schroedel, 1976; Winakur, 1973), such analyses have mostly not been done for disabled workers more generally, with the exception of Barnartt and Altman (1997). Despite a call from Alexander (1976) that theories and conceptions from the study of stratification be applied to workers with disabilities, they mostly have not been, although there has been research on income inequalities and labor force discrimination.

CONCLUSION: MISSED OPPORTUNITIES

As Safilios-Rothchild (1970, p. viii) noted, “for whatever the reason, sociological inquiry into the behavioral aspect of physical illness and the therapeutic process has generally been extremely limited.” The reasons she referred to include the lack of institutional supports such as journals or other good sociological publishing avenues for scholars in the field of disability studies and the lack of graduate school programs which cover the topic. Some of these conditions still exist – the latter more than the former, since there are now several academic journals which focus on disability issues.

The field is beginning to correct this oversight, however. As mentioned above, the creation of a section of the American Sociological Association is both a reflection of, and a spur for, the development of sociological interest

in disability. With the numbers of people with impairments increasing as the population ages, sociology is well-positioned to analyze the impact of this increase on social institutions such as work, family, education, religion, and recreation and on our culture and subcultures. Sociology has begun to shift the focus from ‘*individuals* with disabilities’ to the interaction between society, impairments, and people. It is also well-positioned to analyze the effects of the intersection of the disability with that of other statuses such as gender, race, and sexual orientation on these social institutions – and the effects of these institutions on people who experience these intersections. Overall, it offers the possibility of viewing a physical situation which affects a large proportion of the population at some point in their lives from a sociological perspective. It is hoped that the papers in this volume, described below, will contribute to this effort.

Sharon N. Barnartt
Editor

NOTES

1. An earlier attempt made in the 1960s failed, as will be discussed later.
2. That study received almost no attention, then or since.
3. In fact, in *The Social System* (1951), it is initially discussed in the chapter on Deviant Behavior and Social Control.
4. As we see later, this is a slightly different position than Goffman takes in *Stigma* (1963).
5. Perhaps ironically, one book which presented a sociological vision of people with disabilities, entitled “*Physical Disability – A Psychological Approach*” (Wright, 1960), was actually written by a psychologist. (The author’s son, Eric Olin Wright, would become President of the American Sociological Association in 2012.)
6. However, some of its conceptualizations of persons with disabilities are dated, since it was written before people with disabilities were seen to have civil rights or before there was much social movement activity among persons with disabilities. Its terminology (e.g., “the handicapped”) would be seen by some current readers as offensive.
7. Some members of SCIID, as it was known, broke away to form the interdisciplinary and Society for Disability Studies, which became increasingly humanities focused. SCIID still exists as the Section on Chronic Disease and Disability within the Western Social Science Association.
8. The idea of disability as a role other than the sick role was actually discussed at this time by Thomas (1966). However, that paper which received little attention until recently. In part that is probably because its language and conception of societal expectations for people with disabilities are dated.

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