

Report of the ASA Committee on the Status of Persons with Disabilities (PWD)

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By Sharon Barnartt,¹ PhD, Gallaudet University
Committee Chair

At the request of the American Sociological Association's Council, The ASA Committee on the Status of Persons with Disabilities (PWD) has explored various aspects of the professional experiences of persons with disabilities both within the ASA and in other aspects of their professional life. We analyzed data, provided by the Executive Office, about ASA functions and activities and with the Office, we conducted a small survey of sociology department chairs in the fall 2004. Additionally, we updated a review of literature about disability produced by sociologists.

This report consists of an Executive Summary of research results; an overview of the committee's history; its charge and constituency; the review of literature; recommendations drawn from those results; and three appendices. Those appendices contain the detailed results of the research as well as a series of articles produced by this Committee, which appeared in *Footnotes* over the years.

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Executive Summary

The major findings from the research reported in the appendices and the highlights of the literature review are:

The Status of Disability in Sociology and the ASA

- Very few ASA activities have included topics related to disability
- While a number of graduate programs indicate having a specialty in disability, none in the US have a program in disability
- The number of people who list an interest in disability on their membership form is not insignificant but is below that needed to form a section
- While there have been at least two sessions related to disability at the two most recent annual meetings, more papers related to disability have been presented outside of those sessions than have been presented in them
- Very few of the Introductory Sociology textbooks or readers surveyed include information on disability, while about one third of Social Problems textbooks surveyed include it.
- Some of the items found in these indices used obsolete or derogatory conceptions of disability

These results, as well as data sources and limitations, are detailed in Appendix 1.

Department Chairs' Experiences with Disability Accommodations

- About one third of chairs who responded had been requested by a faculty member to provide a disability-related accommodation
- Almost all of the chairs were able to satisfy the request[s] either partially or fully
- Less than one quarter of respondents expect to have a faculty member need an accommodation within the next five years
- The majority of departments' faculty members had received requests for accommodations by students and had been able to satisfy them
- For only about 11% of the departments were department funds used to satisfy the faculty requests for accommodations;
- For most, the college/university or the office in charge of dealing with students with disabilities provided what was needed to satisfy the faculty request, or the request did not cost anything to satisfy

These results, as well as data sources and limitations, are detailed in Appendix 2.

Literature Review about Disabilities

- There has been scholarship about disability and people with disabilities almost since the beginning of sociology
- The concept of disability has undergone a number of changes over the years, from deviant, stigmatized status to socially constructed status, cultural or even linguistic minority group, and to social movement
- The theoretical perspective most often used in scholarship about disability is that of symbolic interactionism

- Scholarship about disability within sociology and by sociologists appears to have been seldom recognized by publication in ASA sponsored journals
- Recently, there has been increasing interest in the operationalization and measurement of the concept of disability as well as in research barriers to, and challenges in, research about PWD

History, Charge and Constituency of this Committee

This committee was established in 1981 as an ad hoc committee, originally called the Committee on Society and Persons with Disabilities [Emerton 1989]. Its original charge was to ascertain that the ASA annual meeting was accessible to people with disabilities, or to assist ASA in solving problems so that it could become so. It was also supposed to concern itself with PWD in society, although that part of the charge was never defined and has evolved on an ad hoc and somewhat limited basis.

There are many definitions of the concept of disability, which lead to the identification of very different groups of people as being PWD (Altman 2002). One of the primary policy-related definitions, that used by the Social Security Administration, defines people with disabilities as those who have a physical or mental condition that prevents them from engaging in paid employment. That definition obviously does not apply to people who might be working sociologists in universities, governmental agencies or companies. Other definitions are based upon a physical or mental condition which causes a limitation in activities of daily living; having a definable condition assumed to be disabling by its very nature, such as polio, schizophrenia or deafness; using assistive devices such as hearing aids or crutches; or identifying oneself as a person with a disability. In some of these definitions, there is a large amount of overlap with medical diagnoses, while in others there is not. In fact, the legal definition, from the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, includes people who are regarded by others as having a disability, whether or not they think of themselves as having a disability, or whether or not there is any underlying impairment: i.e. there may be a mistaken attribution of disability, or a former impairment.² That broad definition was intended to cover situations of discrimination based on perception of disability. All of the definitions used run into problems of ambiguity, such as whether a person with breast cancer, a person who has a facial

scar, or one who is obese are people who have disabilities. Because of these multiple definitions, it is not always possible to identify with precision who the constituency for this committee is. However, for the committee's practical issues, the definition is easier to state: It is those people for whom the annual meeting poses an accessibility problem, assumed to be related to an underlying somatic or mental condition, which may require an accommodation to be made in order for the person to be able to participate in the meetings.

The ASA does not have any measurement of how many of its members have disabilities under any of the above definitions.³ Because of the variety of definitions, it is difficult in any case to try to conduct a survey that would produce such data. Thus, unlike reports by committees such as that on the status of women, we cannot begin this report by indicating for how many members it might be relevant. Additionally, because disability is a status into and out of which people can move [more than once, it is more correct to think of the Association as having many members who are, in the phrase used by the Disability Rights Movement, "Temporarily Able Bodied." That is, many members of the association may develop disabilities as they age, and the aging of the professoriate in general, as well as the aging of the sociological community, are directly relevant to this report

Patterns of Annual Meeting Accessibility Issues

The early years of the committee occurred before the Americans with Disabilities Act was passed. At that time, only some hotels and convention centers [those in states which had passed accessibility laws] had a legal responsibility to be accessible. Nor did the ASA have anything but a moral responsibility to be accessible. However, because of the urging of several prominent sociologists who had disabilities, ASA did become committed to solving accessibility

² It is perhaps worth noting that the legal definition does include AIDS but does not include drug addiction, although it includes recovering addicts.

³ One estimate, from the National Survey of Post Secondary Education (Department of Education, 1999, from an unsubstantiated email received by this author) is that professors with disabilities constitute 3.6%

problems when possible⁴. Rather, the decision was made to provide accessibility [especially sign language interpreters] for those sessions for which requests were made in advance.

In the early years, accessibility requests, which were added to ASA annual meeting registration in the early 1980s, ranged from having vibrating alarms, captioned TV's or TDD's in rooms to having taped programs to providing sign language interpreters. Many of these types of accessibility are no longer ASA's responsibility but are the responsibility of the hotels—the hotels are now responsible, under the ADA, for making their guest rooms accessible for people with disabilities.

In the early years of the committee, most of the discussion revolved around the meetings and their problems⁵. This discussion resulted in presentation guidelines, originally published in the above cited article by Emerton, as well as an accessibility guide by which to evaluate hotels, written by Barbara Altman⁶. This guide was, and is, used as a checklist with the hotel in advance of the meeting. Further, the Meetings Services staff meet with the hotel at the end of the convention and provide feedback on all aspects of the meeting, including the adequacy of promised services to PWD.

Other discussions by the committee addressed issues of scholarship, teaching, and other disciplinary issues. These resulted in a series of articles in *Footnotes* in 1997, 1998 and 2000 [See Appendix 3].

of the academy. There is no reason to think that Sociology differs, but, because of the definitional problem, there is also no reason to think that this number is accurate.

⁴ ASA did not, however, follow some other associations in attempting to make the entire meeting accessible to all by providing sign language interpreters for all sessions and even social events. It also did not decide to provide an interpreter for a person, so that people needing interpreters would not have to decide in advance which sessions they would attend and would also have the flexibility to change. This sessions in the middle, as hearing people do. This decision was largely an “economy of scale” issue – few people needing the services and a great many sessions.

⁵ Despite ASA's efforts, for many years there did continue to be unanticipated accessibility problems. While ASA does return to some hotels (e.g., San Francisco and Washington, DC Hiltons), most of the time the convention is in a new property. Hotels have many design features which pose difficulties for PWD, e.g., escalators descending into a lobby at an angle...such that blind persons walking in the lobby do not know the structure is there until they hit their head.

⁶ This guide has been shared with aligned associations to help with their conference planning.

At this time, the accessibility functions have become incorporated into the program planning. Accessibility is an item in the annual meeting budget [\$2500 for the 2004 meeting.] Many accessibility requests can now be satisfied for free or at very low cost. These include providing someone to assist a member in getting to a specific room, information about services available, having a podium that is wheelchair accessible, or needing to have a personal assistant [PA] booked in an adjacent room. Some of the accessibility requests cost much less than they used to, as technology has improved. For example, the program can be produced in Braille for a fraction of the time or cost that used to be associated with producing an audio version of the program. It is now also possible now to provide non-Braille users an electronic version of the program to be used with enlarging screen reading software. However, with advances in technology have also come requests for some extremely expensive assistance. At the 2004 meeting there was a request for real time captioning for several sessions, which is not expensive technologically but is quite expensive in personnel. This, in addition to other requests, pushed the expenses \$4000 over budget⁷.

There has been no record kept of how many requests have been received for each meeting, let alone how much they cost or if any could not be fulfilled. In speaking with Meeting Services staff, they report that almost all requests have been able to be filled, and that, in most years, the costs were under \$2500. The staff report that the number of requests has leveled off and possibly declined, because many requests are made directly to the hotel.

The committee has seen a vast improvement in the accessibility of the annual meetings since its inception. At the most recent meeting, the captioning of the Presidential Address marked a new height in accessibility, for which the Committee commends the Association.

⁷ The budget is prepared in October and passed in January/February of the year of the annual meeting. Actual requests for special services come in from April through August. The Meetings Services department certainly looks at past trends in preparing a budget, but the presence or absence of a costly request can skew even the best budget prediction.

Remaining unresolved problems tend to be those associated with the size of the hotels in which meetings are held, a problem that is likely to increase as the size of the meetings and the membership continues to grow. The size of the hotels tends to create accessibility problems for people with reduced mobility capabilities. Problems with hotel signage, again sometimes related to the sizes of the hotels, have continued to present problems for attendees [both with and without disabilities]. In fact, many members with temporary disabilities or special needs (e.g., broken leg, advance pregnancy) ask for rooms close to the elevator, etc., especially in the cavernous hotels. Recently ASA has rented several scooters that are available in the ASA office on site to assist members with “transit” through the hotel to meeting rooms.

The ASA added a room in the main convention hotel called the Comfort Zone, which sought to assist members who needed a place to sit and relax. Some members are overwhelmed by the busy-ness of the convention. Some members do not stay in the convention hotel and simply need a quiet place to regroup if they cannot easily return to their sleeping room. ASA wanted to offer an alternative respite to the lobby or the restaurant/bar.

Finally, a major problem has continued to be accessibility problems associated with paper presentation styles. People who read densely worded documents quickly tend to be very difficult for interpreters or captioners to follow. Presentations given by people who use overheads but do not provide copies and/or do not describe the contents are inaccessible to people with vision limitations. Presentations by people who pass out handouts but do not use overheads are less accessible to people using interpreters or captioners, because they cannot read the captions or interpretation at the same time that they read the handout.

A History of Sociological Scholarship on Disability⁸

The committee has also taken on a scholarly charge: Identifying sociological scholarship on disability as well as barriers to such scholarship within Sociology. In this review,

⁸Adapted from Altman and Barnartt (2000).

we are concerned with scholarship about the social situation of PWD and other aspects of disability in society, and we are not making distinctions about who produced the scholarship.⁹ In this report we present an initial attempt to identify places in which disability scholarship does and does not show up in official ASA activities, including in the annual meeting. We have not yet done a formal review of ASA journals' publications with regard to disability, although a review of the literature shows very little representation in those journals.

Disability is not universally recognized as a phenomenon, which is socially defined, which has enormous social consequences for individuals, and which has a huge impact on societies. This is true whether you are discussing professional who work with PWD or the view of many cultures, including our own. However, within the sociological context there has been some work does which does recognize these points, and the purpose here is to review the older work and to suggest some opportunities for future work.

Conceptualizations and Definitions

One of the areas of disagreement in studies of disability is what, in fact, constitutes a disability. Terminology originally suggested by Nagi (1965), as the result of an ASA funded conference and publication of the proceedings (Sussman 1965), served as a basis for two reports issued by the Institute of Medicine (IOM) of the National Academy of Sciences, (Pope & Tarlov 1991; Brandt & Pope 1997). In the more recent of these, the IOM panel strongly endorsed the use of a conceptualization of disability, which incorporates environmental factors as a primary element in creating disability. It recommended shifting the focus of the definition of disability from the individual and the impairment to the interaction between impairment and environment. This conceptualization challenged the medical model of disability, which sees disability as being primarily a medical condition in need of remediation. In this view, the cultural

⁹ There are arenas, primarily within disability studies, in which scholarship produced by a person who does not identify as having a disability will have less credibility than will a scholarship produced by a person who does so identify (Monaghan, 1998).

category of 'disabled' is socially, rather than medically, constructed (Higgins 1992), in part by cultural definitions and in part by the demands and limitations of the social and physical environments. Based upon this conception of disability, the IOM report distinguished between a pathology, an impairment, a functional limitation, a potentially disabling condition, and a disability (Brandt and Pope 1997). Although Nagi and his colleagues had made a significant contribution to the Sociology of Disability as early as 1965, very little was done to follow up on it until the IOM reports in the 1990's.

Limited by the medical model that equates disability with dependency, predisposing the need for welfare and other forms of social insurance, much of the sociological and social psychological research that was produced between the late 1960s and early 1980s was focused on individuals and their adjustment to a dependent status. Scholars were primarily concerned about adjustment to, and coping with, the impairment (Kelman, Miller and Lowenthal 1964; Cohn 1970; Ludwig and Collette 1970; Saffilos-Rothchild 1970; Ben-Sira 1981, 1983) morale and motivation in rehabilitations settings (Litman 1966; Starkey 1968; Brown and Rawlinson 1976); and levels of social support in the family and community (New et al. 1968; Tolsdorf 1976; Peterson 1979; Smith 1979, 1981). [Only recently has a sociologist (Darling 2000) suggested that family relationships could be examined without assuming that disability is a completely negative component of the family structure.] Another area that received a lot of attention at this time was the study of the attitudes of peers, employers and others toward persons with disabilities (Siller and Chipman 1964; Yuker, 1960, 1966; Richardson and Royce 1968; Shears & Jensema 1969; Richardson 1970, 1971; Schroedel 1978; Altman 1981).

At the same time that sociologists were primarily concerned with the individual with a disability, economists were examining national issues associated with disability benefits and employment, even though many of the issues they examined were sociological as well as economic. Early work focused on the evaluation of the structures and functions of disability

programs, both worker's compensation and social security (Berkowitz, Johnson, and Murphy 1971; Berkowitz 1973; Berkowitz, Burton, and Vroman 1979). Other research focused on the economic costs of vocational rehabilitation or of particular types of disability such as mental retardation (Conley 1965, 1973), analyses of the Social Security system and other public programs directed at persons with disabilities (O'Neill 1976; Worrall 1978; Johnson 1979; Meer 1979; Peck 1983) and the effects of disability on the labor supply (Swisher 1973; Scheffler and Iden 1974; Yelin 1980; Slade 1984). Most of these studies focused on work status and the receipt of benefits such as SSDI. The questions could as well have been posed by sociologists as economists.

The passage of the Rehabilitation Act of 1973, which used a civil rights perspective in its view of disability, ushered in movement by sociologists and others toward a minority perspective toward disability (Gliedman and Roth 1980; Stroman 1982; Hahn 1983, 1985; Christiansen and Barnartt 1987). These authors raised questions about the medical model of disability, with its emphasis on the individual and the biophysiological components of disability, and attempted to shift the focus of attention to the physical and social environment (DeJong 1979; Hahn 1982).

In the United Kingdom, theorists were more explicitly trying to incorporate social and environmental effects into a conceptual model of disability. This work took form through the development of a social model of disability that sought to sever the relationship to medicine by ignoring the individual functional limitations and focusing totally on what was interpreted as an oppressive environment and social structure (Abberley 1987; Oliver 1990; and later Shakespeare 1994).

Early signs of a broader perspective in the American sociological literature could be seen in Bogdan and Biklen's examination of handicapism (1977), Albrecht and Levy's framing of disability as a social problem (1981), Altman's critique of attitude literature (1981) and work by Zola on many social aspects of disability (1982a, 1982b, 1983), and Scotch's examination of aspects of disability movements (1984, 1988, 1989)..

Only since the 1990's has there been a substantial amount of research which uses sociological theories and perspectives. There has been research by sociologists on the demography and epidemiology of disability (Verbrugge 1990; LaPlante 1991a, 1991b, 1993; Ing & Tewey 1994; Kaye et al. 1996; LaPlante & Carlson 1996), theory and measurement related to disability (Shakespeare 1994; Altman 2002) and social movements in deaf and disability communities (Christiansen and Barnartt, 1995; Barnartt and Scotch 2001; Groch, 1994; Rose and Kiger, 1995).

Sociological Possibilities in Studying Disability

Disability has most commonly been discussed within the context of medical sociology, although, ironically, it has not even often been included 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 that needs to be cured or rehabilitated.

In addition, the discipline as a whole has considered disability as a phenomenon that can be analyzed only from a medical sociology point of view and has rarely been aware that many of the core concepts and theories within sociology also apply to disability. For example, many deaf people feel strongly that there is a deaf culture, and many people with other types of impairments feel that there is a disability culture (Barnartt 1996). Are these true cultures? Or are they subcultures or countercultures? These are questions that could sustain a cultural sociology investigation.

Sociologists could also usefully apply the concepts of role and status to disability. The role of 'person with a disability' is a role; but its similarities to, and differences from, other roles have not yet been fully delineated, nor has its influence on other roles such as wife and mother been fully explored. One older paper did consider the question of disability and role (Thomas 1966), but both its terminology and its conceptualization of disability are dated. Sociologists have not considered the question of whether or not disability is a master status, and, if so, how it compares to other master statuses such as race and gender, although Barnartt (2001) made a start at such analyses.

Other specialty areas in sociology including the areas of race, ethnicity, or minority relations, demography, and social psychology could usefully examine disability to a greater extent than has been accomplished to date. Comparisons of traditionally defined racial, ethnic, and minority groups with people with disabilities on issues such as group ties, cultural transmission, power relationships, and prejudice and discrimination might be fruitful avenues of exploration; only laws have been compared systematically (Barnartt and Seelman, 1988.)

Sociologists considering the topic of socialization could discuss the effects of having a disability on early socialization among children, including its affect on parent-child interaction and ways in which parents and society create dependency in children with disabilities. The effects of adult onset disabilities as an example of secondary socialization or examination of disabilities through the life cycle, especially the relationship between late-onset disabilities and aging, would be useful additions to the literature.

Demographic and epidemiological issues have been addressed to some extent (Nagi 1976; Verbrugge et al, 1991; McNeil 1993; LaPlante 1996) but there is room for further understanding about distributions of all disabilities. Particular disabilities, as well as the incidence or prevalence of disabilities by age, by gender, and by race, in the US and in other countries. Demographers have not yet researched traditional demographic variables such as fertility, life cycle transitions and morbidity and mortality rates for persons with impairments.

Sociologists who specialize in deviance have been, along with medical sociologists, those most likely to consider disability, since they have considered it to provide prime examples of stigma-producing conditions (Goffman 1963; Elliott et al 1982) or of how the labeling process works (Haber and Smith 1971). Some work has been done on the ways in which definitions of disability are socially created (Higgins 1992; Goode, 1994) or sustained, through interaction (Gerschick, 1988) or otherwise.

One area in sociology that has paid almost no attention to disability, however, is criminology. Criminologists have paid attention to victimization but not into the experiences of people with impairments as they proceed through the criminal justice system, and the impact of criminal actions as causal factors in the production of disability among some population sub-groups would be natural extensions of criminology perspectives into the disability arena.

Current Social Changes are Creating New Opportunities for Sociological Studies of Disability

Many aspects of disability are changing in ways that open up new research possibilities for sociologists. Although addressing some of these situations will require applied research; basic theoretical and empirical work in sociology will also be necessary. Some examples of the current changes taking place and researchable issues associated with them are as follows:

1. Increasing population size, accompanied by increasing longevity, have resulted from the increased ability of medicine to prolong life in persons with serious diseases and injuries. This has also led to increases in the actual numbers of persons with a wide range of potentially disabling conditions. Increased pollution, violence, military actions, and continuing socioeconomic inequality, as well as advances in medical technology, contribute to high levels of impairment. It is likely that the widely held belief that disability is a "one in ten" phenomenon will have to be re-examined both nationally and internationally. Demographers will want to know if the numbers of persons with disabilities is increasing more in the developed world than in the less developed world.

2. Social movements among persons with disabilities have been increasing in recent years in many parts of the world. Some have built on the disease- or condition-specific groups which have lobbied for resources for many decades. Others built on parent groups which were active on behalf of disabled children in the 40s and 50s or on successful civil rights activity on behalf of blacks and women in the United States and in other western democracies. These movements are challenging the status quo, particularly assumptions about the dependent nature of disability. Demands made by these movements for inclusion, integration, and participation come into direct conflict with expensive social structures which some societies have put in place to support and maintain persons with disabilities outside the workplace, and by default, outside other societal arenas as well. However, the social movements have also created tensions among subgroups of the population identified with disabilities. Social integration and participation for some is limited only by their physical access to the workplace or the voting booth. For others, with more severe impairments or limitations, full participation is simply not possible in society as it is currently structured, but social movement demands do not recognize this (Ferguson 1987).

Sociological studies of social movements have by and large ignored the social movements occurring in the disability community. Even within anthologies about various social movements, such as Goldberg's (1991), the disability movement does not show up. The prime exception is one article in Jo Freeman's *Social Movements of the 60's and 70's*, which considers one 1977 protest (Freeman 1983). There actually have been several social movements, including a disability rights movement, an independent living movement, a movement for deaf rights, a psychiatric survivor's movement, and a parent's movement. These sometimes coalesce and other times focus on issues specific to their own movements (Barnartt and Scotch 2001). Examination of the intricacies of social movements in this community would do much to test the theories and inform the social movement literature that already exists.

3. Demands for inclusion, and needs for planning the distribution of scarce resources, require that measures of population size need to be available. This has created very real issues about the conceptualization of disability and its subsequent operationalization and measurement.

While there is a growing consensus on the theoretical conceptualization of disability, translation of those concepts into useful measurement tools is still in its infancy. Valid and reliable measurement instrument will require much thought and testing. Numerous other problems associated with data collection (Foster 1996; Mathiowetz 2002) and other aspects of research present issues to be considered before accurate estimates of this population can be obtained.

4. Both physical and social environments are pivotal issues in understanding all aspects of disability. Some prior research has studied the roles which physical barriers play in preventing access to the natural and built environments. Other research has examined the role social barriers, particularly discrimination, play in affecting integration, access to employment and other important roles. However, both social and physical environments play a key role in causing impairments and functional limitations. Violence that produces traumatic injury and exposure to toxic chemicals, which can result in cancer or mental deterioration, represent social and physical environmental causes of impairments. Additionally, physical structural and social barriers contribute to the level of disability experienced following the occurrence of impairment. Social and physical environments need to be examined as much for the risk factors for impairments as for their role in turning functional limitations into disabilities.

5. Many factors contribute to the personal experience of disability and the development of a disability identity. Gender, age at onset, visibility or non-visibility, and type of impairment are just a few of the factors which lead to the variety of experience that individuals living with their impairments have. The importance of identity to the person with a disability, and the impact of that identity on psychological and social development, can vary considerably among persons with different types of impairments and from that of persons without impairments or disabilities. Identity can become an essential component for political activism, but it serves other functions

as well. The role of identities in impeding or facilitating integration and inclusion is not known and is a ripe area for research.

6. Rapidly advancing technological is producing assistive devices are changing the lives of persons with disabilities. Factors that improve access to such devices are not well known, nor is the extent of the impact the devices have on the social roles, integration and participation of those who use them. The importance of government programs and insurance in providing these technologies is not well known, and even the characteristics of markets needed to stimulate the growth of assistive technology development, production and availability are yet to be studied. Conceptualizing the role of commerce in dismantling the “dependency” system would contribute to the reassessment of social programs for persons with disabilities.

7. There are many ethical and legal issues that affect persons with disabilities as well as cultural attitudes toward persons with disabilities. Life and death decisions, genetic research, and transplantation all pose serious questions for the value systems of societies. The relationship of the legalization of assisted suicide to the experiences of persons has not been explored, nor do we know if such changes in laws might pave the way for a return to the type of eugenics orientation, which was seen in decision-making in the 19th and 20th centuries. We are currently facing serious ethical decisions related to assisted suicide, cloning and similar questions. Decisions in other countries, such as the Netherlands, to legalize euthanasia need to be observed closely for adverse effects. Additionally, in the US, interpretations of current law are of concern. Recent Supreme Court decisions appear to be eroding rights of persons with disabilities. These ethical and legal issues all provide a rich set of issues that should be of concern to sociologists.

8. Disability occurs in every known culture. Yet definitions, treatments, and experiences of living with a disability are not necessarily the same in any two cultures or even in subcultures within a larger society. Examination of cultural perspectives would contribute to understanding the nature of social barriers and how they are formed. We can learn from other perspectives what

can improve the lives of persons with disabilities as well as what practices to avoid. Cross cultural investigations of economic circumstances, political involvement and value systems would give insights into the subtleties underlying the relationship between culture and disability.

9. Most conceptualization of and research on the issues surrounding disability focus on the transition of an individual from a non-disabled to a disabled status. Improvements in assistive technology, prostheses, implants and pharmaceuticals now offer the possibility of complete or almost complete recovery from some impairments. We know little about the impact of that improvement on the person's access to various roles, their identity, behavior or attitudes.

10. Research in the area of family functioning when there has been a family member with a disability is an area in which some sociologists have worked, but their research has focused almost exclusively on the dysfunctional elements. For example, there has been much written about care giving to persons with disabilities, but little has been done on care-receiving or other family interactions. Family activity and adaptation, distribution of roles, family formation, family integration or disintegration, and the nature of extended family involvement for persons with disabilities are among those areas that have yet to be studied by sociologists.

11. Stratification is another area in which disability has received little attention within sociology. Alexander (1976) suggested the use of a status attainment model, similar to that used in studying the socio-economic status of blacks and women, but only a little has been done in this area (Barnartt 1986; Kirchner and Petersen, 1985). Mostly through the efforts of economists, we know that people with disabilities tend to earn less than people without (Burkhauser and Daly 1994; Johnson and Lambrinos 1985; Baldwin and Johnson 1995). We also know that the incidence of disability varies inversely with social class position, although the causal direction is unclear. The effects of disability appear to be more serious than those associated with race but follow gender patterns of occupational distribution and income (Barnartt 1997; Barnartt and Altman 1997). Many questions remain about the amount of impact disability has on socio-economic variables and the mechanisms by which these impacts operate

12. There are many issues related to health care for people with disabilities which are likely to be of interest those studying the health care system. Questions such as whether people with disabilities use more health care than people without disabilities, whether this is true of only a subgroup, or whether it is not true have only begun to be investigated (Altman & Cornelius 1992). Many aspects of the delivery of care to people with disabilities, for example the use of managed care programs, are relevant areas for social science study. Examinations of disability and rehabilitations organizations, such as that done by Albrecht (1992) and Scott (1989), as well of the professionals who work with PWD, should be of interest to sociologists.

13. Finally, a new development within the disability community offers an intriguing laboratory for the study of identity formation processes: the acceptance of disability as a positive, and even valued, rather than negative and devalued, characteristic. This has been documented recently in media discussions of the choice made by deaf couples to produce a deaf child (Mundy 2002) and the rejection by autistic children of any negative connotations in the label 'autistic' (Harmon 2004).

Conclusion

It is not the case that sociologists have ignored disability, as the citations included here show. However, there has been little in the way of systematic work, and there has not been recognition of sociological studies of disability as being part of the body of work that might be known as mainstream sociology. Much of the work of sociologists in this field has found limited exposure within sociological or social science venues. Journals focused specifically on social science perspectives on disability did not appear until the late 80's or early 90's. Prior to the inception of these journals, sociological examinations of disability issues found outlets mostly in medical journals; in journals related to specific disabilities, such as the *American Annals of the Deaf*, the *Journal of Visual Impairment and Blindness*, or the *American Journal of Mental Retardation*; or in books or edited volumes (Davis 1963; Albrecht 1976; Croog & Levine 1977). Very little of the work done in this area has been published in sociological journals, or, if it has, it

has been published in minor journals. We hope that this will change. In this review we have begun to suggest some areas of the disability experience which we feel would be amenable to sociological theorizing and research

Overall recommendations:

1. **ASA should continue to support this committee.** There are a number of reasons for this:
 - ASA meetings are not perfectly accessible, so monitoring related to the charge originally given to the committee needs to be continued. Specifically, ASA, perhaps through the committee, should publicize on a continual basis the need for accessibility in paper presentations at the annual meeting. This could take the form of including a handout prepared by the committee in the packet sent to those whose papers have been accepted. Alternatively, the information could be included on the association website. The paper acceptance package would then include a statement which presenters must sign and return to the ASA indicating that they will abide by those guidelines. [We strongly feel that following the presentation guidelines would increase the accessibility of presentations for all attendees, not just those with disabilities.] Additionally, we recommend that accessibility guidelines, written by committee members in the 1990's, be updated in time for use for the 2006 meeting
 - The data collected for this report just begin to scratch the surface of what we know about the status of disability in sociology and in society. Missing include examination of: 1) actual teaching patterns, as opposed to textbooks 2) publication patterns 3) problems encountered by PWD themselves as faculty members, staff members in sociology departments, or graduate or undergraduate students.
 - The number of faculty members with disabilities can also be expected to increase, unless people begin to retire before disability hits. The number of students with disabilities is also expected to increase (Lyons, 2004).

2. ASA should support several types of data collection, including

- Data which tracks requests made for accommodations for the annual meeting, including both those which cost money and those which don't, as well as data on the costs of those accommodations
- data on faculty needing accommodations in their departments or universities, to be collected from the department survey
- data on students needing accommodations
- data on difficulties experienced by graduate students and younger faculty needing accommodations

3. The ASA should begin to deal with the inequities in ASA programs and activities which have been illuminated here.

- The ASA, in conjunction with this committee, should set up an ad hoc committee to explore the possibility of setting up a program similar to the Minority Fellowship Program for students with disabilities. Funding should be sought through NIDRR [National Institute on Disability and Rehabilitation Research], perhaps in conjunction with COSSA groups
- Editors of the ASA sponsored journals should be encouraged to consider how the proportions of articles received that are related to disability and the acceptance rates for such articles compare to other status areas such as race or gender
- to have representation from sociologists engaged in disability scholarship
- to include reviewers who are sociologists engaged in disability scholarship
- This committee should set up a way to monitor the inclusion of sociological scholarship on disability in ASA journals.
- ASA should advertise its programs in places that attract the attention of sociologically-minded scholars of disability, including in Disability Studies Quarterly, Research in Social Science and Disability, Journal of Disability Policy Studies, and at SDS meetings.

- In light of the dispersion of disability scholarship throughout the programs, we recommend that the 'status committee' be given an additional session earmarked as a co-sponsored session so that the ASA can begin to highlight disability scholarship as it applied to some of the 'traditional' sub fields of the discipline. (Possible co-sponsored sessions could be on race and ethnicity, aging, symbolic interaction.)
- As an attempt to highlight disability scholarship, the ASA explore adding the category of disability to the *Sociological Abstracts*.
- That the committee itself be charged with attempting to increase both the visibility of disability in ASA and with increasing the numbers of people who identify themselves as having an interest in disability within Sociology.
- The committee should use the information from the preliminary program to contact the presenters and interest them in other disability activities, including the possible formation of a disability section.
- That a pedagogy session be included in the 2006 annual meeting that specifically focuses on including disability in Introduction to Sociology classes despite the textbook situation, and that the publisher's reps be invited to that session
- That the editor of *Teaching Sociology* consider the issue of including disability in introductory sociology classes, despite the lack of mention in textbooks, in an article commissioned by the editors of the journal or one produced by this committee.
- That a survey similar to that described in Appendix 2 be included, with additional questions about graduate students and staff members, in the annual survey of departments, at least once every 5 years.
- That the annual Chair's Workshop include a session about the aging of the professoriate and the implications for disability accommodations—including the many low and no cost solutions.

Appendix 1

Indicators of the Status of Disability in the ASA and in Sociology Departments

This appendix presents the results of analyses of several types of data, which were collected about ASA activities and programs, as well as aspects of department and members. The first section deals with official ASA programs.

Table 1 shows that there have been very few of ASA's official activities that have directly focused on disability-related topics. There are no Rose Monographs or Teaching Enhancement Fund grants and only one Fund for the Advancement of the Discipline (FAD) grant and one Spivack Community Action Research Initiative (CARI) grant that deal with disability-related topics. There are several FAD and CARI grants which might deal with disability, since they address the "boundary" issues such as breast cancer, AIDS, and obesity, but it is not clear from their titles. There is one volume in the Teaching Resources Center that is on teaching disability-related topics within the sociology curriculum—but that is in its second edition (Schlesinger and Taub, 2004). There have been a few FAD grants dealing with disability, but they have been widely spaced over the years. There appear to be no Spivack Congressional Fellows whose interests were in disability, based upon examination of either the committee or the representative or senator to whom the person was attached. Overall, there is a very small representation of disability in these programs administered by the ASA.

It is not clear whether the lack of representation of disability related topics is because people working in those areas have not applied, or whether they have been turned down. If the lack of representation is by choice, there is nothing that the ASA can do. If the lack of representation occurs because the programs are not well publicized to people who do disability scholarship within a sociological rubric but outside of the ASA, this can and should be addressed through better publicizing of these opportunities.

Additionally, it might be noted that one program which has never included people with disabilities, because it is prohibited from doing so, is the Minority Fellows Program. Despite the argument in the literature [mentioned in Appendix 2] that people with disabilities are a minority group, that argument has not been accepted by NIMH, so people with disabilities are prohibited from applying for support from this program.

Table 2 shows that the presence of disability in graduate programs is modest. The only graduate department which has a program in disability is not even located in the US [the University of Leeds], although 63 departments do indicate that they include disability as one of their specialty areas.

For a number of years, there was one Sociology program, at Brandeis University, that produced a number of people with PhDs whose primary interest was in disability. The late Irving Zola, an original member of this committee, was a key scholar and advocate at Brandeis. However, since his death no department of sociology has taken its place. While there is one Ph-granting Department of Disability Studies, at the University of Illinois at Chicago which includes some sociologists on its faculty and which has students with sociological interests, this is not likely to produce scholars with strong disciplinary loyalty to sociology.

Expressed interest in disability is also low, comprising 117 people, out of 13,000 members, who indicate it as one of their areas of interest for the membership directory. These numbers contradict the extensive amount of sociological research about disability which has been

conducted and published throughout the years. Clearly there is a difference between the reality and the perception. Is disability a low status specialty to which people don't want to admit because they will be negatively evaluated? Is it an area that attracted more attention in the past than it does in the present?

Table 3 presents some numbers about papers at the annual meeting, relating to disability, in 2003 and 2004. Since about 1990, the annual meeting program has included at least one session entitled "Disability and social Life." In some years there are additional topical, teaching, or poster sessions, as well as sessions as the Chair's workshop, which deal with disability explicitly.

However, an examination of the programs for the 2003 and 2004 annual meetings shows that there are many papers explicitly relating to disability that are scattered throughout the program but are not listed in the index under 'disability.' These papers included the word 'disability', or words relating to one or more types of disability [such as "impaired vision"] in the title, or they were primarily related to disability laws or policies. In both years there were more papers which were not listed under the disability heading than that were. The sessions in which these papers appeared included aging, medical, social policy, ethnomethodology, parenthood, mental health, sociology of education, collective behavior, and population, among others.

Additionally, there are a number of papers that are possibly related to disability, in numbers at least as large as those in the previous two categories. These included papers on topics such as AIDS, mental health, obesity, breast cancer, rheumatoid arthritis, and hermaphroditism. These papers were presented in sessions related to childhood and family, AIDS, science and technology, and theory, in addition to those mentioned above.

These results, which more than anything else highlight an indexing problem, have the effect of keeping the sociological study of disability hidden from all except the most determined of seekers. The lack of exposure of the topic on the annual meeting program also adds to the perception that disability is not a sociological topic, and it hides the extent to which disability related topics are being investigated under many of the topics and sections included in the program. There are many more papers which are related to disability than one might think from looking at the categorization listing. Thus this listing actually underestimates the amount of interest in disability related topics that exists in the ASA—and also misrepresents it to interested people.

Table 4 shows that there is very little discussion about disability in many of the textbooks our students encounter. Of 56 introductory sociology textbooks surveyed, only 5 listed disability in the index. While we cannot equate an index listing with either quantity or quality of discussion of issues related to disability, it is clear that it is a subject that is not mentioned in most intro textbooks.

Of 24 social problems books surveyed, nine [38%] listed disability in the index. This could be seen to be an improvement over intro textbooks, except that considering disability to be a problem is not neutral and does not really add to a sociological understanding of the subject.

This is a problem for which there is not an easy fix. The ASA does not control the content of textbooks. However, it affects that content indirectly by the topics that are given exposure at the annual meeting and in its journals. If disability were given more exposure in meetings and journals, inclusion in textbooks would be likely to follow. Thus, the ASA might begin to make some inroads into the problem highlighted here, indirectly, by its actions in these other venues.

Table 1: Numbers of Disability-related topics in ASA activities and programs¹⁰

	Number related to disability
Rose Monograph Series Books	0
Sydney S. Spivack Community Action Research Initiative project grants directly relevant	1
Sydney S. Spivack Community Action Research Initiative project grants indirectly relevant ¹¹	9
Teaching Enhancement Fund grants ¹²	0
Monographs in the Teaching Sociology Series	1
Fund for the Advancement of the Discipline Grants ¹³ directly relevant	1
Fund for the Advancement of the Discipline Grants indirectly relevant ¹⁴	6
The Sydney S. Spivack Program in Applied Social Research and Social Policy Congressional Fellows ¹⁵	0

Table 2: Indicators of the Presence of Disability within Sociology [programs or people]

	Number related to disability
Graduate programs which have a program	1 ¹⁶
Graduate departments which have a specialty ¹⁷	63
Listed an area of interest in the ASA membership directory	117

¹⁰ Results are from analyses of the titles. Data were provided by the ASA Executive Office.

¹¹ Includes topics such as breast cancer, AIDS and obesity

¹² N = 30, from 1995 - 2004

¹³ Out of 236 awarded since 1986.

¹⁴ Includes topics such as breast cancer, AIDS and obesity

¹⁵ N = 12, from 1992 – 2005.

¹⁶ Not in the US but listed in the *Guide to Graduate Programs*

¹⁷ Department has several faculty, not adjuncts, with a specialization in that area, several courses are routinely offered, and it is an exam area

Table 3: Numbers of Disability-Related Papers Presented at the 2003 and 2004 Annual Meetings:

Year	Listed under Disability in index and/or included in "Disability and Social Life" sessions	Related to disability but not listed in index or not included in a section related to disability	Possibly related to disability
2003	4	15	18
2004	13	18	12

Table 4: Inclusion of Disability- related Topics in Sociology textbooks¹⁸

	Index items related to disability
Introductory Sociology Textbooks [N = 56] ¹⁹	5
Disadvantaged groups	2
Disability insurance	1
Disability rights movement	1
Introductory Sociology Readers [N = 3] [will add to this]	1
Social Problems textbooks ²⁰ [N = 24]	9
Handicap'	2
Movement	1

¹⁸ The most recent edition was examined when there were several editions.

¹⁹ From 1954 to 2005.

²⁰ From 1962 to 2005.

Appendix 2

Department Chairs' Experiences with Disability Accommodations: Results of a Survey

This appendix presents the results from a survey sent via Survey Monkey to all department affiliate chairs in November 2004. Of the approximately 330 affiliates, 118 chairs responded. Department size ranges from 3 – 42 full time faculty members, with the median being 11. The basic question asked if any faculty member in their department had asked for a disability-related accommodation. About one third of the respondents indicated that at least one faculty member had. Of those, the vast majority (over 80%) were able to satisfy the request(s). Another 13% were able to satisfy some but not all of the requests. Only about 5% were not able to satisfy the requests.

Table 2 provides more detail about the faculty requests for accommodation. It shows that the most common of the 61 requests coded [up to three were coded from each respondent] was a request for a changed classroom location, requested in over one third of the cases. The next most common request was for specialized equipment or software, which was made in a little less than one third of the cases. Less commonly requested accommodations included a change of office location, which comprised 13% of the requests and building modification, procedural change, captioning or interpreter, assistive personnel, and job restructuring, each of which represents less than 7% (or 4) of the requests.

It is worth noting that the most common request was a no-cost accommodation. The second most common was a request that is likely to incur some cost, but often that cost was not actually incurred by the department. In many cases, those requests were satisfied by the university's office for students with disabilities. Overall, 22% of the chairs indicated that this office helped them satisfy the request for accommodation, and another 22% indicated that university money was used to satisfy the accommodation. In only 11% of the cases was departmental money used to satisfy the request.

Table 1 also shows results of several other questions asked on the survey. It shows that the majority of department chairs (over 75%) are not anticipating receiving such request from faculty member in the near future. (This is despite the fact that the comments by respondents indicated that frequently the accommodation was either a temporary one or was made by a faculty member confronting an aging related problem.) The table also shows that most departments (over 85%) have, by now, received requests for accommodations by students. This was only problematic in a small number of cases (less than 17%).

These results suggest several trends, despite the small numbers of respondents involved. One is it is not rare for a department to get a request for a disability-related accommodation. While some of those requests involve temporarily disabling conditions, such as knee surgery, some do not. Departments do seem to be able to handle these requests adequately, often with assistance from their office of students with disabilities—which has clearly become the locus of disability-related information on campus, whether the need comes from students or not.

Table 1: Percentage Distributions of Requests for Accommodations by Faculty and Students

Question:	Questionnaire answers (blank if doesn't apply)			
	Yes	Yes, some	No	DK
Did any faculty member request accommodation? N = 118	33.9%		66.1%	
If asked for accommodation, were able to provide? N = 39	82.1%	12.8	5.1%	
Do you expect faculty members to need accommodations w/in 5 years? N = 113	23.0%		77.0%	
Students asked for accommodations from faculty? N = 118	84.7%		7.6%	7.6
Faculty have had problems satisfying students' needs for accommodations? N = 101	16.8%		78.2	5.0

Table 2: Percentage Distributions of Types of Accommodations Provided, and Reasons Why Respondents Could or Could Not Satisfy Them

Type of accommodation	Percent (N = 61) ²¹
Classroom location(s) changed	36.1
Specialized equipment or software	27.9
Office location changed	13.1
Schedule change	6.6%
Building modification	4.9
Procedural change	1.6
Captioning or interpreter	3.2
Assistive personnel	4.9
Job restructuring	1.6
Why respondents could provide requested accommodation	Percent (N = 18)
College/university money	22.2%
Department money	11.1
Office for students with Disabilities	22.2
University policies demanded it	11.1
It is morally or legally right	5.6
"it was possible"	27.8
Why respondents could not provide requested accommodation	Percent (N = 5)
Lack of money	20.0
Incorrect procedure	20.0
Structural impossibility	40.0
University policies prevented it	20.0

²¹ Up to three were coded

Copy of Survey Sent to Chairs

1. Has any faculty or staff member in your department asked you for a disability-related accommodation? [Examples might be to have all classes on the first floor because of a mobility limitation, for a phone amplifier and TDD, or for voice activated software.]

_____ No [Please skip to Q. 2] ___ Yes

1.a. If yes, were you able to provide the requested accommodation(s)?

___ Yes, all
___ Yes, some but not others
___ No, not able to provide any

1.b. What facilitated or kept you from providing requested accommodations?

1.c. Please describe briefly the types of accommodations requested.

2. Given aging of the professoriate and the relatively slow pace of retirements, do you expect any of your faculty to need a disability-related accommodation within the next five years?

_____ No ___ Yes [How many individuals _____?]

3. Campus offices which serve students with disabilities facilitate accommodations for those students. Have members of your department received requests for accommodations for students?

_____ No ___ Yes _____ Don't know

3.a. Have members of your faculty encountered difficulties fulfilling those requests?

_____ No ___ Yes _____ Don't know

4. How many full-time faculty members are in your department? _____

If you have any comments or information for the committee, please use the space below. Again, thank you very much for your response.

Appendix 3 Footnotes Articles

Teaching and Research on Disabilities - Only for Individuals with Disabilities?

by Rosalyn Benjamin Darling

Indiana University of Pennsylvania

May/June 2000

When I was asked to write an article for Footnotes on research about disability, my first reaction was to decline, because I have not done much research on disability lately. My shift to research in other areas has been prompted, at least in part, by a trend in the disability studies field toward the exclusion of able-bodied researchers. Upon reconsideration, I thought that this trend itself might be an interesting subject for an article and might provoke some thought and discussion among my colleagues in sociology. The discussion that follows is based on my impressions and opinions and is not intended to be a research-based analysis of the subject.

Disability studies are a growing interdisciplinary field that involves sociologists, as well as other academics, primarily in the humanities and social sciences. The field has produced a number of texts and books of readings in the past few years and is represented through the British journal, *Disability and Society* and the American *Disability Studies Quarterly*. The Society for Disability Studies meets annually and attracts an international group of scholars and lay persons with an interest in disability-related research.

The founding members of the Society for Disability Studies included a significant number of sociologists (among them, Irving Kenneth Zola), some of whom had disabilities, some of whom had family members with disabilities, and others with no personal connection to the disability community. More recently, the balance in the membership has shifted to include a much larger proportion of individuals with disabilities. This shift is not accidental. As a result of pressures in the field, many able-bodied researchers today no longer feel welcome to study and teach about disabilities.

These pressures are the result of an exclusionary stance by an outspoken number of individuals with disabilities and are part of a "nothing about us without us" philosophy. This philosophy, which has characterized the disability rights movement, "requires people with disabilities to recognize their need to control and take responsibility for their own lives" (Charlton, 1998, p.17) and suggests that people with disabilities must speak for themselves. In many ways, the philosophy echoes similar stances taken by members of the Civil Rights Movement, the Women's Movement, the Gay and Lesbian Movement, and other social movements. People with disabilities are especially sensitive to the fact that their lives have been controlled to a large extent by medical professionals and by a stigmatizing, ablist society. A strong current in the Disability Rights Movement, especially in Great Britain, has also been a Marxist view of individuals with disabilities as the victims of economic oppression. In recent years, almost all of the leaders of the movement have been individuals with disabilities, rather than non-disabled allies.

The view that people with disabilities must speak for themselves has moved from the streets into the academy. Sociologists and other professionals with disabilities have been arguing that all research and teaching about disability must be conducted by scholars who understand the disability experience; that is, those who have disabilities and who identify as disabled. As one recent statement claimed, "disability studies is a subject for disabled people who are, precisely, its subjects, the people who make it; it is our affair" (Branfield, 1999, p.402). The same writer argues that attempts by "non-disabled" people, who research and work in our area, to justify their involvement...are doomed to failure" (Branfield, 1998, p.143). Although some disagreement exists regarding the inclusion of people with invisible or "lesser" disabilities, those

who take the most radical stance generally insist that scholars in the field view their disability as their primary identity.

This view is troubling to me as a sociologist, and should be troubling to other sociologists as well. Certainly, no researchers can completely understand the experience of groups of which they are not a part. However, carried to an extreme, the argument about own studying own seems to negate a basic premise of sociological research. Weber's conception of *Verstehen* included a requirement that the sociologist "be able to put [him/herself] imaginatively in the place of the actor and thus sympathetically to participate in his experiences" (Weber, 1947, p.90). Some of the best work in sociology over the years has been done by researchers studying "the other." We know a great deal more about women on welfare, men on street corners, homeless people, juvenile delinquents, and various other groups in society as a result of studies by researchers who were not members of those groups. Indeed, many have suggested that outsiders can be more objective than those who have a stake in the findings of a study.

On the other hand, sociology can be exploitative. Commonly, sociological research has involved groups with little power in society. Even with informed consent, we cannot be sure that these groups have really wanted to be studied. Moreover, studies by members of more powerful groups may serve to heighten rather than decrease their subjects' oppression. For these and other reasons, white scholars have generally avoided research on African Americans, and men have avoided research on women. However, research on oppressed groups, including people with disabilities, is important and often receives less attention than it deserves. One might argue that sociologists should only study oppressed groups until those groups become empowered enough to study themselves.

Another alternative is participatory research, in which researchers and their subjects work together in a partnership relationship. In participatory research, members of the group being studied cooperate in establishing the outcomes of the study and may be actively involved in observation, interviewing, or questionnaire administration. In this model, professional sociologists serve as consultants who share their expertise in study design and data analysis in order to help their subjects achieve desired goals. A similar, collaborative relationship might be used in the classroom to "team teach" a course.

I have been teaching a course entitled, Disability and Society, for about ten years. In it, I have tried to incorporate books and articles by individuals with disabilities. I have also had guest speakers with disabilities and have required students to interview people with disabilities. Many of my students with disabilities have also voluntarily shared their experiences with the rest of the class. To the best of my knowledge, the sociology departments in which I have taught have not had any members with disabilities, nor have other members of these departments had the interest or expertise to teach a course in this area. I believe that, if I did not teach this course, students at my university would not have the opportunity to understand disability in a sociological sense, as a devalued status in society. Yet, at a recent meeting of the Society for Disability Studies, a scholar with a disability told me that I should not be teaching the course and that my interview requirement was exploitative.

I suppose I could just teach courses on white, middle-aged, middle-class women, but the demand in that area has not been very great lately. Students major in sociology because they want to learn about the entire spectrum of social life. We would be doing them a disservice if we only taught them about ourselves—regardless of the diversity present in our departments. Although we should make every effort to incorporate the points of view of our subjects in our

work, and to work collaboratively with them at every opportunity, we should not be intimidated by them. We owe our students and our discipline a broader and more inclusive view.

Branfield, Fran. 1998. "What Are You Doing Here? 'Non-Disabled' People and the Disability Movement: A Response to Robert F. Drake." *Disability and Society* 13: 143-144.

_____. 1999. "The Disability Movement: A Movement of Disabled People—A Response to Paul S. Duckett." *Disability and Society* 14: 399-403.

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Public Forum

What Happened to the Interest? Sociology, Disability, and Scholarship

Name withheld by request

June/July 2000

During the academic year, 1997-1998, a series of articles appeared in Footnotes beginning with Gary L. Albrecht's article, "Disability is Area Rich with Sociological Opportunity" (December, 1997), suggesting the plunge of sociology into disability.

Although my counselor, a trained social worker, urged me not to go to Chicago in 1999 I went to learn more about the progress in coupling disability with mainstream sociology. Disability was the subject of less than 1% of the sessions (five sessions out of 527), and the organizing theme of a mere 20 papers, half in medical sociology. Two sessions had a personal appeal, one on new directions in the sociology of mental health and one on neurosociology, but neither satisfied my curiosity. Overall, I felt uneasy listening to everything because something was missing.

I invite readers to reflect, for a moment, on sociology over the final decades of the twentieth century. Sociologists would agree that active inclusion of minorities and women into mainstream sociology has both expanded the range of research questions and the volume of conclusions to enlarge our understanding of social structure, process and oppression as well as agency and liberation. Also, many would agree that the timing for inclusion lagged behind the civil rights pressures of the 1960s and 1970s.

Today many academicians in the Liberal Arts would point to sociology as at the vanguard pressing students and the college-educated population to rethink issues of social justice. Our graduates are pursuing careers in the service sector and make daily decisions that tap into the information and insights sociologists pass on about structured inequalities and restricted opportunities along the intersecting lines of social class, race, ethnicity, gender and sexual orientation. Disability, however, is largely ignored because of the awkward fit between it and structured inequality. The area is examined, typically, according to a traditional viewpoint: People with disabilities are a residual factor in the economy. From this perspective, the area of disability is flawed because the focus is too narrow. The concept remains fixed on a bodily condition, which disallows full participation in social life.

Disability is not only a condition but also a multi-sided social phenomenon, now bleating in the wilderness for attention. The U.S. Supreme Court, has, in fact, thrown a ball straight to sociology, the home team, by ruling a person does not have a disability if he or she can independently correct a bodily impairment without relying on others to modify or remove barriers. In 1999 there were no professional workshops to examine “reasonable accommodations,” a legal buzzword to signal a monumental, political reversal surrounding civil rights protection and persons with disabilities. Federal law now favorably positions people with disabilities to challenge the dominance of the able-bodied on matters that relate to the way their bodies are treated. Medical documentation remains a core element in establishing a protected condition, but a medical doctor’s statement merely verifies an accommodation “need.”

Until sociological research and theory-building extends into the area of civil rights, the profession is performing a disservice to the public, and is at odds with its mission. I survived a Traumatic Brain Injury (TBI), the outcome of a violent event twenty years ago. TBI can never be “cured.” I have, however, reconfigured neurological pathways in the injured areas of my brain. After twenty years, I can identify the situations when my body won’t behave, and also essential “reasonable accommodations” to avoid embarrassments. I am a “graduate” of a state rehabilitation program that followed me for ten years, through therapy, the sociology Ph.D. and into employment as a full-time college professor. However, so far I’m a failure in a second state rehabilitation program. My employment plight almost assuredly revolves around the diversity issue of “reasonable accommodations.”

My first mentor after graduate school had been an activist in the early civil rights movement. The chair believed in my potential because of my credentials and accepted my rights for assistance and patience, as he understood the law to require. Trouble started after the chair retired, and his replacement did not want to be bothered with frivolities like “reasonable accommodations.” I lost my job, filed a complaint with the EEOC and negotiated a small out-of-court settlement without a medical doctor’s deposition.

With my credentials in order the following year, I actively searched for a new position, and became astounded by the naïve mindset of prospective employers in sociology on civil rights and the Americans with Disabilities Act (ADA). I can say, without hesitation, that at least one prospective employer advertising in the “Employment Bulletin” pressed me into an interview format that highlighted my disability, and for a time, another set my application aside after I disclosed my disability. I did, however, secure a new position by following ADA rules: place employers “on notice” in writing after signing a contract, and then identify with certainty, necessary “reasonable accommodations.”

My employer responded by denying all requests, leaving me alone to conjure up solutions. The college reiterated a message to me that has become clearer with time: Persons with disabilities are not worthy of employment rights, and rights are to be interpreted as privileges. At no time since living through the violent acts that caused my disability two decades ago have I felt so alone and isolated.

There is much more to be reported, but this should be enough information to entice sociologists into investigating the multi-dimensional terrain of disability. Disability is a “sleeping giant,” and includes the micro-level topics of interpretation and meaning, mid level topics of organization and struggle, and macro level topics of institutional structures and power. Finally, it is hoped that more sociologists will become advocates for both part-time and full-time faculty with disabilities. The profession sorely needs their presence. Bear in mind the motto of earlier civil rights struggles, i.e., if you’re not part of the solution, you’re part of the problem.

I've thrown the ball to the pitcher. It's time for the profession to play ball.
Please, don't delay.

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