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## Physically Disabled Women and New Directions in Public Policy, 1977-1987.

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Deegan, Mary Jo. 1987. *Physically Disabled Women and New Directions in Public Policy, 1977-1987*. (Public Administration Series: Bibliography P 2307). Monticello, IL: Vance Bibliographies.

ISSN: 0193- 970X

PUBLIC ADMINISTRATION SERIES: Bibliography

December 1987

**P 2307**

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Vance Bibliographies

Post Office Box 229

Monticello, Illinois 61856 USA

VANCE BIBLIOGRAPHIES

Pub. Admin. Series: Bibliography #P 2307

ISSN: 0193-970X

ISBN: 1-55590-607-9

PHYSICALLY DISABLED WOMEN  
AND NEW DIRECTIONS IN PUBLIC POLICY,

1977 - 1987

by

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Women with physical disabilities now demand new directions in public policy. Starting a mere decade ago, in 1977, a driving momentum redefined the self-concepts, expectations, and united actions of disabled women. This burgeoning social movement is documented here through the geometric growth of writings articulating the vision of a more active and independent group. An overview of this literature and its policy implications is provided.

WOMEN WITH DISABILITIES AS A MULTIPLE MINORITY MOVEMENT:  
LEARNING FROM THE CIVIL RIGHTS, DISABLED, AND WOMEN'S MOVEMENTS

In the 1950s, the civil rights movement gained national prominence through its sit-ins and boycotts. In the 1960s, this effort grew and influenced the peace movement and the "second wave" of the women's movement (Evans, 1979). In the 1970s, a disabled rights movement emerged from this process of group recognition and demanded changes to redress discrimination. (Deegan, 1985). In terms of public policy, this resulted in the 1973 Rehabilitation Act, the Education for All Handicapped Children Act of 1975, and a series of state and municipal movements for public access and independent living (Brooks, 1987).

In the late 1970s, disabled women began articulating their special needs and rights. In 1978, for example, Nancy Brooks and I started to advertise for authors to submit research and theory articles for a special issue of The Journal of Sociology and Social Welfare on "Women and Disability" (published in 1981). We soon heard from women around the country, by mail and phone, who were active in both the women's movement and the disabled rights movement. They were excited by the possibility of combining these interests and wanted to tell us about their lives and commitments. Most of these women did not submit written work, they wanted to support our efforts and express their sisterhood (Browne, Connors, and Stern, 1985, p. 9, discuss the same phenomenon). This enthusiasm has snowballed. New writings, concepts, goals, policy demands, and interactions with other minority groups have occurred since then. It is a privilege to document this literature.

#### THE NEW LITERATURE AND ITS EPISTEMOLOGY

The literature selected here incorporates a set of new assumptions challenging the thousands of older books and articles on disabled people. A comparison of the epistemological ideas of "old" and "new" literature is in order. (For a more general introduction to the role of epistemology in social research per se, see Hill, 1984. For a discussion of feminist epistemology, see Smith, 1977; and for a discussion of feminist ethics in research, see the Nebraska Feminist Sociology Collective, In Press.)

#### Disability is Not Gender Neutral

The study of disability encompasses thousands of separate articles and books. This massive, and often vital, literature assumes that disability is gender neutral. In other words, all persons with disabilities are conceptualized as having the same characteristics, demands, services, and needs. For example, I completed a computer search of Psychological Abstracts in 1979 searching for all keyword entries on "disabled," "women," and "disabled women." This search revealed over 7,500 entries on

"disabled" and over 3,300 entries on "women," but only 31 articles on "disabled women." Within this small set, 19 concerned women with cancer, predominantly breast cancer (Deegan, 1985:43).

Disabled women were largely invisible in this vast literature, and in many ways this invisibility continues today. Disability, however, is not gender neutral.

#### Disabled Women Want More Power in the Marketplace and in Education

The appallingly low wages of women with disabilities were invisible until the last decade. Moreover, the pervasive assumption that disabled women were homemakers or restricted to the lower status women's occupations is found throughout the "old" literature. This assumption dramatically restricted rehabilitation counseling, therapy programs, governmental benefits, and job opportunities for disabled women.

Limits in educational attainment further narrowed occupational choices. The various educational formats -- mainstreaming students with disabilities, or developing special education programs, or maintaining separate total institutions -- are all controversial and vital issues. Low expectations of disabled women's academic skills permeated the literature of the past.

#### Disabled Women's Sexuality and Reproduction Are Vital Issues

Sexuality, birth control, and motherhood were taboo topics in past disability literature. The assumption that women with disabilities were sexually inactive at worst or passive at best pervades the old literature on disability. Concern with male sexuality, functioning, and fertility was, however, a more major focus.

#### Disabled Women Support the Disabled and Women's Movements and Demand Recognition of The Disabled Women's Movement

The traditional literature on disability was and is written by experts for their own professional use or by the disabled population for popular consumption. The new literature is often

written by disabled women for an articulate, politically aware audience. This may include experts and the public, but it always includes disabled women. This shift in audience and voice is important. Women with disabilities are not "patients," or "those who need sympathy or charity." They are women whose physical limitations have been translated into massive forms of social discrimination.

"Women's issues" such as violence and low wages are shared with the disabled women's movement and the women's movement. Independent living and access are "disability issues" shared by the disabled women's movement and the disability movement. "A disabled women's issue" is the recognition by the women's and disability movements that all of these issues -- e.g., violence, low wages, independent living, and access -- affect disabled women.

#### THE NEW LITERATURE

A brief summary of the books and articles is presented below. This is not intended to be a comprehensive introduction, but a tool to orientate the reader. Before proceeding to this task, I do mention a few notable, historic studies that share some surprisingly contemporary assumptions.

#### "Old Literature" with "New" Epistemological Assumptions

As I mentioned earlier, thousands of books and articles have been written on physical disability. I have been reading this literature since 1969 and found only a few writings that reflect the particular epistemological assumptions of the new literature included here. These studies are worthy of mention here.

First, Erving Goffman's landmark study *Stigma* (1963) is not specifically on disabled women, but it is a critical text on disability and uses women's autobiographical statements to ground the theoretical discussion. I have met several women with disabilities, including myself, who found their lives radically changed after reading this book (See Deegan, 1987).

The first study of disabled women that I have found was done by the sociologist Lucille Eaves and published in 1921. After searching for a copy of this study for several years, including an unsuccessful interlibrary loan search, I found it on the shelf in the Bancroft Library of the University of California - Berkeley. This small pamphlet shows the historically low wages, limited occupational choices, and desperate financial need of disabled women who lived over half a century ago.

In the late 1960s and early 1970s, several articles were published that are particularly helpful today. For example, Skipper, Fink, and Hallenbeck found in 1968 that married women's roles in the home were dramatically changed by disability. This not too surprising finding was integrated into an analysis that was quite sophisticated, however. They showed that role ambiguity often caused strain in marriage, while medical or rehabilitation counselors tended to stress the severity of the disability as a source of strain (i.e., severe disability may make roles unambiguous, but minor disabilities may involve continual decisions on daily tasks). They also stressed that rehabilitation therapists needed to consider emotional needs as well as physical needs. Finally, the positive opportunities for self-discovery in confronting a physical disability were often hidden by a too negative expectation and definition of disability by rehabilitation personnel. Another major study of this era was Kolodny's 1972 research on diabetic women. This was the first study to document that diabetes affected the physiological, sexual functioning of women. This information is vital for women with diabetes and their sexual partners. These two articles and two others (Gillespie and Fink, 1974; Meissner and Butler, 1967) are listed in the bibliography here.

### The New Literature: Books

The books on women with disabilities are central to making the disabled women's issues widely known. Two anthologies by disabled women are pivotal here. Campling's 1981 anthology includes the voices of British women, revealing the commonality underlying disabled women's experiences across national boundaries. Browne, Connors, and Stern's book, *With the Power of Each Breath* (1985), was awarded the President's Commission on Employment of the Handicapped 1986 Book Award. This book's powerful documentation of the everyday lives of disabled women has been important in fueling the disabled women's movement.

Social science research is also beginning to articulate the lives and aspirations of disabled women. Deegan and Brooks (1985) provide several general overviews of disabled women, as well as specific papers on hearing and visual impairments, renal failure, spinal cord injuries, and breast cancer. Spellman (1987) documents the various types of cancer that impact on women's lives. In addition, epidemiological information, variation across ethnic groups, and the health risks of tobacco are presented.

All the books provide coherent statements on disabled women and their interests on specific policy issues. Their titles usually provide a key to their contents and emphases.

### The New Literature: Articles

In general, the articles are written for more specialized audiences and on more specific topics than the books. This allows for more precise information on a topic but this may limit each article's generalizability. In addition, the distribution outlets of articles remains small. College and universities may be the only repositories for these writings, making it difficult for local policy makers and disabled women to gain access to this information. Articles, nonetheless, articulate the forefront of concepts and research and continue to be available through interlibrary loan services. Hence, the particular utility of this bibliography.

At this time, cancer, hearing and visual impairments, and orthopedic restrictions (in this order) are the most researched topics. The literature for rehabilitation counselors is rapidly growing, as well as the writings by disabled women. The social science information is slowly growing, but the need to obtain funding, conduct research, interpret the data, to get peer reviews of the research, and then to fit an accepted paper into a publication schedule is a process requiring considerable time and patience. Hopefully, the social science data base will improve in the very near future.

#### THE TEN MOST IMPORTANT POLICY ISSUES

Ten policy issues recur in various forms throughout this literature. I have made some attempt to order them, with the most important issues first. This is somewhat arbitrary after the first 4 or 5 points, but I felt that a "best guess" was better than no ranking. All of these policy issues are important and interconnected, but a hierarchy helps to organize demands and articulate specific interests.

- 1) Changes in the Marketplace -- Wider Choices, Higher Wages, More Training
- 2) Increased Government Benefits -- Recognizing the Work of Homemakers, Discrimination in the Marketplace
- 3) Independent Living -- Housing for Disabled, Degrees of Auxilliary Care Required in Daily Living
- 4) Access -- Building; Transportation; Public Institutions, Such as Restaurants and Auditoriums
- 5) Changes in Education -- More Higher Education, More Control over the Classroom, More Power to Define Literature and Rights
- 6) New Definitions of Beauty, Femininity, and Sexuality -- New Images of Disabled Women in the Mass Media, Technology Safe for Women with Disabilities, Supportive Information on Sexual Choices

- 7) A More Responsive Health Care System -- Recognizing the Rights of Patients to Know Their Treatment and Alternative Care Choices, Respect, Rights to Services, A More Active Role in Rehabilitation Services and Institutions
- 8) New Definitions of Disabled Mothers and Homemakers -- The Right to Motherhood, the Recognition of Homemaking as an Economic Contribution
- 9) Recognition of Unique Interests by the Disability and Women's Movements -- (See Discussion on pp. 4 and 5 above)
- 10) Decreased Violence -- Special Interests of Institutionalized Women, Rape and Wife Abuse as Particularly Problematic Issues for Disabled Women, Fear of Violence on the Street and in the Home

#### SUGGESTIONS FOR NEW DIRECTIONS

In both the literature and the social movement, several areas of vital importance are currently overlooked. A brief review of these issues is therefore in order. Hopefully, it will be possible to report that these issues have been addressed at some future date when this bibliography is revised.

- 1) A Large Number of Special Interests and Needs Are Not Being Addressed -- Elderly women, women of color, lesbians, overweight women, and multiply disabled women are rarely studied and their needs are not addressed adequately.
- 2) Policy Issues Per Se Are Rarely Addressed as the Topic of Study -- The literature tends to stress the individual, adjustment, coping, and everyday life. Broader social goals need articulation (See Sapiro, 1987).

- 3) Theoretical Sophistication Is Lacking — Concepts articulating the experience and social forces impinging on disabled women need considerable development (For theoretical statements on disability see Goffman, 1963; Deegan, 1975, 1977a and b, 1978, forthcoming; for theoretical statements on disabled women, see Deegan, 1985, 1987, In Press).

#### CONCLUSION

An exciting change in disabled women's lives and ideas occurred within the last decade. For the first time, women with disabilities are articulating their rights, interests, and needs with voice that will not be quieted. This social movement has its own momentum and power that has increased every year over the past decade. This bibliography documents this explosion and hope. This literature is now readily available not only to disabled women, but also to policy planners and program analysts.

Martin Luther King spoke for Black people when he said "I have a dream," but his powerful message is just as true for disabled women today. They, too, have a new vision of a more liberating future. The literature included in this bibliography transforms these dreams into specific goals for a new world. Disabled women demand new directions in public policy.

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ISSN: 0193-970X  
ISBN: 1-55590-607-9

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