Women with Disabilities: 
The Long Road to Equality

Sherry R. Fairchild

ABSTRACT. Although the passage of the Americans with Disabilities Act (ADA) was instrumental in raising societal conscious awareness of the issues and discriminatory practices towards people with disabilities, the evidence points to a lack of full inclusion in the mainstream of American society. Due to the double discrimination of gender and disability status, women with disabilities confront major obstacles even more boldly to achieve equality and full participation in society. This article examines some of the current meanings of disability, vital statistics, and current discriminatory practices in specific areas for women with disabilities such as, human rights and abuse, relationships and sexual functioning, health maintenance issues, employment, and environmental barriers. Positive strategies for social workers to become involved at both the macro and micro levels of practice as well as social policy level are identified.

KEYWORDS. Women with disabilities, discriminatory practices, vital statistics, macro/micro positive strategies

INTRODUCTION

During the past two decades there have been numerous attempts to include persons with disabilities in the mainstream of American soc-
People with disabilities face many obstacles, such as societal attitudinal barriers, physical environmental conditions, institutional practices, isolation and poverty, functional/mobility limitations, and often chronic conditions and diseases. Although both men and women with disabilities are susceptible to discrimination, women with disabilities are often at a larger disadvantage due to a double discrimination, based on their gender and disability status. Women with disabilities from minority ethnic and racial groups are marginalized even further. This article will attempt to explain some of the current meanings and statistics of disability in our society, and identify some of the major issues those women with disabilities face, discrimination practices, and possible strategies for overcoming the related obstacles and inequities for women with disabilities.

**DISABILITY OVERVIEW IN THE UNITED STATES**

There are currently four prevailing models that are used to define what it means to live life with a disability: (1) The *moral model*, historically the oldest and least prevalent model today, stresses the guilt and sin of the person with disability. However, there are still many cultures that associate disability with sin and shame. For the individual with a disability, this model is particularly onerous, often resulting in family members isolating the disabled person from substantial involvement with others. Often this model has resulted in an attitude of self-hatred by the disabled individual; (2) The *medical model* is the most familiar in our society because of the emphasis of “modern” medicine and the accepted view of the ability of medical professionals to define and treat people with disabilities. This model emphasizes that problems that are associated with disability reside within the individual, and they have a need to be “cured.” Here the person with a disability is in the “sick role,” and therefore, they can be excused from normal obligations of society: personal and family responsibilities, education, employment, taxes, etc. (Kaplan, 1999; Gill, 1996). Often persons with a disability desire to work, but they face complicated problems related to risk of loss of certain public benefits such as Personal Assistance Services and/or health care coverage (“Help Disabled Work,” 1998); (3) The *rehabilitation model*, which was first used widely by returning disabled veterans from World War II, focuses on the needed services provided by rehabilitation professionals. The goal of these services is to bridge the deficiency caused by the disability. Examples of some rehabilitation model ser-
vices are specific skills training, physical or psychological therapy, support group counseling, etc., and (4) The social model focuses on a strengths perspective of people with disabilities by regarding disability as a normal aspect of life, not as an anomaly where individuals with disabilities are viewed as somehow “defective.” Both the disability rights and independent living movements have chosen this model as their operational base, stressing the need to examine and modify the social environment to enable all persons to fully participate in all areas of life. Advocates of this model stress that most people will undergo either permanent or temporary disability in their lifetime, and that the concerns of disability need to be normalized more in our environments and social systems (Kaplan, 1999; Miller & Sammons, 1999; Morris, 1992; Oliver, 1996).

The disability rights movement, through the passage of the important Americans with Disabilities Act (ADA) of 1990, has been instrumental in altering society’s perception of what constitutes a disability and the realities of individuals with disabilities. Advocates of this growing movement believe that persons with disabilities are quite capable of participating in society, and they view disability legislation as a form of civil rights, similar to those enacted in the 1960s (Asch & Mudrick, 1995; Barnes, 1999; Leipoldt, 1999). The 1990 Americans with Disabilities Act defines disability as a “physical or mental impairment that substantially limits one or more of the major life activities” (Littman, 1998). This means that a person is considered to have a disability “if he or she has difficulty performing certain functions (seeing, hearing, talking, walking, climbing stairs, or lifting and carrying), has difficulty performing activities of daily living, or has difficulty with certain social roles (doing school work for children, working at a job and around the house for adults). A person who is unable to perform one or more activities, or who uses an assistive device to get around, or who needs assistance from another person to perform basic activities is considered to have a severe disability” (U.S. Census Bureau, 1997). The term “disability” has varied connotations with different interpretations that can be either narrow or broad. For example, the ADA and the Social Security Act define “disability” in different ways. The Social Security Act uses a narrow definition, because the basic purpose of this law is to provide benefits to people who are so disabled they can not work. Advocates of the disability rights movement stress that the primary purpose of the ADA is to protect people from discrimination, emphasizing that no individual has to be very disabled to experience discrimination and be treated unfairly by an employer (Stothers, 1999).
According to the Survey of Income and Program Participation (SIPP), the number of persons with disabilities are increasing steadily as our population increases and ages. The SIPP uses a “broad definition of disability that considers limitations in specific functional activities, activities of daily living (ADLs), and instrumental activities of daily living (IADLs), as well as the use of special aids, the presence of certain conditions related to mental functioning, and questions pertaining to the ability to work” (Ians & Stoddard, 1999, p. 4). In 1995, of the total U.S. non-institutionalized population, an estimated 20.6% (53.9 million people) met the criteria for disability, while women and girls with disabilities are estimated to number 28.6 million, which is 21.3 percent of the total female population. Women with no disability were estimated at 105.3 million. In comparison to men and boys with disabilities, there was an estimated 25.3 million or 19.8 percent of the population reported. Males with no disability were estimated at 102.6 million. Summarily, one in five Americans has a disability, with more than half (53%) of those persons with disabilities being female (see Figure A1).

Considering the rate of disability by race and ethnicity, women also have a higher rate due primarily to women’s higher average longevity. In 1991-92, the Survey of Income and Program Participation reported that women have higher disability rates than men in all of the major ethnic and racial groups except Native Americans. “Among females, Native Americans face the highest disability rate (21.8%), followed closely by Black females at 21.7 percent. White women have a disability rate of 20.3 percent, and the rate for Hispanic women is 16.2 percent. Among the female population, Asian/Pacific Islander women have the lowest disability rate of 10.7 percent” (Ians & Stoddard, 1999, p. 9). See Figure B1. Several researchers indicate that further research is needed to comprehend the ethnic differences in disability rates regarding variability of such factors as income, education, and other socioeconomic factors (Ians & Stoddard, 1999; LaPlante & Carlson, 1996; LaPlante, 1991).

MAJOR ISSUES OF WOMEN WITH DISABILITIES

During the International Leadership Forum for Women with Disabilities held in Washington, D.C. in 1997, some 614 women representing
80 countries around the world met to discuss the empowerment and major issues of women and girls with disabilities. Madeleine Albright, U.S. Secretary of State, focused on the marginalization of women with disabilities stating:

There are more than three hundred million women with disabilities in the world. In many societies, they are consigned to the margins—not admitted to schools, rejected by employers, denied access to health care. We cannot afford this loss. We need your
strength and skills. If we are to build the kind of future we want, women with disabilities cannot be marginalized, women and girls with disabilities must be empowered . . . At this conference’s center, and at the heart of the disability agenda, is the simple premise that every individual counts. That is the philosophy of America at its best. And that has been the motivating force for the movement to advance the status of women and women with disabilities for longer than any of us have been alive. (Albright, 1997, p. 24-25)

Following the Beijing, China, 1995 Fourth World Conference on Women, the Beijing + 5 Conference in March 2000 reviewed and appraised the implementation of the original 1995 Beijing Platform for Action. During both of these conferences the Disabled People’s International (DPI) women’s committee lobbied for the concerns of women with disabilities to be appropriated reflected in the platform of action. Twelve core critical areas of concern were adopted as the focus for improvement in the lives of women and girls: human rights of women, poverty, education and training of women, the economy, women in power and decision-making, women and the environment, violence against women, the girl child, women and armed conflict, the media, women and health, and the institutional mechanisms for the advancement of women. Due to the effective advocacy efforts of DPI and other disability representatives, eight of these core areas included specific paragraphs that focused on socio-empowerment issues for women with disabilities (United Nations, 1999; Disabled People’s International, 2000).

Although these are ennobling goals for an accessible and inclusive world society, the reality for many women with disabilities in the U. S. depicts a different picture. Women with disabilities continue to rank lowest on most scales that measure progress, specifically in the areas of employment, poverty, and self-esteem (Heumann, 1997). The road to equality for women with disabilities is a long one!

**Human Rights, and Abuse.** Throughout the centuries people have reflected upon the issues of death and dying. While most people recognize that death is inevitable, fear of the process of dying with an incapacitating chronic disability, illness in unbearable pain, or being kept alive in intolerable circumstances is predominant. This fear and concern have created the 1990s heated controversy about the “death with dignity” issue of legalization of physician-assisted suicides for including women with disabilities. For many women with disabilities the message internalized from the work of Dr. Jack Kervorkian, “Dr. Death,” is a devaluing of their life because of the “burden” they create for other family
members and society. Some medical professionals maintain that abortion on grounds of disability, as well as assisted suicides for women with severe impairments such as quadriplegia, Huntington’s disease, or Alzheimer’s disease is a desirable choice for women with disabilities (Asch & Mudrick, 1995; Hubbard, 1997). Several research studies on the life satisfaction of women with chronic physical impairments do indeed indicate that disabled women rate their life satisfaction as lower than women without physical disabilities (Brown, 1997; Mullan & Cole, 1991; Nosek, 1995).

The issue of all types of abuse: physical, sexual, and emotional is prevalent among women with disabilities. Disability acts to increase vulnerability to abuse and many times disabled women are seen as passive and needy by their caregivers, whether by family members, friends, paid or volunteer caregivers, institutional staff, or police. A large-scale national prospective study with a nationally representative sample of women with and without physical disabilities found an alarmingly high abuse rate of 62 percent for women in both categories. Particularly distressing was the finding that women with physical disabilities continued to suffer all types of abusive treatment for an even longer duration of time than other groups of women. More husbands and live-in partners abused women with and without disabilities emotionally (26%), and physically (17% and 19%) than other perpetrators. Parents were the next most common perpetrators of physical abuse for both groups of women, while strangers were most often reported as sexual abuse perpetrators for both groups, 11 percent for women with disabilities and 12 percent for women without disabilities (Nosek, Rintala, Young, Foley, et al., 1995). Waxman (1992, p. 66) stresses that society can no longer deny that violence is often the “hidden truth about disabled people’s lives.” Another abuse study for disabled women ranked abuse and violence as the highest priority area by the women participants for social service systems. These women with disabilities ranked as the highest-rated objective (85%) “to disseminate information to women with disabilities about how they can advocate for themselves in protecting themselves against violent caretakers” (Freeman, Strong, Barker, & Haight-Liotta, 1995). Often disabled women are abused by paid and volunteer caregivers, as well as institutional staff (O’Toole, 1999). Sobsey (1994) emphasizes that abuse by caregivers of women with disabilities often results from social and emotional defects of the caregivers, rather than stress resulting from dependency of abuse victims.

Relationships and Sexual Functioning. In our society many persons maintain the belief that a woman’s worth is measured by physical
beauty, ability to establish a romantic relationship with a man, become a nurturing mother, wife, homemaker, and lover. Examining the limitations women with disabilities face regarding many of these cultural roles provides insight into the lower levels of relationship satisfaction reported by women with disabilities (Danek, 1992; Asch & Fine, 1988). Numerous researchers (Asch & Fine, 1988; Danke, 1992; Hanna & Rogovsky, 1991; Nosek, Young, Rintala, Howland, Foley, Bennet, 1995; Rintala, Howland, Nosek, Bennet, Young, Foley, Rossi, & Chanpong, 1997; Waxman, 1991) have reported that women with physical disabilities are often viewed as asexual, devalued, and discarded by partners. Compared to men with disabilities and women without disabilities, disabled women are more likely to never marry, marry at a later age, become divorced, or live separated from their partners (Asch & Fine, 1988; Hanna & Rogovsky, 1991). However, the findings from the final report of the Nosek, Howland, Rintala, Young, & Chanpong, (1997) national study reported a more positive outlook than in previous disability studies for women. Women with disabilities in this study indicated that they thought their disability was not a major cause of ending a marriage or other serious relationship. A higher number of women with disabilities (87%) had been involved in at least one serious romantic relationship or marriage than reported in previous studies. For women with disabilities, 38 percent had borne children as compared to 51 percent of women without disabilities. However, the finding that women with disabilities were more likely to remain in a bad marriage for fear of losing custody of their children does mirror other research findings (Asch & Fine, 1988).

Summarily, regarding significant relationships for women with disabilities, several factors involved in providing insight as to why women with disabilities have trouble attracting partners and/or staying married are: (1) some partners may not be able to deal with a woman’s disability, (2) perceptions of societal barriers to dating someone with physical impairments, (3) social isolation experienced by disabled women due to lack of transportation needs, therefore limited opportunities to establish romantic relationships, and (4) lack of development of social dating skills (Rintala, Howland, Nosek, Bennet, Young, Foley, Rossi, 1997).

Regarding sexuality issues for women with disabilities, many women report a lack of sexual education provided either by family members or medical professionals (Welner, 1996). Women with disabilities often encounter a lack of knowledge about disabilities by health care providers (Becker, Stuifbergen, Tinkle, 1997). Contrary to societal assumptions about sexual functioning of women with disabilities, they “have as much
sexual desire as women in general; however, they do not have as much opportunity for sexual activity” (Nosek, Howland, Rintala, Young, & Chanpong, 1997, p. 6). In the large national study by Nosek et al. (1997), 94 percent of the women with disabilities reported being involved in sexual activity with a partner during their lifetime, as well as 49 percent of the women with physical disabilities being currently sexually active. Since there is an epidemic of sexually transmitted diseases (STDs) in the U.S., women with disabilities who are sexually active should have routine testing for STDs, as should women without disabilities. Three major categories of women with disabilities have been identified as needing appropriate counseling about contraceptive needs: women with mobility impairments, women with chronic diseases, and women with cognitive impairments (Welner, 1996).

Health Maintenance Issues. As reported by LaPlante (1996), the primary causes of activity limitation by women with disabilities are: (1) deformities, orthopedic impairment, and disorders of the spine or back–15.3%, (2) arthritis and allied disorder–13.3%, (3) heart disease–9.7%, asthma–5.3%, (4) orthopedic impairment of lower extremity, mental disorder, excluding mental retardation–4.2%, (5) diabetes–3.3%, (6) learning disability and mental retardation–2.5%, (7) cancer–2.4%, (8) disorder of the eye–2.1%, orthopedic impairment of shoulder and/or upper extremities–1.9%, and (9) hearing impairments–1.5% (p. 49).

There is a movement among disability researchers to approach women with disabilities’ health issues from a wellness model rather than a deficiency model (Abood & Burkhead, 1988; Nosek, 1992; Nosek, Howland, Young, Georgiou, Rintala, Foley, Bennet, & Smith, 1994). Often women with disabilities will delay medical treatment until symptoms reach a crisis level. Several reasons that women with severe physical disabilities hesitate to attend to their health maintenance issues are: lack of access, unavailable medical information, lack of finances, and the need for additional personal assistance to prepare and get to a medical appointment (Mullan & Cole, 1991; Nosek, 1992; Nosek, Young, Rintala, Howland, Foley, & Bennett, 1995).

DISCRIMINATION ISSUES

Negative Stereotyping. Attitudinal barriers are predominant towards women with disabilities. Often women with disabilities are not perceived as human beings of value and worth, but rather as a disability diagnosis. All too often there is a tendency to focus on the disability, with
an overemphasizing about what the person is unable to do. Labeling women with words such as: deformed, wheelchair person, midget, retarded, invalid, confined, etc., only creates distancing and stigmatizes the individual (Spires, 1995).

**Employment.** While men with disabilities have serious employment problems, women with disabilities confront numerous obstacles to full participation in the workplace. As mentioned previously, women with disabilities face a double discrimination in the workplace because of their gender and their disability status. According to the Survey of Income and Program Participation (SIPP), in 1994-95, whether or not they have a disability, women are less likely than men to have a job or business. Considering gender and severity of disability among people, ages 21-64, severity of disability has the most impact on employment: “only 24.7% of women with a severe disability and 27.8% of men with severe disability had a job or business. Non-severe disability also adversely impacts the likelihood of working, particularly for women. Among those with non-severe disability, 68.4% of women and 85.1% of men were working at a job or business. In comparison, 75.5% of women with no disability and 89.8% of men with no disability were working” (Ians & Stoddard, 1999, p. 18, Figure C1). Summarily, less than one-quarter of women with severe disabilities have a job or business, and employment rates drop, as the disability becomes more severe for both women and men with disabilities.

Compared to men, more women with disabilities are employed at higher rates and in greater numbers in the service and in the managerial/professional occupations (LaPlante, 1996; Ians & Stoddard, 1999). However, women with disabilities are underrepresented as computer programmers and computer equipment operators, when compared to men with disabilities (Ians, & Stoddard, 1999).

Regarding the income gap, women with work disabilities are more likely to be poor than women without disabilities. One-third of women with a work disability live in poverty with higher rates (33.8%) than men with a work disability (24.2%). National surveys show little evidence of improvement in the economic well being of Americans with disabilities. Figures D1a and D1b illustrate that the income gap between female and male workers with and without disabilities has not narrowed in recent years (1990-95). The median income for women with disabilities was $1,511 monthly, or 13 percent less than the $1,737 income for women without disabilities (Ians & Stoddard, 1999). Furthermore, women with work disability received Social Security benefits at lower rates than men (25.6% of women, 30.6% of men). However, women re-
ported higher rates of other need-based benefits compared to men, such as food stamps (29.1% of women, 19.8% of men), Medicaid (36.2% of women, 27.2% of men), public housing (6.8% of women, 4.4% of men), and subsidized housing (4.6% of women, 2.7% of men) (Figure E1).

Environmental Barriers. Physical barriers such as inaccessible public buildings, curbs not being cut, and communication barriers, such as inequitable access to telecommunications products, all contribute to women with disabilities feeling excluded from the mainstream of American society. Many disability researchers now realize how much the environment produces obstacles to participation for women and men with disabilities (Quinn & Walsh, 1998; Nosek, 1995, 1992). Despite some signs of progress in environmental issues, our goals need to stay focused on becoming an inclusive society, with universal design for all of our U. S. citizens.

**STRATEGIES FOR POSITIVE CHANGE**

Women with disabilities have been facing “double jeopardy” discrimination and inequality for many years in the United States. Perhaps only since the passage of the American with Disabilities Act in 1990, has our society really begun to attempt to understand the struggle of
people with disabilities. In working with women with disabilities, social workers need to continue to develop an understanding of the disability rights movement that stresses the importance of advocating against the isolation and marginalization often associated with people with disabilities. This marginalization is related to institutional barriers, environmental barriers, and attitudinal barriers that exclude full participation of people with disabilities in society.
Social workers need to continue to be involved significantly in both the macro and micro levels to assist women with disabilities in concrete ways to develop legal and political solutions for people with disabilities. We need to become effective advocates to ensure that appropriate, funded legislation and policies are developed and implemented. Including the principles of James Midgley’s (2000) social development model for women with disabilities would provide a powerful strategy for working with this population. A hallmark of the social work profession is the concept of working with clients from the strengths perspective. In working with women with disabilities in the micro level of social work practice, social workers need to maintain the theoretical perspective of the strengths perspective in developing appropriate interventions.

Leipoldt (1999, p. 409) proposed four major strategies that would be most helpful for social workers in working with women with disabilities:

1. The identification and explication of current approaches to disability.
2. An assessment of the values and pitfalls of those different approaches and the relationships between them.
3. If we are all saying we are acting in the interest of furthering the cause(s) of people with disabilities, how can we productively use and organize our diverse roles, approaches, and theories and minimize any potential negative outcomes to people with disabilities?
4. How do we keep directly in touch with disability issues on the ground and how do we best use academic work in support of grassroots change?

In considering positive strategies to combat the high rate of abuse and violence towards women with disabilities, several significant recommendations are noted by a leading research team of “professional” women with physical disabilities, Nosek, Howland, and Young (1997). These policy suggestions could have a tremendous influence in both the macro and micro level of social work practice by stressing: (1) the importance of changing the physical environments for programs for battered women in order to become more sensitive to the architectural, attitudinal and policy barriers, (2) the need for effective education and training of service providers in order to recognize abusive situations, ensuring appropriate referrals of individuals, (3) the need for educating clergy and staff members in local churches who often are the initial point of contact for abuse women with disabilities, (4) the need for extensive training and advocacy of staff members of Adult Protective Services to insure disability sensitive services, (5) the need for national legislation to provide funding for trained personal assistants as an option to combat disabled women’s dependence on abusive caregivers, (6) the need for extensive training in accommodations required by individuals with disabilities for police personnel and court justices, (7) the need to provide affordable legal services for women with disabilities, and (8) the need to develop and integrate communication among community services to meet the needs of women with disabilities.

As stated so poignantly by Haynes and White (1999): “The critical test of social justice must be measured from the point of the ‘least among us.’ ” Women with disabilities are not second class citizens, but are as important as any other individual in the fabric of our society. Social workers need to take up the gauntlet of social justice for women with disabilities and help them to close the gap in their road to equality.

REFERENCES


U.S. Census Bureau, 1997.


