

THE JOHN STANLEY COULTER LECTURE

Overcoming the Odds: The Health of Women With Physical Disabilities in the United States

Margaret A. Nosek, PhD

IN THE 47 YEARS that I have lived with disability, I have witnessed an accelerating demolition of the barriers that have impeded us for so long from participating as equal citizens in society. Medical science has made dramatic advances that have enabled people with progressive disorders such as mine to live well past their predicted 20-year lifespan. I am continually amazed at how vastly improved is the health and quality of life of people with disabilities over the past few decades.

But as I look forward in my life as a woman aging with a disability, I am terrified. The odds are seriously stacked against me. I have little hope of enjoying the benefits of my hard work in a retirement of healthy peace and comfort. The cost of maintaining the attendant care and technology that has enabled me to be well and productive will be prohibitive as my income diminishes and government resources to assist with these expenses drop away. I will always be entitled to sacrifice control over my life and live in a nursing home, but there is no entitlement to use the same funds to maintain the support system that has worked so well for me in my own home. Medical science has grabbed me from the jaws of death on many occasions, but it reaches the end of its expertise when I present the secondary conditions and other effects of living with very severe physical impairment for such an extended time. As I study the lot of my sisters aging with disability around the country, I see that the rising tide of social and medical progress has not raised our ship along with the others. The vista of our future is not a positive one.

My goal in this Coulter Lecture is to present an overview of the health of the population of women with physical disabilities and offer my thoughts on how we can work together to increase the odds for successful aging. I have gathered my information from four main sources: first, a national study conducted by the Center for Research on Women with Disabilities¹ that involved more than 500 women with physical disabilities and an equal number of their non-disabled women friends; second, an analysis of the 1994 and 1995 census data that I am conducting with researchers at the National Center for Health Statistics, using data from the National Health Interview Survey; third, a recently compiled chartbook on women with disabilities by Lita Jans and Susan Stoddard at InfoUse in Berkeley, CA; and fourth, the results of the first meeting of about two dozen authoritative women with disabilities and researchers in this area convened by the Centers for Disease Control and Prevention in 1997 to establish a public health agenda for this population. After presenting general demographic information and a review of secondary conditions affecting women aging with disabilities, I will review some basic statistics on inequities and gaps in several of the areas delineated at the CDC meeting: general health, reproductive health, mental health, and access to

health care. I will then discuss current trends in programming to improve the health and wellness of women with disabilities, and conclude with my perspective on pathways for change.

DEMOGRAPHICS

I would like to describe the tapestry that is the population of women with disabilities in the United States. When I mention women with physical disabilities, I am referring to women who report limitations in at least one of the eight functional abilities listed in the National Health Interview Survey. Those functional abilities are (1) lifting 10 pounds, (2) walking up 10 steps without resting, (3) walking a quarter of a mile, (4) standing for about 20 minutes, (5) bending down from a standing position, (6) reaching over the head or reaching out, (7) using the fingers to grasp or handle something, and (8) holding a pen or pencil.

This is a population that is substantial and growing. According to the 1992 Census, 26 million women have disability-related work limitations, comprising 20% of the entire population of women.² The prevalence of disability is highly correlated with age, with 40% of women 65 years and older having at least one functional limitation. The most prevalent disabling condition in women is back disorder (15.3%), followed by arthritis (13.3%), heart diseases (9.7%), asthma (5.3%), orthopedic impairment of lower extremity (4.2%), mental disorders (3.3%), diabetes (3.3%), and learning disability and mental retardation (2.5%).³

The 1994 and 1995 National Health Interview Survey provided a sample size of approximately 11,500 women aged 18 and over. Roughly 2,000 of the 11,500, or 16%, had at least one functional limitation, and of that number, 77% were White, non-Hispanic; 13% were Black, non-Hispanic; 7% were Hispanic; and 3% were non-Hispanic of other races. This racial/ethnic distribution is similar to that for women with no functional limitations, with a slightly higher rate of disability among African American women in the 45-64 age group. Compared to women in general, women with three or more functional limitations were less likely to be married (40% versus 63%), more likely to be living alone (35% versus 13%), more likely to have a high school education or less (78% versus 54%), less likely to be employed (14% versus 63%), more likely to be living in households below the poverty level (23% versus 10%) particularly in the 18-44 age group, and less likely to have private health insurance (55% versus 74%).

Rehabilitation professionals are very familiar with the secondary conditions that worsen with age for women with disabilities. Cardiovascular problems include hypertension, more about which I will discuss later, and dependent edema. Decades of propelling manual wheelchairs can result in nervous system disorders such as carpal tunnel syndrome. For those of us with scoliosis combined with muscular weakness, respiratory problems become more life threatening. Decades of infrequent urination or bowel and bladder management programs result in numerous genitourinary problems. The thinning of skin with age increases the tendency for pressure ulcers, not only in spinal cord injury, but also in postpolio and other disorders that do not affect sensation. Increased muscle weakness that accompanies

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Reprint requests to Margaret A. Nosek, PhD, Center for Research on Women With Disabilities, 3440 Richmond, Suite B, Houston, TX 77046.

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aging with disability can seriously diminish physical and social functioning. Very early in life we experience osteoporosis from reduced weight bearing. It may or may not increase after menopause—we don't know. There also seems to be a high rate of endocrine disorders, such as diabetes, that demands further research. A lifetime of taking prophylactic antibiotics and other medications can lead to immune system problems. Other common complaints that we hear in our wellness workshops are pervasive fatigue and difficulty with weight control.

INEQUITIES AND GAPS

There are significant inequities in health care services for these conditions and there are gaps in our knowledge of the course of these health problems in women with disabilities. In terms of general health, I know many women with disabilities who live in robust health, including some who use a ventilator and can move only one finger. Statistics show, however, that there is a strong inverse relation between self-rated health status and number of functional impairments. Only 12% of women with three or more impairments across all age groups rated their health as excellent or very good, compared to 66% of women with no impairments. Census data confirm that weight control is indeed a problem of women with disabilities in middle age, with 42% of women with three or more limitations being overweight. Hypertension increases substantially with age and severity of impairment. This may be related to the physical and emotional stress associated with living with disability.

We don't score very well on certain health maintenance practices. Although many of us are very active physically, women with disabilities in general are significantly less likely to be engaged in an exercise program. Smoking among younger women with disabilities is nearly double the rate of younger women in general, again, I believe, an indicator of stress and a greater need for social acceptance.

REPRODUCTIVE HEALTH

There is an unfortunate stereotype that women with physical disabilities are asexual; we have no interest in sex, nor should we, heaven forbid, reproduce. This stereotype plays out in the assumption of some physicians that we are not sexually active and that if pelvic exams or mammograms are too much trouble because of inaccessible exam tables, they can be overlooked. Few physicians truly understand the effect of our disability on our reproductive health. This is never taught in medical schools, so physicians have very little information with which to help us make decisions about contraception, pregnancy, or hormone replacement therapy. They are much less likely to discuss these topics with their disabled patients.

Our research has shown that older women with more severe disabilities were the least likely to receive regular pap tests.⁴ The primary reason was their difficulty in getting onto the exam table, reflecting the problem of inaccessible facilities. Other reasons include lack of time and inability to find a suitable doctor, which I interpret to mean a doctor who understands disability. We found the same result for mammograms.⁵ Among the top three reasons given by women with physical disabilities over 40 for not having mammograms was being unable to get into the required position, and because no doctor recommended having one. Some women believe their risk of cancer is low because they have a disability. We see here some excellent opportunities for physician and patient education. Even though the rates for both exams were similar for younger women with and without disabilities, we suspect that the exams given to women with disabilities lack thoroughness, possibly resulting in diagnosis at later stages of cancer. We know nothing about

how cancer treatment affects the disabling condition or the woman's functional capacity over the long term.

MENTAL HEALTH

Disability is both a major stress factor and an isolating factor in the lives of women.⁶ The sources of stress are numerous; they include interruption of ordinary activities, inability to independently carry out self-care activities, changes in appearance, increased need for personal assistance, and dealing with everyday, unrelenting, life hassles such as increased time, planning, and effort to do things.⁷ Other sources of stress are poverty with resulting inadequate nutrition; lower levels of fitness; pain and illness; vulnerability to abuse, environmental barriers; and lack of social support.⁸ In a study of persons with spinal cord injury, Rintala and coworkers⁹ found that women reported significantly more perceived stress than men, and that life satisfaction, depressive symptomatology, self-assessed health rating, and severity of pressure ulcers were all significantly related to perceived stress. I believe that many of the secondary conditions that are attributed to disability are more the result of the stress of living in an unsupportive environment than from the disability itself.

In our national study of women with physical disabilities, more than three-quarters of the sample had high self-esteem and a positive body image, regardless of the severity of their disability. For the remainder, however, high rates of unemployment, abuse, and lack of intimate relationships took a serious toll on self-esteem. In analyzing the census data, we found that feeling depressed or anxious and experiencing major depression in the past 12 months was a serious problem among younger women with more severe disabilities.

ACCESS TO HEALTH CARE

Younger women with impairments were much more likely to delay seeking medical care (33% vs. 11%) or to be unable to get medical care at all (18% vs. 3%) than women without disabilities or all women over age 65. Problems with finances or insurance was the reason cited for being unable to get medical care by more than three-quarters of women in all three groups. Younger women with more severe disabilities have the most difficulty obtaining mental health care, dental care, prescription medicine, and eye glasses. This may be related to the high rates of poverty and low rates of private health insurance reported earlier.

These figures illustrate the extent to which women with physical disabilities are unable to get the medical care they need, but as researchers we have an obligation to look for the reasons why this is so. Beneath the major barrier of lack of health insurance coverage lie many more obstacles that are more transparent but none the less insidious. For many women, just getting from their house to a doctor's office is a major effort. Inadequate accessible public transportation, lack of attendant services to accompany the woman on the visit, lack of child care, and long waiting times for appointments in overcrowded public health care systems all discourage women from tending to health problems at early and more easily treatable stages. Many women with disabilities know from experience that specialists are the type of health care provider that can best meet their needs, but strict gatekeeping regulations in managed care organizations impose additional barriers to obtaining appointments. In our national study, 31% of the women with disabilities reported that a doctor had refused to see them because of their disability. Just getting in the front door or using the restroom, not to mention getting up on the examination table, are serious barriers to health care in many physicians'

offices. The medical establishment seems to be the last bastion of resistance to full compliance with the Americans with Disabilities Act.

CURRENT TRENDS

Despite the dismal picture painted by these statistics, I am here to state that the majority of women with physical disabilities are living well; they are going beyond surviving, they are thriving. Federal funding agencies have recently taken an interest in finding ways to enhance the wellness of women with disabilities. The National Center for Medical Rehabilitation Research at the National Institutes of Health and the Center for Disease Control and Prevention have invested in projects that are developing wellness interventions for women with limitations in physical functioning. The National Institute on Disability and Rehabilitation Research has also issued calls for proposals related to the needs of women. What a revolution in principle this represents! Historically, disability and illness were synonymous. To talk about wellness in the context of disability is to break the strangle hold the medical model has had on disability interventions for far too long. Helping women discover strategies for reaching their maximum levels of vitality and fitness within their physical limitations is the motto of this new kind of programming.

Wellness programs for women with disabilities are being tested at five sites under an NIH-funded initiative: at the University of Michigan by Denise Tate and Sunny Roller; at Temple University by Kathy Coyle and Mayra Santiago; at The University of Texas by Alexa Stuijbergen and Heather Becker; at the Medical College of Georgia by Bob Gutin and Kristy Woods; and at our program at Baylor College of Medicine's Center for Research on Women with Disabilities. These programs offer an array of activities in a workshop format covering physical activity, nutrition, and stress management. We are examining motivational interventions for adopting new health promoting behaviors. We are also investigating abusive relationships as a corollary to health problems such as depression, substance abuse, and fatigue in women with physical disabilities. Glen White at the University of Kansas and Jim Rimmer at the University of Chicago are developing interventions to encourage women with physical disabilities to engage in exercise programs.

Service programs of note are the Women's Health Resource Center at the Rehabilitation Institute of Chicago, under the direction of Judy Panko-Reis, Shirley McKenzie's Breast Health Center for Women with Disabilities at Alta Bates Hospital in Berkeley, CA, and the Ohio Disabled Women's Health Network, directed by Louise Fisher. These represent innovative programming to meet an observed need, advancing the state of the art.

PATHWAYS FOR CHANGE

In order for women like me to look to the future with hope instead of terror, change must happen in several dimensions of our current health care system. First, in the education of physicians, disability must be treated as a minority characteristic rather than merely as a pathology. Multiple sclerosis is more than the degeneration of the myelin sheath. Spina bifida is more than the incomplete formation of the spinal column. Arthritis is more than an inflammation of the joints and connective tissues. These conditions create a spectrum of personal and environmental contexts than can alter the effectiveness and appropriateness of traditional medical practices. Primary physicians in training should be required to do a rotation through physical medicine and rehabilitation to see the real life health concerns of people with disabilities.

The second pathway for change is through the women themselves. We are our own best advocates. Programs to enhance our physical, psychological, and social health must expand to offer us the tools of self-advocacy and help us realize our own power to improve our well-being. I look to the day when every independent living center has a women's self-esteem enhancement support group, when the National Organization for Women has a powerful disability caucus and includes disability issues as part of its platform, and when every battered women's program is fully accessible and accommodating for women with disabilities so abusive relationships in our lives can be resolved.

The third pathway is the Americans with Disabilities Act. This declaration of equal access and full integration into society as a civil right has given us a powerful philosophical and practical tool. The regulations detail the specifications for accessibility and offer various means for accommodating our special needs. I would like to see all medical offices meet the letter and the spirit of this law, and to go beyond it by creating ideal environments for women with disabilities. It is no longer acceptable for a doctor to ask for a urine sample, but not have an accessible restroom. It is unthinkable for a gynecologist to turn away a woman in a wheelchair because he has no one to lift her onto the exam table. We can no longer tolerate the serious lack of access to mammography facilities. Solving these problems is no big mystery. It is merely a matter of priorities. We must all rally to the cause of the Americans with Disabilities Act and advocate for access wherever we see a barrier.

Health researchers and educators are the fourth pathway for change. Because we confound research designs with co-existing conditions, we are generally excluded from clinical trials and epidemiologic studies. The effect of certain types of chemotherapy for breast cancer on the spasticity associated with cerebral palsy or spinal cord injury or multiple sclerosis is unknown because there have been no such studies. Except for a few specially funded adjunct studies on women with disabilities, the Women's Health Initiative has generally left us out by default by holding its clinics in facilities that are not completely accessible and offering interventions, such as exercise programs and calcium supplementation, that may be contraindicated for some of us. I want to see a substantial increase in federal and private funding for research on the health and wellness of women with disabilities. I want to see all efforts at health promotion include issues of concern to women with disabilities just as they include issues of concern to women of color. In addition to a dramatic increase in the number of web sites on disability, I want to see every health-oriented web site include information on the effect of disability. Of the hundreds of web sites addressing breast cancer, I found not one that even mentioned women with disabilities.

The final pathway for change that is the catalyst for all the others is the media. By creating a public interest in the serious inequities and gaps in health care for women with disabilities, we can raise the consciousness and spur to action the funding sources, educators, and clinicians who hold the power to advance the practice of medicine in our direction. When new knowledge is generated, the media can help us disseminate it to both the women and their physicians, thereby increasing the demand for excellence. And most important of all, by promoting an image of the healthy and vibrant disabled women, the media can offer hope to women who have no role models. When we were doing our national study, I received mail from women all over the country saying, "Thank you so much for asking these questions. I thought I was the only one!" We are not alone. There is no telling what advances in medical practice, what

revolutions in the physical environment, what changes in the minds of people will come from the power of our partnership.

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