

## Commentary

# The Changing Face of Women with Disabilities: Are We Ready?

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**I**DO NOT THINK THE WORLD has ever been ready for me. As a woman with a severe lifelong physical disability, I have always had to force open doors to maintain my rightful place in society. Made wise from confronting architectural and attitudinal barriers, I greeted the millennium with all my hard won rights in hand but continue to deal with a healthcare establishment that essentially has no clue about what it takes to live with disability.

For all my 50-some years, medical professionals have been challenged to help me keep this body running. Even though the law says medical facilities must be accessible and accommodating to people with disabilities, mounting the table for a well woman examination still takes a heroic effort, and mammograms are totally out of the question. When I am sick, the challenges increase exponentially. Medical science, for all its miraculous achievements, has little more to offer me than i.v. antibiotics for the tracheal infections that are the natural consequences of around-the-clock ventilator use, the latest addition to my armamentarium of assistive devices.

People like me, born disabled, with progressively more health conditions, were never supposed to live this long, but we are. Contrary to expectations and stereotypes, we are living well and maintaining our productivity as long as we are connected with state-of-the-art medicine and technology. But what of those who are not so well connected? If the world is still not ready for me,

how could it possibly be ready for all the newcomers?

### SOME FACTS

We all know about the coming tidal wave of aging boomers. Census projections show that by the year 2050, women aged 65 and over will constitute 23% of the U.S. population, compared with 14% today.<sup>1</sup> The number of working persons per elderly person will decrease from five to three.<sup>2,3</sup> The combination of higher life expectancy and increased disability rates is expected to more than triple the number of elderly persons with severe or moderate disabilities in the next 50 years.<sup>4</sup>

At the other end of the spectrum is the improved survival rate of low birth weight newborns accompanied by higher rates of children with activity limitation and permanent disability.<sup>5</sup> We are already witnessing 20% of U.S. households with children who have special healthcare needs,<sup>6</sup> particularly respiratory diseases and mental impairments.<sup>7,8</sup> This new generation of children born and raised with severe disability and sustained by advanced technology is creating a whole new set of demands on families and healthcare systems.

An increase in the number of people with disabilities in the young adult and middle-age ranges has resulted from increased environmental and lifestyle risk factors, countered by ad-

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vances in trauma care.<sup>9</sup> A growing number of people in their prime have physical and mental impairments resulting from war, and women are newly among them. Our society and healthcare systems are beginning to experience the impact of a population that is more impaired than ever before.

### **THIS IS NOT YOUR MOTHER'S DISABILITY**

Women today are coming to disability from very different routes compared with women 50 years ago. Their response, however, reflects more options for receiving health information and modernized attitudes toward disability. The generation coming up behind us baby boomers is the one that went to school with a disabled classmate sitting at the next desk. That generation expects to see ramps and curb cuts and knows how to express outrage at people parking illegally in designated spots. A cane, a wheelchair, or even a ventilator no longer needs to symbolize decline or end of life. Somewhere in the last half-century, we learned to define ourselves beyond the expectations of others, reject stereotypes, and not be afraid to demand answers.

### **IMPLICATIONS FOR THE SOCIAL INFRASTRUCTURE**

Some major changes need to happen in the social infrastructure before it can accommodate the oncoming barrage of feisty disabled women. The growing number of women like myself who do not have the benefit of an available and cooperative spouse or grown children with the time or interest to provide for our daily physical needs must rely on our own devices and financial resources until society finds a way to meet our needs with a flexible system of reasonably priced in-home personal assistance providers.

Cuts in retirement programs and social services must stop because they are disproportionately hard on women with disabilities. With substantially higher rates of poverty, less access to higher education, rock bottom employment rates, and lower rates of marriage,<sup>10</sup> our avenues to retirement benefits and private health insurance are already seriously limited.

Options for accessible housing must expand so that those who become disabled will not find themselves forced to live in an environment that is impossible for them to navigate, imposing unnecessary additional functional limitations.

Healthcare systems must go beyond the acute care model and increase their capacity to treat chronic conditions. As someone who is very familiar with the early symptoms of serious illness, I have had to use emergency department services far too often because they are the only place to go for the immediate intervention I know I need. Similarly, I have had to stay in the hospital far longer than would be necessary if I could have had easier access to more affordable in-home health care.

### **ARE WE READY?**

We will know we are ready when we accept that "we" means "all of us." I, as an individual, am prepared for disability because I have known it all my life and have learned over time how to listen to my body's messages and respond by working the healthcare systems to meet my needs. For those who enter into disability later in life, the challenge is much greater. Not only must they learn to live with new limitations and filter through confusing and often contradictory medical information, but they must also transcend their own prejudices toward and stereotypes about disability. I wish I could visit with them and share a bit of what I have learned.

When it is available, family is the richest resource of all. The greatest gift I received from my family was their help in shaping my understanding of myself and my potential, in addition to the emotional and tangible support they offered throughout my struggle to achieve and maintain independence. They modeled the rights-bearing attitude for me when they confronted the able-bodied-only school systems of the 1950s and 1960s. As they entered their later years, I was able to provide support to them in return. The extent to which families are ready to deal with disability is a function of their creativity and open-mindedness as much as their financial resources.

We all know it takes a village, but how can we live that axiom in a society that fosters isolation more than connectedness? Social networks are the lifeline for many people with disabilities, es-

pecially women. We have seen in recent natural disasters the importance of neighbors as first responders. Social networks must thrive so that information and assistance can reach people who struggle with the still pervasive barriers to social participation.

There are so many questions about our health that cannot be answered. For example, what is the natural course of osteoporosis after menopause in someone who has had it since she was in her twenties? What can be done to minimize the chronic yeast infections that plague those of us who sit all day? What is the definition of fitness for those who have substantially reduced muscle mass and respiratory capacity? It is up to medical researchers to acknowledge and be ready to address these problems, and it is up to federal agencies to make funding for these investigations a high priority.

Medical educators must teach about wellness in the context of disability as a part of general curricula. By whatever means necessary, medical schools must establish minimum competency requirements for the treatment of people with disabilities in primary, reproductive, and gerontological care.

It is essential that all medical professionals, even those trained many years ago, become computer and Internet literate to be ready for the coming changes in our population. Until medical educational curricula offer avenues for learning about the complex healthcare needs of people with long-term severe disabilities, it is up to practitioners to discover for themselves the best way to serve such patients. In my teaching of medical professionals, I focus on honing their information searching and listening skills and helping them learn to work with their patients as partners.

It is obvious that healthcare systems are totally unprepared for the new generations of people with disabilities, both young and old. Some adults with severe congenital disabilities today continue to see their pediatricians for primary care because there was no plan available to transition them to adult systems of care, nor were the adult systems of care prepared to serve them. Networks of doctors, hospitals, and outpatient clinics will only be able to survive the coming economic crisis in health care if they are able to make major changes in their structure and capacity for treating people with chronic conditions and extremely complex healthcare needs throughout

their life-span. We, indeed, are the litmus test for health care in the 21st century.

## AN URGENT POLICY RECOMMENDATION

As alternative energy sources are discovered and brought into the hands of the public and as our society slowly and painfully learns to eliminate the causes and profits of war, resources will become more available to support the health and wellness of all of us. I breathlessly await a universal focus on prevention and cost-effectiveness for the enhancement of physical and mental health. It is all a matter of money and the motives of the people who decide how to spend it.

The notion of wellness in the context of disability is revolutionary and will be the catalyst for a major refocusing of our healthcare systems. For women, who remain the primary caregivers and nurturers in our society, it is especially critical to adopt this concept wholeheartedly. We are the most likely to live a major part of our lives with chronic conditions, and even when saddled with functional limitations, we continue to be the backbone of our culture. When society rises to meet our needs, everyone will benefit.

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