

Rights, Realities, and Issues of Women with Disabilities

By Laura Hershey

Dinner Conversation

It was a typical conference banquet — mediocre food, long-winded speakers. Six women, some strangers and some friends, shared a table. Five of us had physical disabilities. Eventually, we began sharing personal memories, and suddenly, revelations lay on the table, clattering against the near-empty plates. Of five women with disabilities, three related memories of extreme abuse in medical settings. Not just the stuff nearly every disabled woman can describe, like being an eight-year-old nude model for medical students. These were deeper violations. Molestation. Rape.

One woman remembered a childhood interrupted by frequent hospitalizations. She had cerebral palsy, and had undergone several surgeries plus intensive physical therapy. These procedures, scary enough for a child, were accompanied by a series of sexual assaults by a staff member. This was her first recounting of the crimes, a disclosure that created a bond of sisterhood among six exhausted conference-goers.

If I stopped here, I'd be presenting a simplistic, disempowering picture of disabled women's experience. From news stories to horror movies, women with disabilities are falsely presented as natural victims — vulnerable, passive. In reality, the disabled women's community confronts its problems with the fierce creativity of a resistance movement.

While a majority of the women at that dinner table had been victimized as girls, none could now be described as passive victims. Each had grown into a strong disabled woman, conscious of injustice and equipped to fight it. One woman, institutionalized and assaulted during childhood, had become a lawyer, facing down the legal profession's sexist and disability prejudices. She related the power she felt when, several years earlier, she'd returned to the institution where she'd once lived — this time, to represent current inmates in their legal complaints against that institution. Another woman had become an advocate and researcher, exploring issues of disability, identity, and pride. Even the woman with the freshest disclosure was actively engaged in a project training medical students about the needs and rights of people with disabilities.

I think of that table as a metaphor for our community. We choose activism for our own survival, or in solidarity with our disabled sisters, or from an indistinguishable combination of the two.

Who We Are

There are about 26 million women with disabilities in the U.S. Although the (rare) media images of



disabled people tend to be white and male, the reality is different. More women than men have disabilities, and disability impacts women of color disproportionately. In African American and Native American communities, approximately 22 percent of women have disabilities; European American women have a disability rate of 20 percent.

Our impairments run a gamut: Some affect the brain, some the body, some the senses, some involve a combination. Certain conditions are stable, others erratic; some originated at or before birth; others result from acquired diseases or injuries. Yet with all this diversity, we share many experiences — a proud assertion of difference, survival against the odds, and also, systematic discrimination, crushing poverty and social isolation. By most measures of social status, we find ourselves in last place. Yet we're also workers, students, artists, athletes, lovers, friends, mothers, grandmothers. We adapt to profound change, devising unusual, practical, elegant ways to accomplish what we cannot do through standard approaches. We pave the way for all women — any of whom might join our community at any moment.

We're also leaders, grassroots activists, organizers. Every day, we resist society's compulsion to punish or banish us in encounters major and minor — from being called a fire hazard and told to move our wheelchairs to the back of the theater, to being termed helpless, incompetent, or crazy, and sent to an institution. From this anger and pain, we wrench new visions of how society might respond to the inevitable, natural fact of disability. No single article can hope to detail every aspect of the disabled women's movement, but citing a few key issues and notable activists may illustrate our struggles and straggles.

Access to Safety

In addition to medical abuse, disabled women (like all women) suffer violence at the hands of partners, spouses, family members. The same factors — sexism, male rage and entitlement — fuel brutality toward women, regardless of disability. Additional factors make escape more difficult for disabled women. They may feel less able to find jobs or housing, to build a life apart from their abusers. They may stay in such relationships from fear of going to a nursing home, preferring to endure abuse from one individual than from a whole staff. They may stay because they fear losing their children: Judges have been known to award custody to an abusive parent rather than a disabled one. Police, service providers, and advocates

rarely know how to communicate with deaf women in American Sign Language. Hotlines have no TTY access for deaf callers. Shelters often have stairs and inaccessible bathrooms, bans on necessary medications, or policies prohibiting attendants from visiting to provide needed assistance.

Women and girls with disabilities also experience abuse by service providers and/or authority figures: nursing-home aides, nurses, doctors, group-home supervisors, van drivers. (These perpetrators have effective weapons: They can deny privileges, withhold help, or use a victim's disability to discredit her.)

Activist disabled women have confronted these injustices. For example, the Domestic Violence Initiative for Women with Disabilities (DVI), formed in Denver, Colorado, in 1985 as a grassroots response to the high incidence of battering of disabled women and the shelter system's inaccessibility to these women. Sharon Hickman, DVI's founder and director, has created a network of volunteers and staff to provide information to domestic-violence service providers.

Living in the Free World

Elaine Wilson and Lois Curtis were two women with mental disabilities who lived in institutions in Georgia. Both wanted to live more independently, in small group homes. The state refused, because there were no such "slots" available at the time. So Wilson and Curtis sued the state of Georgia under the Americans with Disabilities Act (ADA). In 1999, the US Supreme Court ruled that states cannot unnecessarily institutionalize disabled people. Justice Ruth Bader Ginsburg's majority opinion stated, "[U]njustified isolation of individuals with disabilities is properly regarded as discrimination based on disability." The decision (*Olmstead v. Lois Curtis*) was regarded as a victory by the disability-rights community. Advocates like Lucy Gwin, Tia Nelis, and Stephanie Thomas then built on this triumph, fighting for non-institutional living options. Gwin, who survived a brain injury, a coma, and a service system trying to control her life, now edits *The Mouth*, an in-your-face magazine that confronts patronizing, professional do-gooders. Terming *Olmstead* "a clear recall from exile," Gwin created the Freedom Clearinghouse, an internet-based project to help connect advocates in different states and provide them with an advocacy tool-kit.

Nelis adapted that tool-kit for members of her group, People First. "Some of that stuff is hard for people to understand," says Nelis, who organizes her peers with cognitive disabilities. She's developed trainings and materials in easier language, and educated People First members, who then wear buttons reading "Ask me about *Olmstead*" — in turn educating others about the importance of independent living options.

Meanwhile, organizers like Stephanie Thomas of ADAPT (American Disabled for Attendant Programs

Today) have been pushing federal legislation to ensure community support services to disabled people nationwide.

About nine million Americans with disabilities — at least half of them women — require personal assistance for everyday activities: getting up, bathing, dressing, cooking, remembering routines, monitoring safety, and doing housework. The Medicaid Community Attendant

Services and Supports Act (MiCASA) would offer "real choice" to people who need such assistance and currently have no options but nursing homes. "Institutions are not our main way to go," Thomas insists, "We need to focus on the person, not the building."

"The building" may be a nursing home, a long-term rehabilitation hospital, a state institution, or a psychiatric hospital. All these facilities thrive by confining people who need assistance of some kind and who, because of current policies, can't get it elsewhere. Disabled women are particularly susceptible to forced institutionalization. Although wives, daughters, sisters, and mothers provide most of the informal at-home assistance needed by disabled and older people, women are much less likely, when we need it, to have such assistance from husbands, sons, brothers, and fathers. (It should be noted that low-income women, including many women of color, provide much of the cheap labor that makes institutions so profitable to those who own them.)

When dependable, responsive, high-quality assistance is available — e.g., through Medicaid-funded programs in some states — people with significant disabilities can be as independent as anyone. Without this assistance, many of us lose what most Americans take for granted: freedom.

Employment

Almost 100 years ago, social-justice campaigner Helen Keller, who was deaf-blind, offered a sophisticated analysis of the social construction of disabling poverty. "Facts show that it is not physical blindness but social blindness which cheats our hands of the right to toil," Keller said.

Workplace barriers and the rule-bound US benefit system combine to create deterrents to employment for disabled women. In a 1997 survey, only about 30 percent of women with severe disabilities were employed, earning a median income of \$12,030. The reasons are complex and include discrimination based on ableism and sexism, lack of retraining opportunities, and employers' failure to provide such reasonable accommodations as modified schedules, adaptive equipment, and on-the-job support. In addition, many women with disabilities decide, reluctantly but rationally, not to apply for jobs because of penalties for working built into the disability-support programs like Social Security and Medicaid.

A number of disabled women have responded to these problems by starting their own small businesses. Barbara Knowlen fought an indifferent bureaucracy to get

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the necessary equipment and services to start Barrier Breakers. She succeeded because she learned the system's rules better than most of the people who work for the system. Now she helps others with disabilities win bureaucratic battles to obtain the necessary resources for going to work or starting a business.

Health Care

Women with disabilities worry about the same health issues as other women, but have less access to health care. Disabled women and our allies have begun taking control of this situation via several projects. One is the Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago. The Center began as a coalition of disabled women's health advocates and supportive medical professionals. It provides appropriate, accessible health-care services — including training for parents with disabilities, mentoring for teenage disabled girls, and clinical services. It also educates new health-care professionals (including some women with disabilities) in a supportive, disability-conscious environment, and advocates for improved state policies. Judy Panko Reis, director of the program and a disabled woman, says, "Our goal is to promote self-determination...which means physical and emotional wellness in teenage and adult women with disabilities."

The women's health movement has largely failed to serve disabled women, who are denied necessary services because of "environmental, attitudinal and information barriers." For example, many physically disabled women can't access standard diagnostic equipment. We can't stand before scanners, climb onto high tables, or wrench our legs into stirrups. Consequently, we are less likely to have mammograms and regular Pap tests.

Projects organized by and for disabled women stand out as bold assertions that disabled women's lives are worth saving — that we have a right to expect good health and good health care.

Sexuality and Relationships

Our disabilities play a variety of roles in our erotic lives. A disability may cause awkwardness; and/or demand creative adaptation, cooperation, and communication between partners; and/or be a source of connection and excitement. All these experiences can be exciting, life-affirming, and pleasurable.

Women and girls with disabilities face significant barriers in trying to form romantic and sexual relationships. Myths abound that we are asexual, incapable of giving or receiving physical pleasure. This translates into more difficulty with dating, decreased likelihood of marriage, and higher divorce rates. Bombarded by negative messages about our sexuality, many of us struggle for a sense of sexual identity. The media-morphed perfect female does not look like someone we can aspire to be.

But do we want that persona? Our distance from that gendered ideal is a double-edged sword, taunting some disabled women with impossible aspirations, releasing others from restrictive stereotypes. Corbett O'Toole, who uses a wheelchair and has been organizing in the disabled

women's community for 30 years, recalls, "My disability gave me incredible freedom to break with gender stereotypes. When I didn't use makeup in high school, when I didn't date boys, when I wore gender-neutral clothing, there were knowing nods that it was because 'she's different.'"

It takes time and a sometimes painful process of self-exploration to discover not only what we weren't, but what we could be; what we are. Only after that journey can we take the more rewarding step of realizing and claiming our true sexual identities. Even then, when we come out — whether as lesbian, bisexual, heterosexual, transgendered, sensuously chaste, or whatever — we may have to journey further to find a community where we can be our full sexual selves.

With the leadership of women like O'Toole, we've developed our own networks for exploring issues of identity and community. Speaking frankly with each other and our partners, we affirm our sexiness in all kinds of ways.

Revolutionary Principles: Feminism and Disability Rights

I'm a feminist because I feel my own future and our collective human future depend on achieving real gender justice, and on ending patriarchal domination of culture and nature. I'm a disability rights activist for very similar reasons: I want freedom and opportunity for myself, and I believe that acceptance of and accommodation to human variation are essential strategies for our human species' survival.

But despite my passionate commitment to both movements, I sometimes feel marginalized by both, as, I know, do many feminists with disabilities. Disability organizations often fail to consider gender issues. And urgent disability-related concerns rarely achieve a prominent place in feminist magazines or conferences.

And why should they? Aren't these the concerns of a small minority? I'd argue that disability rights and feminism directly serve two overlapping majorities. More than half the human species is female, and a substantial percentage of people will, at some time in their lives, be affected by disability resulting from illness, injury, or old age. Furthermore, both disability rights and feminism address compelling, universal, human needs.

Disabled women are working for change on fronts too numerous to explore here, given space limitations: education equity; access to technology; media representations; artistic and cultural activities; reproductive rights: including both the right to abortion and the right to bear children; the right to raise children; body image, and identity development.

I believe deeply in the revolutionary principles expressed by the disability experience. For women like myself to deviate dramatically from prevailing norms yet expect the rights and privileges of any other citizen, is radical. By demanding full participation in society and the accommodations to make that participation possible, the activist disabled women's community offers a liberating vision of human connectedness — for everyone.

This essay is dedicated to the memories of Barbara Waxman Fiduccia and Connie Panzarino. It is reprinted with permission from Sisterhood is Forever: The Women's Anthology for a New Millennium, compiled, edited, and introduced by Robin Morgan (2001, Simon & Schuster, New York). © 2001 by Robin Morgan.