

Considering the mountain of barriers blocking access to health care services for women with disabilities, it's easy to become overwhelmed. First, there are financial concerns, such as unemployment, poverty, and being single that make it more difficult for many to access wellness checkups, prescriptions, eyeglasses, and mental health care — and, of course, insurance is its own peak to be scaled. And for wheelchair users, “Will I even be able to fit my chair through the front door?” is still a common question.

Nearly a third of women with physical disabilities have been denied services at a doctor's office based solely on their disability, according to the 1999 *National Study on Women With Physical Disabilities*, published by the Center for Research on Women with Disabilities. Kristen Jones is one of these women. “I called every doctor on my insurance plan! The mere idea of having a *quadriplegic patient* frightened most doctors, so they wouldn't see me,” says Jones, a doctoral student in the multicultural special education program at the University of Texas.

The discrimination Jones experienced was blatant. But some health care providers mask their intent through demeaning policies. According to Theresia Degener, a visiting professor of law at University of California, Berkeley, a woman with cerebral palsy was refused contact with the doctor and told not to return to the office unless she brought an attendant with her. What merited this exclusion? She took more than 15 minutes to undress and put on a gown.

Once a woman with a disability is granted an appointment with a doctor, she may face further insults to dignity and access when she arrives. Many women report having to park their wheelchairs outside the office and being carried inside for treatment. More than a few women undergo pelvic examinations while lying on the floor because they cannot climb onto the examination table or aren't trusted by the office personnel to maintain their own balance.

How Long Has This Been Going On?

Bliss Temple is a medical student and wheelchair user. During college, Temple was one of few students focused on the impor-

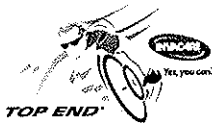
The Road by Melina Fatsiou-Cowan



The Uphill Push

Women Wheelchair Users and Access to Health Care

BY KARA B. SHERIDAN

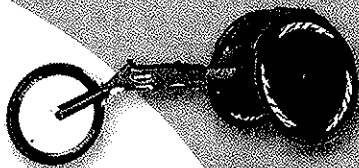


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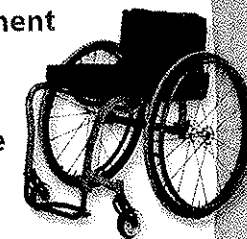
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tance of preventative health care, so after reading an advertisement, she immediately signed up for a well-woman checkup through her campus health office. "The door was too narrow for me to get through, the room was too small for my chair to fit, and the exam table too high," Bliss says. "The lack of accessibility at the outset was just the tip of the iceberg. The nurse practitioner told me, 'We'll just do a breast exam in your wheelchair, and then skip the rest and assume everything else is OK.' I was so outraged! I mean, the whole point of well-person checkups is to *screen* people — you don't assume things are OK, you check to make sure they are!"

A few months later, Temple returned to the office with a pressing need for services. She wrote on her intake form that she'd been struggling with a cold for weeks and was worried it may have become a sinus infection. "The doctor walked in reading my form and then looked at me over the top of the paper. 'How long has this been going on?' he asked. 'About three weeks, but it's been worse yesterday and today,' I replied. 'You've only been in a wheelchair for *three weeks*?' he said. I eventually got my antibiotics, but how on earth could I expect good general care from someone who could only see my wheelchair and hadn't paid any attention to what I saw as my medical problem?"

Temple's dedication to maintaining her own health could have been squelched because of the treatment she received from health care providers on several occasions. Thankfully, it was not, and she translated her experiences into the development of a curriculum to teach medical professionals about how to better serve women with disabilities. The curriculum is currently being used at Duke University and Wake Forest University Schools of Medicine.

The education of medical professionals may be a contributing factor to attitudinal barriers that block access to health care for so many women with disabilities. For many doctors, lack of information seems to be the problem. They may not understand a person's primary disability or the implications of this condition on other areas of general health. Studies indicate that women with physical disabilities have an average of 14 secondary conditions, so it can be daunting to find effective and integrative treatments to achieve optimal health for this population.

It's understandable that doctors generally focus on their cases from a medical model perspective. They are taught to seek out the cause of an illness and develop a plan of attack to eradicate the condition. Finding a cure is the ultimate goal. However, the social model of disability counters this view with the assertion that physical barriers, prejudice, and exclusion by society are the actual determinants of disability, and that disability is a natural and normal part of the human experience. Understanding the social and cultural components of the disability experience is essential to treating someone as a whole person. We want our doctors to see us as individuals in a cultural context, consider



Bliss Temple designed a curriculum on health and disability for medical professionals.

the years of expertise we have developed about our own bodies, respect our decisions, and work with us to improve our quality of life.

In the United States, we live under a health care system where time is money. For doctors to specialize in rare conditions is thought of as less profitable. People with disabilities are not seen as desirable customers, but given the large consumer base among people with disabilities, this view

makes little sense. Individuals with disabilities comprise approximately 21 percent of the overall U.S. population, and women with disabilities account for 53 percent of this figure. According to CROWD and other organizations (see resources below), women with physical disabilities are more likely than women without disabilities to have used every major category of health care provider within the past year. Significantly more women with disabilities are seen by general practitioners, rehabilitation therapists, obstetricians/gynecologists, and other specialists.

Gender and Health Care

Women with disabilities are doubly marginalized in our society. For example, what little research that has been conducted to better understand people with disabilities has historically focused on men with spinal cord injuries. But women, too, deserve the focus of researchers to improve specialty health care services specific to the needs of women. Gender differences are especially apparent when women with disabilities seek reproductive health care. Despite medical training that often stresses the need for sexually transmitted disease testing and contraceptive education for *everyone*, many doctors have absorbed the cultural stereotype that women with disabilities either cannot or would not have sex.

"People seem to have such a mental block when it comes to believing that women with disabilities might be sexual beings, and/or be interested in having children," says Temple. What she and so many of us have noticed during yearly checkups is what Harlan Hahn, a political science professor specializing in disability issues, has termed *asexual objectification*. While women without disabilities are frustrated by their treatment as sexual objects, women wheelchair users are often considered unattractive, undesirable, asexual beings. "Objects" are not capable of making love or making the choice whether or not to have children. The fixation on a person's primary disability can be so intense that it can feel like gender is not even considered.

"Disability is such a strong overarching category that often they [doctors] pay attention to little else and thus barely notice my gender," says Temple. "This would explain why I feel that my gynecological care is so much worse than other kinds of care — because that's the main

thing that is gender-specific."

The assumption that women with disabilities are sexless couldn't be further from the truth. In fact, CROWD has found that 94 percent of women with disabilities report sexual activity at some point in their life. With this involvement comes the risk of acquiring an STD. While women wheelchair users are no more likely to acquire STDs than nondisabled women, it may be more difficult to recognize the signs and symptoms of these and other reproductive conditions. The attitudes and assumptions of health care workers further block the prevention and timely treatment of STDs for women with disabilities because few are screened.

When Jones, a quad, had the foresight to request an STD screening, she was told, "Oh, you'd know if you had something." Her own dedication to understand her sexual health let her know that this was dangerously untrue. "At that moment, I felt they thought it didn't matter," says Jones. "To them, I'm just a kid and I'm in a wheelchair, so why would I be having sex. A nondisabled woman would never be told that."

Nondisabled women don't have to be concerned with the type of examination table their gynecologist chooses to use. This problem was mentioned repeatedly when women wheelchair users were asked about their experiences accessing health care. Stacey Milbern, 20, is a junior at Methodist University and a wheelchair user. She is already extremely versed in advocating for her own health care needs and organizes other youth with disabilities through groups such as the North Carolina State Independent Living Council and the National Leadership Network. She needs an adjustable examination table, but says she has "only heard about them in myth."

Temple was forced to endure her first pelvic examination while lying on the linoleum floor on a paper sheet, even though universally accessible examination tables have been available for several years. Sandy Welner, a pioneering doctor dedicated to improving the gynecological care of women with disabilities, invented the "Welner table." Because this option could also improve care for women without disabilities who may be taller, shorter, or heavier than most, there may be economic incentives for doctors who choose to order accessible equipment. Still, the majority doesn't, which denies access to countless

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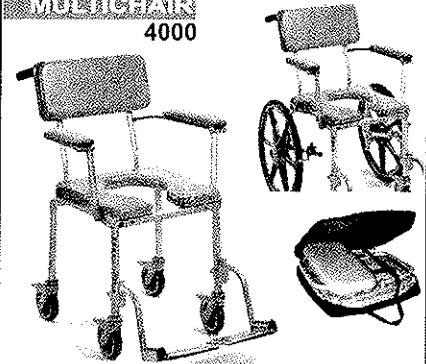


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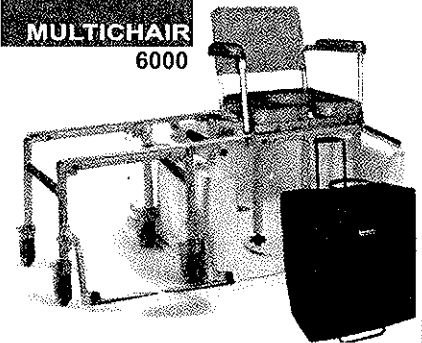


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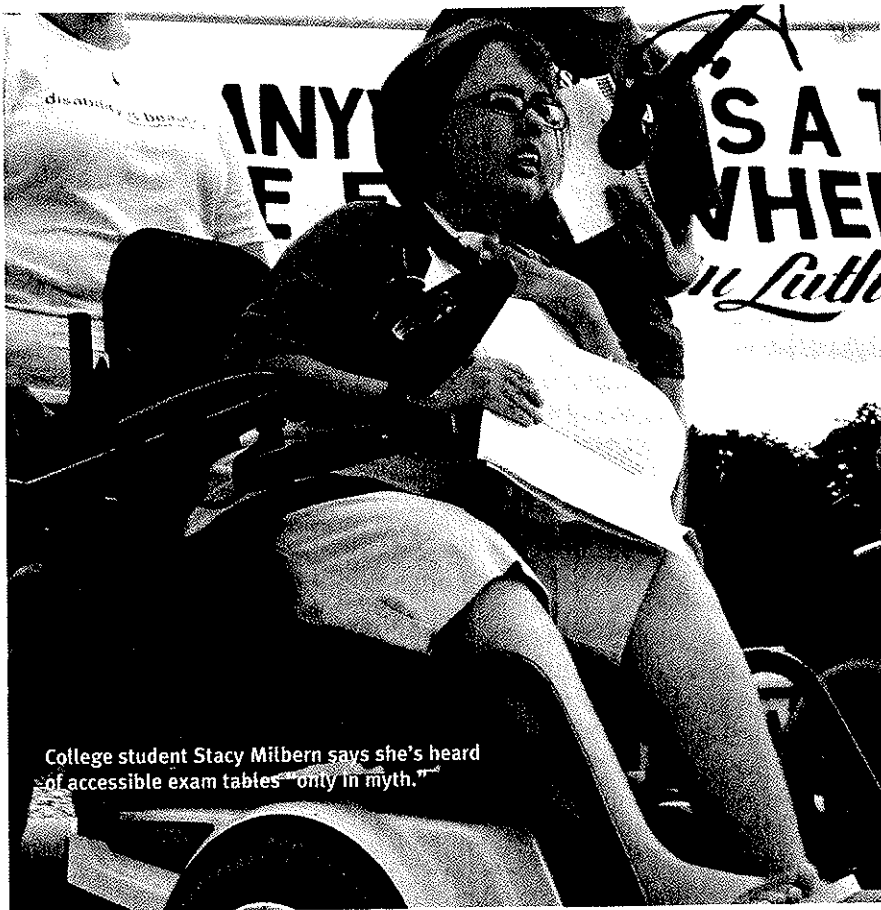
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College student Stacy Milbern says she's heard of accessible exam tables "only in myth."

women with disabilities. Iowa's Sen. Tom Harkin has recognized the barriers that equipment can pose for people with disabilities with his sponsorship of the "Promoting Wellness for Individuals with Disabilities Act of 2007." The bill establishes accessibility standards for diagnostic equipment, requires that dental and doctors' training programs increase competency in treating patients with disabilities, and funds grants to provide money for preventative health programs targeting people with disabilities.

It's possible to question a receptionist on a particular doctor's equipment, but it's not as easy to uncover negative attitudes held by medical practitioners about women with disabilities. For example, many feel it's a selfish and negligent act for a wheelchair user to make the choice to become a mother. My own disability, osteogenesis imperfecta, is genetic, and part of making an informed reproductive decision involves consulting with a genetic specialist.

At 22 years old, I made my first visit with a supportive friend. The doctor was astonished that my parents did not accompany me, and he assumed their absence must signify their opposition. Before he even began my consultation, he remarked, "If I was your parent, I'd do anything in the world to convince you to adopt." This statement wasn't based on his medical expertise, but on his own prejudicial beliefs that were already standing in the way of my attempts to become truly informed about my choices.

Assuming a woman with a disability desires biological children is equally insulting. Milbern has experienced a range of unsolicited opinions from medical professionals about her childbearing. "Some are cheerleader-like supportive and others advise against it when I didn't even ask them."

Another young woman in a wheelchair, Jennifer Fitz-Roy, says the combination of her feminine persona and her spina bifida sometimes elicits seemingly more positive and friendly responses from medical professionals. "I have a very sweet, docile personality. Many physicians and nurses seem to enjoy taking care of me. I'm sometimes given much more attention and care than I think I would otherwise. This care, however, is often given out of pity, and many nurses and physicians assume that I'm incapable of taking care of myself." Whether these types of attitudes are blatantly discriminato-



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ry or masked in paternalistic intentions, the outcome is the same for women with disabilities: unequal access to all forms of health care services.

Access to Mental Health Care

Since medical equipment is usually not needed in mental health treatment, are these services more accessible to women in wheelchairs? Many doctors assume a woman's disability must make her depressed, anxious, and in need of treatment. Even a positive adaptive response to an acquired disability is often questioned. Jones remembers being barraged by psychologists during her rehabilitation experience because they declared her "too perky to have just sustained a spinal cord injury."

In general, women with disabilities do experience a greater number of risk factors that are associated with mental health conditions. However, these factors involve the



Yes, Jennifer Fitz-Roy uses a wheelchair. No, she says, that doesn't mean she needs therapy.

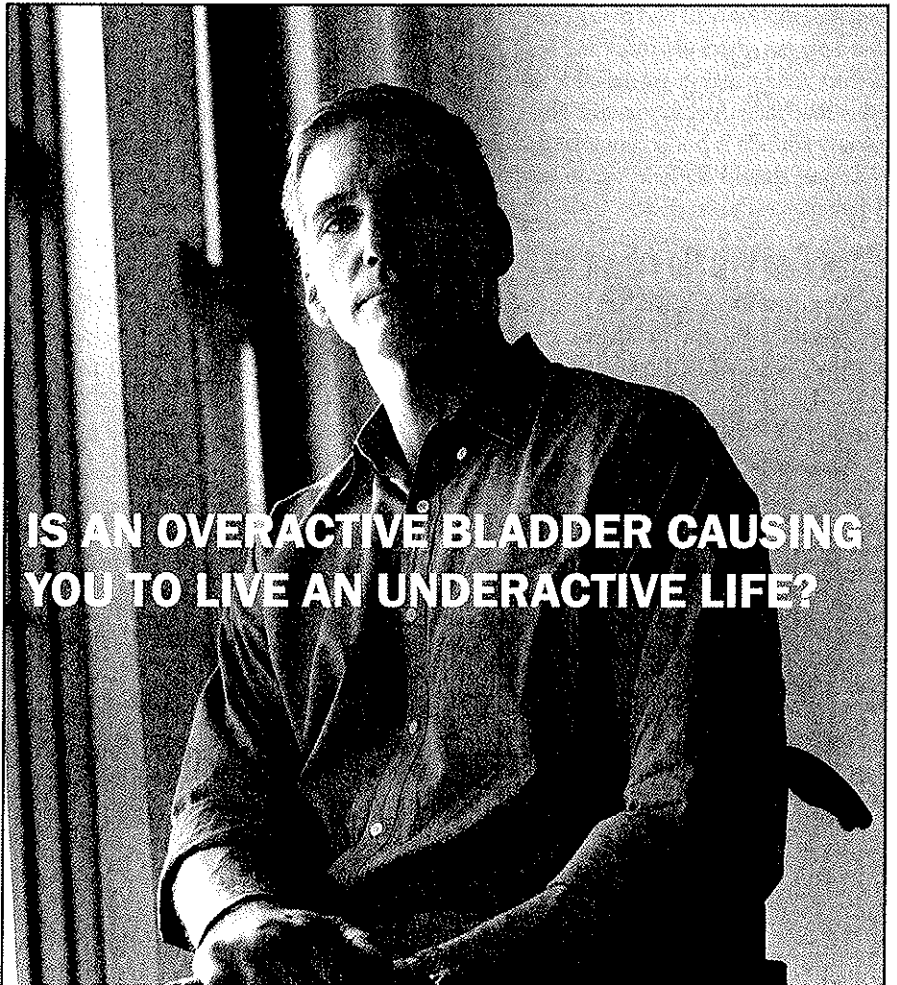
social context, including poverty, isolation, and stigmatization. Women in wheelchairs may be more likely to experience depression and high levels of stress, but psychological research has failed to include this population in much of the research that drives treatment. The experience of living with

a disability is unique for each individual, and there are no simple answers to the mental health repercussions that may arise from the daily frustrations related to a person's physical disability.

By focusing solely on a woman's disability as a red flag that she needs mental health care, professionals may miss other important indicators. Fitz-Roy dealt with assumptions that she must need counseling that focuses extensively on her congenital disability. She explains there are other factors

that have encouraged her to monitor her own psychological health, but says she's capable of deciding for herself what she needs. "I experience chronic pain, I experienced the death of a parent as a child, and there is a strong history of mental illness in my family. I receive appropriate screening tests for depression and anxiety regularly and go to occasional intake appointments with a pain psychologist, but at this time, I do not need mental health services."

Many other people with disabilities do



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benefit from support groups, family therapy, individual therapy, and other mental health services. It is essential that professionals in the field understand that a person's disability status should be considered as an element of their cultural background, but not the primary defining factor of one's identity. In a recent visit to an online forum for psychologists, one marriage therapist replied to my question about ADA compliance by saying, "My office doesn't need to be accessible because I don't specialize in treating people with disabilities." It was clear this professional had never considered that a person with a disability and his or her partner might seek treatment for an issue other than their disability status. This exclusionary attitude is not acceptable, and professionals should be held accountable for denying access to services.

What Can We Do About It?

Women with disabilities need to assume responsibility for advocating for improved access to health care. Learning from other women with disabilities may be our best resource to find professionals, equipment, and services that address our unique needs.

By asking other women with spinal cord injuries, Jones found she's best served by seeing a separate urologist and gynecologist, both of whom are familiar with issues affecting women with quadriplegia. Temple has tapped into the medical profession's increased focus on cultural competence to urge the inclusion of education on women with disabilities as a cultural minority. Milbern and Fitz-Roy mentor youth with disabilities who will soon be charged with managing their own health care and advoca-

ting for changes to a system that has denied access to women with disabilities for far too long.

As women in wheelchairs, we are encountering similar attitudinal barriers that prevent us from receiving adequate health care. By uniting our voices in advocacy, supporting other women wheelchair users, and inviting the medical community to hear our concerns, we can begin plotting out the most effective route to accessible health care.

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Resources

- For more information on Bliss Temple's curriculum for medical professionals, contact her via e-mail at maieutical@google.com
- *Access to Preventive Health Care Services for Women with Disabilities Fact Sheet* by the Association of State and Territorial Health Officials, www.astho.org
- *A Health Handbook for Women with Disabilities*, www.hesperian.org
- *Disabled Women and the Right to Healthcare*, [/www.disabilityworld.org/Aug-Sept2000/Women/HealthCare.htm](http://www.disabilityworld.org/Aug-Sept2000/Women/HealthCare.htm)
- Center for Research on Women with Disabilities, www.bcm.edu/crowd/
- PowerPoint presentation, *Women with Disabilities Reproductive Health Care*, www.hms.harvard.edu/coewh/DisabilityConference/PPT/ReproductiveCare_Potter.ppt
- Book review of *Welner's Guide to the Care of Women with Disabilities*, www.disabilityworld.org/06-08_04/women/bookreview.shtml

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