Recalling Barbara: This collection of papers is named for Barbara Waxman Fiduccia, a pioneer in the field of Women and Disability Studies. Barbara lived her life boldly and gracefully on the cutting edge of disability and women’s issues as they also intersected with many other realms. This piece offers recollections of Barbara’s work and life, and reflections on disability feminism and the impact of activism on personal power.

In her writings, speaking, activism, as well as her personal life, Barbara took the lead in exploring disabled women’s sexuality, reproductive health, marriage disincentives, assisted suicide, violence prevention, disability hate crime, personal assistance services, eugenic ideology, architectural accessibility, and many other issues. Barbara wanted it all and she went for it.

Barbara, a close friend of mine, was a unique, sometimes quirky character. Her forthright manner and sharp mind made her an appealing mentor and colleague. Barbara, along with her brother, had spinal muscular atrophy, requiring her to use a wheelchair and, eventually, a portable respirator. Barbara rode in her chair as if she was a queen on a magnificent horse. She was visible as a Jewish woman and sometimes wore pretty hand woven yarmulkes, a statement of her Jewish feminism. She loved beautiful clothes, dangly earrings, low-cut necklines and high heels (which she didn’t have to walk in.) She sucked on and waved around her respirator tube as if she knew it was a good look for her, talking animatedly between puffs.

Her forthright personality often startled her public and even her large circle of close friends. She was always ready with confrontative personal questions, insightfully probing a (straight, lesbian, bi or trans) client or friend’s health or intimacy difficulties. She would ask who you were dating, what your birth control method was, if you’d had your pap smear this year. She made us laugh and she made us think. I remember sitting in the living room of her beautiful home in Cupertino CA with some other women, all of us laughing so hard it hurt. I think we were talking about a conference or something, and... sex.

Barbara grew up in Los Angeles. In her twenties she worked at Planned Parenthood directing the Disability Program and 504 Compliance Office and continued on in consulting, writing and training, most significantly with the Center for Women Policy Studies. In the mid-1990s she married Daniel Fiduccia, whom she described as the man of her dreams, having won a five-year fight with Medicaid policy that imposes marriage disincentives for people with disabilities (see references below). Barbara died in 2001, too young, in her forties, due to failure...
of her respiratory equipment, and only a few weeks after her beloved husband, Daniel, had died from cancer, their large circles of friends and family stunned.

Barbara held out for us a vision of disabled women, as well as disabled men, as unique but also ordinary human beings, deserving of intimacy, of full inclusion in every aspect of life including sexual intimacy, whatever their body, mind or circumstance.

One myth of disability discriminatory attitudes is that disabled women are not real women. Women with disabilities may have experienced significant loss of body parts, or limitation in physical or mental function. A disabled woman’s body may be unusual in appearance and judged unattractive by cultural standards. Disabled women and girls may live in pain, may cost the community extra money, may die young. Through the process of personal empowerment, we have come to realize, and then to communicate to others, that our lives are worth the effort, that we are beautiful just as we are, that we are wonderfully woman!

Disability Feminism: Disabled women have developed our own feminism, with inspiration from leaders like Barbara, and our growing assertion of ourselves as essentially female and powerful. Narrower definitions of feminism have tended to exclude women with disabilities. Some feminists imply that women with disabilities cannot be “real feminists” if we cannot meet traditional feminist stereotypes -- if we cannot be powerful, autonomous, highly intelligent, financially or physically independent, in the typical ways. These notions hurt and limit all women, but they especially have kept women with disabilities disconnected from the feminist community. But, “feminism is strongest when it includes its weakest,” wrote Bonnie Klein.

Disabled women, as individuals and as a group, are still among the most marginalized of any constituencies, though it is not useful to compete for the title role in victimization! It is important, always, to attend to the full range of factors in any constituency’s status, or individual’s marginalization -- to address the intersections with class, race, age, sexual orientation and all factors that line up in our oppressive societies to decrease personal power, visibility and access to society’s resources.

As women and girls with disabilities, we have particular insights and experiences that we bring to the community; we have unique views of what it means to be female. This is the disability feminism we can offer to each other and to all women. As disabled women, we may need assistance in daily living activities, such as dressing, bathing, preparing and eating meals, communicating, moving, getting places. These experiences of “dependence,” viewed through the veil of oppression, tend to portray the need for help as a burden to others. But we can choose to regard this “dependence” as intimacy, as opportunities for close, valuable collaboration with our family members, friends, or our paid assistants, enabling the community’s access to our important contributions. We can realize that the effort to include us is as useful to our helpers and to everyone as it is to us.

These are important lessons for nondisabled people who may live within the illusion that humans are separate, autonomous, isolated. Interdependence is essential and unavoidable for anyone who hopes to live a full life – and not only because aging entails dependence on others. Anyone who knows and cares for young children seeks to validate the needs of our young to feel unconditionally loved and accepted just as they are. Comfort with interdependence is fundamental for everyone who is human, and who, almost by definition, may need help at any time.

We must not confuse the value of helping disabled people with the traditional devaluing of women in the caregiver role. Women can indeed be overwhelmed and oppressed by the work
of caring for loved ones who have disabilities. But this is not caused by the disabilities or the people who need help. Instead, it is the result of the sexism and isolation inflicted on women caregivers. Any work, if sufficiently shared and validated, can become meaningful, important, and joyful. This is particularly true of caregiving, when done with ample support and connection.

Barbara emphasized that disability feminism regards our disabled young, infants and girls with disabilities, as precious and essential members of the community. These little ones are our community’s present and future and deserve our attention and encouragement to regard themselves as deeply valued and magnificently female.

Meeting Up with Barbara: I recall how I first met Barbara, in the era before the internet, the mid 1970s. All around the world, local groupings of disabled women began to form: disabled women’s support groups in self-help or rehab centers, kitchen table conversations with women friends, disabled girlfriends in “crippled schools,” hospital schools, and colleges; disabled women in the women’s room or at the coffee table at early disability rights conferences. We disabled women found each other and raised the issues. My disabled women’s group was in Boston; Barbara’s was in Los Angeles.

Those of us in our local groups got together and listened to each other begin to say, tentatively at first, then more boldly: “We are marginalized by sexism as it intersects with disability, in our communities, in dating, in marriage, in school, in work, in our political voices! Marginalized, even within the disability community. We are treated significantly worse than disabled men by society, often treated badly by men, and sometimes treated badly by disabled men.” We began to speak out, to write, and to publish our stories in collections, newsletters, and newspaper articles.

I kept seeing Barbara’s name in these publications; she saw mine. We mailed notes (snail mail!), got phone numbers, called each other: “We have a lot in common, let’s talk!” She was as thrilled as I was, to find a new comrade, to share other names of disabled women leaders, projects, ideas. National, then international, networks evolved, and our movement arose. Books and articles were published with our stories and our perspectives, our growing literature. Our struggle was validated by research. Our movement was recognized as real, important, powerful and growing worldwide. In 1997 Barbara and I wrote the “Disabled Women’s Manifesto.”

Barbara was key in inspiring me and others to take on the issue of reproductive rights and genetic discrimination. In her nuanced understanding of the impact of eugenic ideology, she offered her crucial observation that disabled women were marginalized as females out of society’s deep terror of our possible procreation. Barbara came to realize that there was never anything inherently “unsexy” about us! In society’s eugenic perception, we must be regarded as, at best, unattractive, child-like, and incompetent as mothers. At worst, we would be viewed as disgusting, monstrous, hideous freaks, worthy only of incarceration, sterilization or death, or else we would, heaven forbid, reproduce ourselves, rampantly! So society forbade our sexuality, our sensuousness, our intimacy, our motherhood, through the tangle of myths and prohibitions.

Also in the 1990s, Barbara initiated a conference for health providers about disabled women’s reproductive health. She asked for my help along with many other disabled women leaders. Together we created a powerful training event in Oakland, California, but Barbara was at the helm. Nurses, doctors and other providers gathered to be taught by disabled women about our needs for sensitive, accessible, high quality reproductive health services. The conference was a huge success. Triumphant and heartened I flew back to Boston where I was living at the time.

When I got home I had a dream; I eagerly called Barbara to tell her about it the next day. The dream was about the years that I had spent in Shriners Hospital for Crippled Children (as it
was called in my childhood) frightened and alone. An adult, I was still having occasional nightmares about my experiences in the hospital, where we were socialized to believe that our defective bodies needed to be made acceptable, and we should be grateful. While the treatment was often helpful, the mixed messages were not. I was hospitalized for a cumulative two years of my childhood. I sometimes felt, even as a grown up, that some part of me was still stuck in the hospital, waiting to get out, and certainly still subject to the messages that we had been given about ourselves as disabled children.

But in this dream (after this wonderful conference) I planned and executed my escape from the hospital! I remember the details vividly (including my escape vehicle, a gleaming red and white ‘57 Chevy sedan!) When I told Barbara about the dream, she was thrilled! We analyzed it: the conference had given me a powerful view of the value of our experiences and our skills as trainers of health providers. We had crossed the barrier of doctor-patient into the realm of peers -- educating other professionals. The conference had given me a new confidence at a deep level. After that dream I have never had another nightmare about my childhood surgeries. This was testimony to the transcendence of our activism: it actually changes our views of ourselves in our deep unconscious. I am now a frequent trainer of medical professionals about disability issues.

**If Barbara Were Alive:** If Barbara were still alive, she would be excited and proud of our successes -- the increased visibility of disabled women leaders in our national and international community, the *United Nations Convention on the Rights of Persons with Disabilities* and its attention to disabled women, the steps that the feminist and domestic violence movements have taken to include and address disability and disabled women, the many new publications in our rich literature, the increased disability, ethnic and cultural diversity of our movement’s leaders.

And she would be outraged and actively challenging the Congressional undermining of the *Americans with Disabilities Act*, the devastating budget cuts of services and entitlements, the still substantial resistance of many women’s organizations and services to become accessible and welcoming to women with disabilities.

She would encourage us to build mentorship programs for girls and younger disabled women. She would insist on full inclusion of older disabled women in every aspect of our community. She would claim her right to be a beautiful, sexy, older disabled woman! She would continue to challenge us to fight for ourselves, to speak out, to connect, to lead, to have lots of fun, and push the limits on our sexuality and our beautiful, fully-female selves. Barbara’s spirit lives on!

**References**


*Barbara Faye Waxman Fiduccia Papers on Women and Girls with Disabilities*, published by the Center for Women Policy Studies:


**About the Author:** Marsha Saxton, Ph.D. teaches Disability Studies at the University of California, Berkeley, and works as a principal investigator at the World Institute on Disability, in Berkeley, CA. Saxton has presented in the last three years in Australia, Japan, Britain, Finland, Qatar, Canada, and the USA. She received the 2008 Irving Kenneth Zola Memorial Lecture award. In July of 2003, Saxton was interviewed on *60 Minutes* about “wrongful birth” lawsuits. In May of 1998, Saxton was a guest on *Talk of the Nation* with Ray Suarez, addressing issues of reproductive technologies and the disability community’s view of selective abortion. She has published three books, two films, and over one hundred articles and book chapters about disability rights, personal assistance, women's health, and genetic screening issues. She has been a board member of the Our Bodies, Ourselves Collective and served on the Council for Responsible Genetics, and the National Institutes of Health (NIH) Ethical, Legal Social Implications (ELSI) Working Group of the Human Genome Initiative.