

better support for scholarship and research. For instance, it was through the efforts of the A.C.L.S. that the National Endowment for the Humanities was created by the U.S. Congress. The A.C.L.S. also offers its member associations a very wide range of opportunities for acquiring new knowledge and skills from meeting planning advice to projects that assist in electronic publication, to events that explore the most challenging aspects of the contemporary intellectual and educational climate.

Acquiring membership in the A.C.L.S. takes a certain amount of effort because the relation of the scholarship supported by the candidate organization to that of existing A.C.L.S. member groups needs to be articulated informatively. But, in terms of the opportunities it offers the members of the Society for Disability Studies to build audiences so as to increase appreciation of the lives of people with disabilities in the general education curriculum, and subsequently in the general culture, the benefits would time and again repay the effort's costs.

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Health Care Services for Women With Disabilities

Lois J. Shaevel

"There is a puzzling myth that people who are ill or injured (especially women) are obsessed with their health - always talking about their problems, showing off their scars, bragging about their doctors. The reality for women with long-term disability or chronic illness is very different, however. Just as we learned at an early age not to acknowledge disability in others ("Don't ask," "Don't stare"), so too we learned not to confront others with our own disabilities - "Don't tell!"... "And there is much to tell." (Marsha Saxton)

In regard to health care services for women with disabilities there certainly is "much to tell." Much to tell because little has been written to date to guide disabled women through the maze of health care services that even confounds their non-disabled sisters. Much to tell because cultural attitudes towards medicine and towards disability still prevent the ready coordination of health services for disabled women. And much to tell because recent decades have reframed the social issues surrounding disability from old views of charity and care to new views of discrimination, civil rights, and self-directed services.

My purpose here will be to explore these new views of (1) discrimination, (2) civil rights, and (3) self-directed services that are working to shape a new future in health care services for women with disabilities.

(1) Views of Discrimination: Sexuality and Reproduction for Women with Disabilities

"My first period was truly welcome. . . . At last my body had done something right...something every female body is supposed to do." (Ann Cupolo Carillo)

In the "Women and Disability Think Tank" of the Boston-based Project on Women and Disability, a discussion was held regarding the topic of "disability, menstruation, and menopause." The group of women shared stories of their first periods, of adapting menstrual products and

procedures to their disabilities, of difficulties with birth control methods, of dealing with hot flashes and symptoms of changing bodies.

One common point was clear: their own mothers, their teachers, doctors, and nurses had barely a clue as to how to help them with their struggles to claim their own bodies as female, capable of fertility, pregnancy, and birth. Every woman in the group had been discouraged by health practitioners or family members from even considering pregnancy. All had encountered remarkably similar barriers to getting information about sexuality and disability. They all had to figure it out themselves and they did.

According to the Federal Register of October 1994, over three million women of childbearing age in the United States have some type of disability. Many of these women are regularly discouraged by families, friends, and health care providers from considering the option of parenthood. While most women experience social and emotional pressures to have children, disabled women are under pressure not to have children. Yet disabled women feel the same needs for emotionally satisfying relationships as other women.

"Women with disabilities are not perceived as people with sexual lives," says Cindy Blank-Edelman, executive director of the Project on Women and Disability. "Because of this, they are often not given information on birth control and other reproductive health concerns." The attitude is: "You do not need gynecological care because you are not sexually active or sexual."

So astonishing is it to some physicians that disabled women might be sexual that Galler (1984) reported a completely unnecessary appendectomy for one woman because no one even considered that someone with cerebral palsy could have the symptoms of venereal disease.

This discrimination is but one of the reasons, according to disabilities activist Barbara Waxman, that women with disabilities are underserved when it comes to their health care. Almost nothing is known about the physical life of disabled women, says Waxman. Little has been written about their life-cycle, from menstruation to menopause. There are no studies specifically on the number of disabled women of childbearing age. Almost nothing is known about their rates of fertility, pregnancy, birth, and abortion as well as sexually transmitted diseases and reproductive cancers.

Worse, science has not yet researched the interaction of contraceptive pharmacology on disabled women's bodies. What literature that does exist is derivative, yet such data is essential for monitoring the reproductive health of disabled women and planning truly responsive services. Many gynecologists, ignorant of the adverse consequences of some birth control methods for women with particular conditions, prescribe unsafe methods.

There are no studies comparing how family planning information is relayed to disabled and non-disabled women. To understand whether a disabled woman has reproductive health, one needs to evaluate the quality and amount of information she has about her own body, her ability to access services, the way in which she receives services, and the capacity of the health service system to change to accommodate her needs. Current literature on health services for women with disabilities consists either of "how-to's" for providers or the personal horror stories of prejudice and abuse that women with disabilities face in medical settings.

You may have many unpleasant and even quite painful memories about your medical care, especially if you have had your disability since childhood. Long, anxious waits in crowded

waiting rooms, hurried nurses, receptionists who ignored you, painful surgeries, and lonely nights in hospital beds; embarrassing examinations by strangers; years of unanswered questions - these may be among your memories.

Many women speak angrily of the unavailability of adequate counseling on sexuality, birth control, pregnancy, and childbirth from either gynecologists or rehabilitation professionals. In the preface to Mother-to-Be: A Guide to Pregnancy and Birth for Women with Disabilities, Judy Rogers and Molleen Matsumara note that disabled mothers-to-be have many of the same concerns and experience many of the same changes as able-bodied pregnant women, "but they are often unsure whether what they are feeling is disability-related, which can be a major source of anxiety."

Compounding the problem is the difficulty of finding doctors and midwives to provide help through what they are likely to view as high risk pregnancies.

For these and other reasons, motherhood is often proscribed for women with disabilities. Many states even have laws forbidding people with histories of epilepsy, mental retardation, and psychiatric disability from marrying. The fear that disabled women would produce children with similar conditions is nearly always groundless since the vast majority of disability is not hereditary.

There is also the irrational fear that women with disabilities would harm, deprive, or burden their children. The result is encouragement to do sterilizations on women with disabilities to prevent "inopportune" pregnancy.

Pregnancy in women with disabilities is a societal attention-grabber. A pregnant woman with a visible disability not only deviates from society's ideals of physical perfection, but also may be seen as flaunting the fact that she has a sexual relationship with a man. In a culture quick to judge women by their appearance, women with visible disabilities are at a significant disadvantage.

"Western society places a premium on wealth, youth, physical strength, and attractiveness," says Jeffrey Z. Rubin in his foreword to Women with Disabilities. "Disabled girls and women, then, are the denizens of this apparently worst-of-both-worlds combination of being female and being quintessentially unattractive through disability." Many of these women become silent and "invisible," not likely to be assertive about their choices in health care or much else, for that matter, and certainly unlikely to seek medical attention for reproductive problems such as infertility.

One woman in six experiences difficulty or delays in becoming pregnant - this includes woman with disabilities as well. Although it is embarrassing for anyone to disclose intimate details of a sexual relationship, an important part of the infertility workup, it is especially difficult for disabled women to do so. They may be even more reluctant to seek clinical intervention for fear that they will be judged for their desire to become pregnant.

What is particularly interesting is that there is a significant medical emphasis and focus on spinal cord injured men's fertility, a prioritization that is influenced by economic, political, and social factors. Men who experience an adult onset of disability tend to bring to their disability experience their able-bodied sense of sexual entitlement and a demand for the rehabilitation of their sexual and reproductive capacity. They drive the research that helps to make them better able to function sexually while women with sexual problems have an underlying need to appear asexual and, therefore, try to hide their problems.

Until women with disabilities (as well as the rest of society) develop a level of comfort with their sexuality and nurturing capabilities, this discrimination and imbalance are likely to continue.

(2) Views on Civil Rights for Women with Disabilities

Despite the limitations in their gynecological and obstetric care, women with disabilities are often subjected to much more medical attention than nondisabled women. Many of them report years of feeling like inanimate objects on one examining table after another.

In her article "Up Against Eugenics," Barbara Waxman notes that women with disabilities are regularly treated by physicians and health workers who do not listen to them or believe what they say, who withhold knowledge, lie to them, treat them without their consent, fail to warn them of negative effects of treatments, experiment on them or use them as teaching material, administer treatment that results in iatrogenic illness and death, and remove reproductive organs that are in no way diseased. Within the medical community, the civil rights of women with disabilities have barely been recognized.

For patients with hearing impairment or other impediments to communication, medical treatment can be especially terrifying. Often, little effort is made to assure that the patient understands what is happening to her and horror stories abound:

"Following Helen's thyroid surgery, there was some question about the possibility of cancer. Helen's dad had just died from cancer the previous March, and Helen made the decision to not tell her mother about this new concern unless it became a reality. When Helen's physician called her hospital room to check on her post-surgery condition, Helen's mother answered the phone. The doctor assumed that Helen's mother was her ASL interpreter and proceeded to communicate through her with Helen. In this process, his concern about the possibility of cancer was revealed. Helen was furious to have been betrayed in this way by her physician, whom she had greatly respected until this incident." (recent, real-life occurrence)

As well as being discounted, women with disabilities are often treated like children by medical professionals. Doctors have a tendency to talk to their care givers or companions rather than to them: "When I go into a doctor's office, instead of talking directly to me, the doctor asks the person I'm with why I'm there. Once when a doctor did this to me, I confronted him, 'Why do you assume that just because I'm in a wheelchair, I cannot talk for myself?' He said, 'Because I see a lot of people in wheelchairs.' I didn't answer back, but I'll tell you what I was thinking...he gave a truly dumb answer! . . . Once I did have a good doctor. When I first met her, she surprised me by talking to me directly. That was most important to me because, in order to trust a doctor, you have to have one who will talk to you." (from "Speaking Out" by Mary Ambro)

More than just "talking," the responsibility of the medical provider is to inform the patient of procedures and prescriptions and to offer emotional support. This may be difficult to achieve with some levels of disability, but there is no less obligation to try. Marsha Saxton recalls that in all her hospital experiences, the saddest part was always the same. "All those people trying so hard to help me, yet never did any one of them ask me what it was like for me. They never asked me what I wanted for myself. They never asked me if I wanted their help....I just wish all disabled children would say to their helper: 'Before you do anything else, just listen to me.'" For little girls, the problem was, in the past, compounded by the absence of female clinicians to serve as role models and advocates: "Then they would all come, the surgeons, the residents, the interns.

All men. On rare occasions a woman physical therapist accompanied them, but, like the nurses, she stood in back, out of the way, and never spoke unless she was asked for information." (Marsha Saxton, from With Wings)

The result of these years of silence is a whole generation of disabled women who were never offered the opportunity to consent to medical procedures, who were never asked to participate in the medical decision-making that so profoundly influenced their lives. To evaluate whether a disabled woman freely gives informed consent to services, it is necessary to ask two questions: "How is the information being relayed?" and "What is being left out?" Only recently has this begun to happen. The new views on civil rights for women with disabilities are finally raising the group consciousness of the disability community and allowing women for the first time to collectively demand respect from their health care providers and inclusion in health care decisions.

Most women with disabilities are fully capable of understanding the health services provided to them, if only the explanation is given in an appropriate form. Many disabled women are experts on their own bodies. They know what makes them worse and what makes them better. The medical system, not only male doctors but even female midwives, physical therapists, and nurses, is often reluctant to surrender its own aura of expertise and include women with disabilities in the health care decisions it makes about their bodies. This, of course, holds not just for disabled women, but for all patients.

There is currently some controversy as to whether women with disabilities should be mainstreamed for their health care. Historically, disabled women have been treated within the confines of the rehabilitation center for all of their health care needs. Some women with disabilities believe that this specialization is still in their best interest and that the rehabilitation centers should be required to dramatically raise their standards.

Others believe that women with disabilities should have full access to all health care facilities under the auspices of the Americans With Disabilities Act (ADA). Would the needs of women with disabilities be best met in a specialty facility focusing on disabled women's health needs, or would they be best met by pushing all providers who treat women to learn more about disability (including how to use consultations with rehabilitation doctors as needed)?

Disabled feminists believe that women with disabilities will be better served by the existing mainstream health care system and that it is well worth the effort to push this system to comply with the provisions of the ADA. They are demanding that women with disabilities be given more information, more control over what is being done to their bodies, a stronger voice in the planning and evaluation of services, and more sensitivity from health care workers to the diversity of the population they serve.

One problem is that the medical community has not yet made all the adaptations necessary to treat women with disabilities with comfort and respect. Reception desks and examining tables are still too high, many services are inaccessible, and the culture at health centers is still, in most cases, geared to treating nondisabled patients.

This is true also of Medicaid clinics, where many disabled women (who are underemployed and even less likely to be covered by pension and health plans than are disabled men) receive their health care. These clinics must be made to comply with the ADA and remove barriers to health care for women with disabilities.

Another problem for disabled women is that they are severely under represented in the ranks of clinical providers. As people with disabilities demand equal access to educational opportunity, it is to be hoped that more clinicians with disabilities will be available to serve patients with disabilities.

It is also to be hoped that more people with disabilities will enter the political arena. Only recently have women with disabilities become politicized. Until now, they have not been on the political agendas of the reproductive rights/feminist movements, or the disability rights movement, and they have not tried to mobilize politically. The time is right for them to set the political course of their reproductive rights movement. This excerpt from a story by Carol Gill called "When is a Woman Not a Woman?" highlights the need for women with disabilities to mobilize and together demand reform in their health care services: "My primary physician and several specialists I respect all practice at a major university medical center fairly close to my home. Recently, though, when I requested a gynecology referral there, I was told that I would not be seen unless I could bring my own assistants to help me get on the examining table. This is a huge world-renowned hospital. This is the era of the ADA. Still, I am treated as though I don't belong with the other women who seek services in OB/GYN unless I can make my disability issues go away. I have been placed in this ridiculous position because the health service system, like society, views me as anomalous - as some special version of human unlike all others. Medicine says the needs of disabled people are not the business of all medicine: our needs are to be addressed in special departments, usually rehab. How foolish of me, then, to seek reproductive health services in my neighborhood at a highly regarded clinic where other women I know go. Question: When is a woman not a woman? Answer: When she's disabled. But are my disability-related needs any more unique than the unique needs of African-American women, battered women, or lesbians? Are all minority women to receive health services in their own special places? Or is it that I am more disabled than I am a woman?"

There are many reasons why women with disabilities are segregated in their health care services. Among them are access problems at health care facilities, providers who are unfamiliar with and untrained in disability-related care, and primary care providers who are likely to focus on the disability instead of the presented health concern.

Women with disabilities must take collective action on a national scope to force 4,000 federally funded clinics to fulfill obligations under Section 504 and the ADA. (Increasing numbers of women with disabilities will be dependent on these clinics as decreasing numbers of physicians accept Medicaid for payment.) They must take this action as advisors, as employees, and, worst case, as litigants.

Those who are unable to join in the larger political movement must at least work to protect their own interests. At every step in their search for excellent care, women with disabilities must question - themselves, their loved ones, their providers. When considering pregnancy, it is important to ask: How will pregnancy affect my disability? How will my disability affect the course of pregnancy and the health and development of my baby? How might my disability influence the way I fulfill the emotional and physical tasks of child-rearing?

If these questions can be answered satisfactorily, then the next step is to find a provider who will be supportive and helpful throughout the process, someone who can take a positive approach to pregnancy and disability, viewing the disabled mother-to-be as a pregnant woman and

using a team approach to pregnancy and birth. The provider needs to be his patient's advocate working with her to develop a course of treatment on which they both agree, communicating with her, and planning ahead. Only with this sensitivity, education, and careful planning can women with disabilities hope to achieve the best possible outcome to pregnancy.

(3) Views on Self-Directed Services

Disabled women's lives are changing. "More and more," say Rogers and Matsumara, "women with disabilities are taking part in the efforts of all women to increase their freedoms and their responsibilities....They are claiming the right every woman should have - the right to decide whether and when she should become a mother."

In both legal and medical spheres, traditional rules about how and when people make decisions and choices about themselves, their bodies, and their immediate social environment are in a state of flux. Projects are now being funded that will move towards a national awareness for women with disabilities: self-advocacy literature, leadership training, mentoring projects, women's clinics in rehabilitation hospitals, research.

More extensive education of health care providers and consumers in the medical and psychosocial aspects of disability and in the area of human sexuality and communications will improve health services for women with disabilities. Little research has been done to date on the long-term effects of oral contraceptives and other hormonal treatments for women who lead sedentary existences and often have compromised circulatory systems. Ob/gyns have only limited experience with health issues of various types of disabilities. Education in special pregnancy-related needs of women with disabilities is limited, as are the numbers of ob/gyn clinicians who are themselves disabled and thus more likely to make a personal commitment to the needed research and education.

Among the emerging reproductive issues in the media and in the lives of women with disabilities are sterilization, abuse, and forced abortion; prenatal screening and selective abortion; adoption by parents with disabilities; and birth control for developmentally disabled women. Like the controversial topic of abortion itself, these issues are emotionally charged and highly volatile. Programs like the Project on Women and Disability in Boston are working to educate the public so that people with disabilities and their able-bodied fellow citizens can make informed choices about the reproductive rights of women with disabilities.

Under the direction of Marsha Saxton, Special Projects Coordinator, and Cindy Blank Edelman, Executive Director, the Project on Women and Disability is advocating for full reproductive and parenting rights for women with disabilities by (1) increasing access for women with disabilities to reproductive rights and health care options and resources in the Boston Area; (2) involving women with disabilities in reproductive rights organizations, and (3) educating women's groups, health care agencies, and the general community about disability as it relates to reproductive issues.

These are important efforts and not to be undervalued, but they are only the beginning. Also needed are: a study of the impact and risks of pregnancy and childbirth for women with various physical disabilities; identification of the weaknesses in training of practitioners and consumers regarding gyn and reproductive care of women with disabilities; improved communication and collaboration among various health care practitioners relevant to pregnancy and childbirth in women with disabilities; identification and evaluation of methods for improving

training for health care providers regarding the medical and psychosexual aspects of disability and reproductive issues; dissemination of information to health care providers and women with disabilities through appropriate channels; greater availability of clinicians who are themselves disabled; and new attitudes toward and awareness of women with disabilities as sexual beings who are fully capable of loving, birthing, and nurturing.

"In the past couple of years, I have become aware of my body and have decided it's not distasteful. Before I had concentrated on developing and using my mind. My body I'd just cover up so I looked ok. Now I've decided my body is fine: it's just different from other people's. Now I adore my body, dress up. I swim and take karate which centers just on me and my body." (Ann Capulo Carillo)

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The Americans With Disabilities Act was created in 1990 to protect the civil rights of people with disabilities; but only when affordable and comprehensive reproductive health services finally become accessible to the disability community will women with disabilities be able to fully exercise their most personal civil right.

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Post Script: I asked one of my colleagues, who is co-chair of our Council of Employees With Disabilities, to jot down her thoughts for me on the topic of this paper: "One of the most common themes I hear from people like me with hearing loss is that providers will often mention hearing loss as a possible "side effect" of a medication. To every one of us, hearing loss is not a side effect - it is a LIFE-THREATENING EFFECT! We can't emphasize that enough. It is life-threatening because, depending on the degree of loss we already have, this medication could mean that our whole life would change. For those of us with severe, profound hearing loss, a loss in hearing caused by a prescription medication could be the difference between living in a hearing world and living in a deaf world.

"When I pointed this out to one provider who had conceded the possible side effect of hearing loss with a prescribed medication, the provider very helpfully went through the drug book to see what could be used that wouldn't have this side effect. Providers need to take the time to make sure that the drugs they are prescribing are not in conflict with the disability of their patient. They also need to work with the pharmacy to ensure that the patient is not given any medications that can cause complications. The unwary patient might assume that the doctor and the pharmacist would never prescribe something that could cause their life to change that dramatically. Unfortunately, that is not the case.

"A personal acquaintance of mine, at the age of 35, lost her hearing completely after surgery for something unrelated. At the time, she had a job, a boyfriend, family, and friends. After she lost her hearing, she could no longer communicate the same way and needed to learn to sign and lipread (no easy task in itself). As a consequence, she lost her job, lost her boyfriend, and lost her friends. Due to the fact that her life had changed so dramatically, she went to her provider and requested mental health services to help her out with this change. Her mental health provider recommended a workshop, which she could not hear. Then the provider offered to tape the workshop so she could listen to it. Of course, that would be of no help at all. The final insult was when, after listening to my friend's difficulties, the provider proclaimed that her problems in

life were not due to her hearing loss but to her attitude. What outrage! There she was, on the brink of suicide, and that provider might just as well have given her a gun!

"In my experience, especially in ob-gyn exams, I am often at a loss as to what is going on. I always explain at the start of the visit that I have a hearing impairment and will miss what they say, unless they face me and allow me to lipread. Often what happens is that when I am being examined, they are in a position where I cannot see them while they explain what is going on. That does not make for a comfortable visit.

"On one occasion, I had a migraine headache that was too painful to bear. When I went to the health center, the first thing they assumed was that I had been raped. At that point I could not lipread because I was in too much pain. I finally realized what they were saying and made myself understood. But what if I had not been able to? In this same incident, the staff decided to turn the lights out to help my migraine, which meant that I could no longer "hear." I asked for an interpreter or someone who could stay with me throughout the visit so that I would only have to lipread one person. They found someone who knew a bit of sign language and pulled her from her job. It was not a good solution for either of us.

"One of my more successful visits was with my migraine specialist at the HCHP Kenmore Health Center. We were reviewing therapies and medications. My provider had many options, but the only one that I heard was the one to put me on medication every day. Being the suspicious person that I am, I asked my provider to document the visit and mail me a letter so that I might be fully apprised of all that we discussed and make my decision accordingly. Once I received that letter, I realized that one of his other recommendations was to take a stress management class and some other holistic options. I decided on that route and, to my amazement, it was the best thing I could have done. I would have missed these options had I relied on my lipreading abilities in that appointment! This made me realize how easy it is to misdiagnose or mistreat someone with a hearing disability, or for the person to not comply with the medical recommendations simply because the recommendations were not understood."

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