

# Reproductive Health Care Experiences of Women With Physical Disabilities: A Qualitative Study

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**ABSTRACT.** Becker H, Stuifbergen A, Tinkle M. Reproductive health care experiences of women with physical disabilities: a qualitative study. *Arch Phys Med Rehabil* 1997; 78 Suppl 5:S-26-S-33.

**Objective:** To explore the reproductive health care experiences of women with physical disabilities and how reproductive health care experiences could be improved.

**Design:** A qualitative interview study was conducted.

**Participants:** Ten women, ages 28 to 47 years, with physical disabilities, including multiple sclerosis, cerebral palsy, and paralysis, were recruited through the investigators' contacts with local disability groups.

**Results:** Interviewees encountered numerous barriers to quality reproductive health care services, including inaccessible equipment and facilities, limited contraceptive options, health care providers' insensitivity and lack of knowledge about disabilities, and limited information tailored to their needs. Providers sometimes appeared surprised that they would be sexually active, and did not ask about contraceptive use or assess for sexually transmitted diseases. Although most interviewees had private health insurance, some had problems seeing preferred providers. Accessing reproductive health care services is so difficult that some women avoid regular gynecologic visits. Suggestions for improving services included involving women with disabilities in teaching health care providers about their special needs and self-advocacy training to help disabled women become more knowledgeable partners in their own health care.

**Conclusions:** Additional research should address the gaps in knowledge about the reproductive health care needs of women with disabilities.

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**A**LTHOUGH THE 1992 CENSUS reported that 26,020,000 women have disability-related work limitations, we are only beginning to understand their health care needs and how these needs affect the quality of their lives.<sup>1</sup> Women with disabilities may lack knowledge about their bodies and sexual function. Parents of children with disabilities are often overprotective and set up the expectation that their children will never marry, reproduce, or have intimate relationships.<sup>2,3</sup> Women with physical disabilities may also have low self-esteem and diminished perception of social acceptance relative to able-bodied women.<sup>4</sup> With limited knowledge and low self-esteem, women with physical impairments may not have the self-efficacy to advocate for themselves in relation to their reproductive health.

Reproductive health issues have often been ignored in part because society tends to view persons with disabilities as asexual beings and therefore not in need of reproductive health care

services.<sup>5</sup> As more women with a variety of physical impairments live independently in the community, however, their needs for such services have increased. The purpose of this study was to explore the reproductive health care experiences of women with physical disabilities and to identify how their health care can be improved.

## BACKGROUND

Gans and colleagues<sup>6</sup> identified five commonly recognized reasons for inadequate health care services for people with disabilities: transportation problems, inaccessible offices, inadequate knowledge among health care providers, provider attitudes, and inadequate insurance coverage. With respect to reproductive health care, much of the research literature has focused on men with spinal cord injury. Tepper<sup>7</sup> found that more than half of his respondents with spinal cord injuries indicated that the sexual education and counseling they received in rehabilitation did not meet their needs, and women respondents were twice as likely as men to report having received no sexual education or counseling.

Nosek and colleagues<sup>8</sup> interviewed 31 women with disabilities to identify issues about sexuality and reproductive health care. They found that patterns of interaction with the medical system are set in childhood, often based on frequent negative encounters, and that these experiences can have lifelong traumatic impacts. Women reported emotional, physical, and sexual abuses. Some reported that they lacked basic knowledge about their reproductive health, in part because they had restricted access to such information as adolescents. Women who experienced traumatic injuries later in life said they received inadequate information about the sexual impact of their disability when they were in rehabilitation facilities. Many women also had difficulties obtaining reliable contraceptive information. Women also reported encountering barriers to obtaining health insurance and to accessing offices and equipment. They reported that the most difficult barriers were the negative attitudes of health care providers. These barriers are particularly problematic, because the women reported a higher-than-average incidence of health problems, such as respiratory infections and urinary tract infections, which can have an untoward impact on their lives. Based on these interviews, the investigators developed an analytic model positing that environmental factors, such as access to health care and attitudes of medical professionals, and internal factors, such as a woman's attitudes toward the health care system and previous medical experiences, contribute jointly to reproductive health maintenance. These factors are, in turn, influenced by the woman's disability and are moderated by her demographic characteristics, such as socioeconomic status.

Women with physical impairments (such as paralysis, cerebral palsy, or multiple sclerosis [MS]) have limited contraceptive options and they may experience complications if they become pregnant.<sup>9</sup> The oral contraceptive may not be a choice for women with decreased mobility, diminished muscle tone in a lower extremity, or pre-existing circulatory problems, because of an increased risk of a thrombosis.<sup>10,11</sup> Barrier methods such

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as the diaphragm and cervical cap are problematic for women with limited use of their hands. Although an intrauterine device (IUD) may be an option for some women, decreased pelvic sensation may reduce the woman's ability to perceive discomfort or pain, which signal infection or displacement of the device.<sup>10</sup> Women with limited manual dexterity may be unable to check for the presence of the string that assures that the IUD is in place. Progestin-only methods such as Depo-Provera and Norplant have been associated with periods of irregular bleeding and other side effects that may not be acceptable for women with impaired mobility. The symptothermal method of natural family planning, with Basal Body Temperature (BBT) charting, has also been shown to be of limited use, particularly among women with spinal cord injuries. Reame<sup>12</sup> found that among 20 women with spinal cord injuries followed prospectively, the ability of the BBT to predict serum progesterone (a measure of ovulation) was low (43%). Women had day-to-day fluctuations in their temperatures, highlighting the compromised ability individuals with cord injuries have in maintaining a well controlled body temperature. They also had temperature elevations associated with irregular sleep episodes, bladder infections, and flu-like symptoms that might have masked the expected thermal shift in the luteal phase.

Welner<sup>11</sup> argued that women with disabilities face some special issues in detecting and treating sexually transmitted diseases (STDs). Because these women may have sensory deficits, providers must be trained to recognize other possible signs of STDs, such as sensations of pressure, spasms, urinary tract infections, vaginal discharges, or decubitus ulcers. Both symptoms and findings may operate differently for women with disabilities. For example, differentiation of lesions may be difficult in these women. Providers prescribing medications need to consider how the woman can take medication; they should prescribe liquid forms for women who cannot swallow large pills and they should choose medications that come in easy-to-open packages.

In the past, women with severe physical disabilities were discouraged from having children. Consequently, there have been few studies of pregnancy among these women. One exception to this is an interview study conducted by Smelzter<sup>13</sup> among 15 pregnant women with MS. She found that the decision to become pregnant was difficult for many of the 15 because of the lack of information about pregnancy within the context of their disability, as well as the uncertainty associated with the disease itself. Some women had experienced negative reactions to their pregnancies from family members, close friends, and health care providers. Age, length of time since diagnosis, and previous course of the MS all influenced women's child-bearing decisions. For many women, childbearing had become more important to them after they were diagnosed with MS. One woman explained that the diagnosis of MS made her feel abnormal, but the prospect of motherhood made her feel normal again.

Jackson<sup>14</sup> studied pregnancy among 472 women with spinal cord injury. She found a significant decrease in the number of pregnancies following injury, but the reasons for the decrease were unclear. After their injury, women had a significantly higher incidence of complications during delivery, particularly blood pressure instability, and were more likely to deliver low-birthweight infants.

Information about how women with disabilities experience menopause is limited.<sup>11</sup> Because many women with physical disabilities enter menopause with decreased weight-bearing and aerobic activity histories, they may be at greater risk for cardiovascular problems and osteoporosis. Other symptoms of menopause, such as vasomotor instability, may be particularly problematic for women with spinal cord injury with high lesions

above T6 and to women with MS because of their sensitivity to temperature fluctuation. Although hormone replacement therapy may be particularly beneficial for them, concerns about increased risk for complications in women with disabilities have discouraged some clinicians from prescribing hormone replacement therapy.

Available literature on reproductive health care for women with disabilities suggests that women have difficulty acquiring satisfactory reproductive health services. There are gaps in needed information, particularly in the areas of pregnancy, menopause, contraception, and sexually transmitted diseases. Krotoski and colleagues<sup>1</sup> pointed out that a qualitative study can provide important insight into women's reproductive health care experiences. Such an approach can elucidate the issues that should be pursued in larger quantitative investigations and, most importantly, enables women to say in their own words what is most important to them about their reproductive health care needs.

## METHOD

We developed a semistructured interview to elicit perceptions about reproductive health care experiences, including access to health care information and services, access to birth control, experiences with pregnancy or sexually transmitted diseases, barriers to quality services, and suggestions for improving reproductive health care services. The interview protocol was based on existing literature on the health care experiences of women with disabilities and the investigators' previous research. We also collected information concerning age, educational level, ethnicity, marital status, type and length of disability. To determine the appropriateness of the interview protocol, we interviewed three women with physical impairments who provide services to other women with disabilities. After they completed the interview they were asked if the questions were appropriate for this topic area. None of the three suggested substantive changes to the interview protocol. Where appropriate, their comments are included in this report.

Following approval by our Institutional Review Board, we recruited the 10 women interviewed for this study through contacts in the disability community. Our inclusion criteria included women with physical disabilities who were between the ages of 18 and 50 years and could communicate in English. We attempted to recruit a heterogeneous sample with respect to length and type of physical disability. Two of the interviewees responded to notices posted by local disability services, while the remainder were identified through personal contacts in the disability community. We conducted face-to-face interviews at locations convenient for the women. The three investigators, all of whom are women without apparent disabling conditions, conducted all interviews.

Interviews were tape-recorded, transcribed verbatim and entered into the NUD\*IST computer program<sup>15</sup> for analysis. Transcriptions were compared to audiotape recordings to verify accuracy. After reviewing the interview transcriptions, analysis of interview data began with coding into broad categories dictated by the interview questions. Graduate research assistants were trained to code the transcripts and enter them into the computer program. The categories were refined through repetitive scanning of data. During this process subcategories or new categories were identified and analysis continued until no new categories emerged. The graduate assistants independently coded the interviews. The first and second authors reviewed their coding and resolved any disagreements. The NUD\*IST computer program then sorted the interviews by categories, which facilitated analysis and identification of illustrative cases for each major

theme. One of the women who participated in the interviews critiqued the preliminary report, as a check on the validity of the investigators' conclusions.

**Sample description.** The 10 women interviewed had a variety of physical impairments. Two had MS; two had cerebral palsy; one had cerebral palsy, arthritis, and fibromyalgia; two had paralysis resulting from spinal cord injury; one had arthritis; one had a degenerative disk disorder; and one had muscular dystrophy. They ranged in age from 28 years to 47 years (median, 39 years). Four women had congenital impairments, one had become disabled at 16, and the other five had become disabled as adults. All had some college education (two had graduate degrees), and all were Caucasian. Six were single, three were separated or divorced, and one was married. All 10 worked or attended school.

## RESULTS

Eight major themes were identified from the analysis of the interview data: barriers, facilitators, issues regarding birth control, pregnancy, and STDs, menopause and aging, sexuality, and suggestions for improvement. This section is organized according to these themes.

### Barriers

The women identified several barriers to good reproductive health care services confronting them and other women with disabilities. Some of these barriers are structural, for example, physically inaccessible tables, stirrups, and examining instruments not designed for women with impairments. Offices and parking lots are not always fully accessible for wheelchair users, and some participants reported transportation problems in traveling to providers.

The most commonly discussed problems concerned interactions with health care providers. Women described providers as insensitive or lacking awareness of disability issues as they impact reproductive health care. One woman, who was paralyzed in an accident, expressed surprise that providers were not more knowledgeable about how to treat women with disabilities. When she almost fell off the examining table because no one was holding her legs, she realized she had to help them understand what she needed.

Another woman with a spinal cord injury told this story about a provider's analysis of her bone scan: "You have to fill out this whole questionnaire . . . and they ask you if you've ever had spinal fractures. I wrote that I had had a spinal fracture but it was due to a car accident, not osteoporosis. When my bone density [report] came back . . . it said, 'your spine is fine and your femurs are low,' and then gave the recommendation that I can start walking three times a week. Then it said the spine fracture could be a sign that I had osteoporosis and the rib fracture could be, and at that point I'm like, I took all the time to write the explanation." This woman's story illustrates not only insensitivity to her condition, but the fact that the information women give about their health is often ignored by providers.

Women, especially those with spasticity, also sense that some providers are uncomfortable or nervous about treating them. A woman with cerebral palsy described the situation: "Somebody standing over me, and they are nervous . . . which causes a downhill cycle. It gets worse and worse because the more nervous they are, the more nervous I am, which increases my spasticity."

Other women believed they were not listened to, were patronized, or were not given adequate explanations of their condition

or of upcoming procedures. One woman stated, "Sometimes they are not honest about things they tell us. . . . They just basically treat us like children instead of the adults that we are." The following story exemplifies the problems women with mobility impairments have when they are not adequately prepared for the examination: "Once they put me up on this high table. With my back, I don't have control. And they say, 'Now take your shirt off.' Had I been told to take my shirt off when I'm sitting in my chair, I could do it by myself, but I nearly fell off and two people had to help me. . . . Therefore, things were harder and more complicated than they really needed to be."

The lack of good communication leads women to avoid asking questions. According to one woman, "It's pretty difficult to continue to ask questions when you get looked at like you're coming from Mars." She continued, "They always assume that it's a disability problem instead of a real health problem and that's not just with reproductive stuff. That's with everything." Another respondent stated that physicians sometimes talk down to the woman or talk to the person accompanying the woman, as if the patient herself is not in the room. To feel comfortable when asking questions is particularly important for these women, however, because they may experience symptoms that are difficult for them to interpret. For example, one woman who had fibroid tumors related that her physician asked if it hurt when he examined her. Her response was, "Well, how would I know?" Another respondent discussed the special problems people with speech and hearing impairments have in communicating with health care providers. Even when a translator is present, the translator may not accurately and completely communicate the necessary information.

Other women said they were treated as asexual beings. One woman stated that the health care provider seemed shocked that she wanted to use birth control or protect herself in any way. By contrast, one woman commented positively on a provider who asked about her partner: "He assumed I had one."

When asked if women with disabilities have access to the information they need, some interviewees mentioned that providers do not discuss prevention issues with them, although one woman stated that her provider routinely reminds her about breast self-examination. Two interviewees pointed out that some women with disabilities have trouble reading health care information. One of the experts initially interviewed for this project suggested that women who have a history of multiple surgeries or other medical procedures tend to disassociate from their bodies, thus making it difficult for them to self-monitor. Another woman feared having a mammogram, because it had never been explained to her and she did not know what to expect. Yet another woman stated that information is not necessarily individualized or takes into account the functional limitations experienced by people with disabilities.

Finally, some women discussed the problem of access to preferred providers. Because most of these women were working and had health insurance, they did not have difficulty accessing private providers. In some cases, however, they found the primary care practitioners available to them through a managed care plan lacked knowledge about the impact of their disability on the health care questions they were asking. Coordination of care for women with multiple providers was also a problem. Some would prefer to be treated by a psychiatrist, or another health care professional they believe to be knowledgeable about their condition. However, they found it difficult to get a referral to a particular provider, even when they were able to find individuals with whom they were comfortable. One woman personally paid out of her own funds to see a provider

in another city, because she had heard he was sensitive to the needs of women with disabilities.

The results of these barriers are often uncomfortable, embarrassing, or painful examinations. As one woman said, "This is a very sensitive area for a woman. You feel a lot of shaming very quickly." Consequently, women tend to avoid routine examinations, and seek gynecologic services only when they are experiencing a problem or are in need of medically prescribed contraceptives.

### Facilitators

Women also discussed what facilitates satisfactory reproductive health services. As might be expected, these factors were often contrasted with the barriers the women had encountered. A common theme was a positive attitude on the part of the health care provider and his/her office staff. One woman mentioned the favorable impact of having someone in her physician's office actually offering to help her with her wheelchair. When asked if she had difficulty getting onto the examining table, this woman answered, "No. I was slow and they were patient."

More specifically, providers who ask questions, are willing to learn, and respect women as partners in decision-making about their health are viewed positively. One woman with paralysis reported that her gynecologist consulted with two physiatrists to make sure there were no contraindications before prescribing oral contraceptives: "I was real impressed with her willingness to contact the doctors who know about rehab." Finally, women spoke of the importance of providers who consider the whole person, not just the disability, in their treatment. One woman with MS said of her provider, "He treats me as a whole person who has this disease. He doesn't treat one specific area. I mean, he really sees the big picture and I'm real comfortable that if there were a problem he would refer me for special care. . . ."

Physically accessible offices and equipment also contribute to quality reproductive health care services. For example, one woman described a chair that converts into an examination table, making it easy for a woman with mobility impairments to transfer to the "chair" from a wheelchair. Another woman, who works at Planned Parenthood, asks people who call for appointments if they have a disability so that appropriate accommodations are in place when the client arrives.

Some women identified patient characteristics that enhance good quality health care, such as their own knowledge or assertiveness skills. One woman stated, "I hear the horror stories and it's like, you don't have to put up with that. You can do it. You get on the phone and you tell them, 'I will not tolerate this'."

### Access to Birth Control

The women were asked if they had found birth control methods accessible and effective. One woman had a hysterectomy. Another woman who already had children before being diagnosed with MS was advised by her physician to have a tubal ligation once she began taking other medication to control the MS. This illustrates the concern about potential drug interactions between hormonal contraceptives and other medications women are taking.

Because some of the women were not sexually active at the time of the interviews, birth control was not a concern for them. However, many mentioned problems finding good birth control options at various times in their lives. Six discussed using oral contraceptives or Depo-Provera at some time, but three of the

six reported problems. Two women had family risk of cancer and another had experienced negative side effects (ie, weight gain and water retention). Women with limited manual dexterity spoke of problems using mechanical devices, such as diaphragms, as illustrated in the following comment: "I remember trying to use . . . a diaphragm and it was ludicrous trying to manipulate that thing with hands that were not working."

An interviewee who works with Planned Parenthood detailed a number of issues concerning contraception for women with disabilities. "Pills are great, but not everyone can take them. Some women have physical disabilities and can't physically take the pills. They can direct an attendant. One of the questions was, 'If you have someone who can't use their hands, how do you instruct them on how to use a condom?' . . . One of the answers was, well, they get their partner to do that. . . . If their partner also can't do it . . . you bring, say, the attendant, which is a whole huge issue." She also pointed out women who have mobility impairments have special problems if they experience heavy bleeding when using a chemical contraceptive. Using pads all day long may increase the functional limitations they experience.

Because so many women have difficulty finding birth control that works for them, many women simply do not use contraceptives. Unfortunately, this exposes them to unwanted pregnancies and STDs.

### Pregnancy Experiences

Two of the women with MS had children before being diagnosed. Only one of the other women was a mother, and only two others indicated they had considered having children. One woman with cerebral palsy and visual impairment mentioned that other people express concerns about a woman with disabilities having children and believe that they should have their tubes tied. She related that health care professionals discouraged her from becoming pregnant because they were concerned about her size and ability to take care of a baby. When asked how she felt about that advice, she stated, "In a way, I feel cheated. I would have liked to at least have had the chance." Another stated she would like to have children, but would not discuss a possible pregnancy with her physician because she feared she would not get support.

One woman with multiple sclerosis mentioned that young women in her support group have been concerned about genetic issues, as well as the impact on their own health, when considering whether to have a child. In addition, they wonder if some of their medications can cause abortions.

One respondent who has worked in family planning services identified several issues that would need to be considered. For example, how will pregnancy affect the woman's disability? What are the implications for attendant care services? Other interviewees also emphasized the importance of considering available supports if a woman with disabilities is thinking about pregnancy.

A mother with arthritis described the conflicts she experienced between her need for medication to control her symptoms while she was pregnant and her concerns about the effects of this medication on her fetus. Her physician, she said, respected her decision to forego medication to ensure a healthy baby: ". . . When I had my third pregnancy it was debilitating. It got quite out of control, and the doctor sat down with me on several occasions and said, 'You need to consider what's going on here . . . If I can promise you that I could give you medication that would relieve the symptoms and wouldn't hurt the baby, would you take it?' . . . I said no, I can't believe the promise . . . and he respected that, and . . . I appreciated that."

## STDs

Most interviewees indicated that they did not have information about how much of a problem STDs were for women with disabilities. As one woman said, "That's another topic area that wouldn't be easily talked about. I think you would have to build a rapport before you could even address some issues." None of these women reported that they had been diagnosed with an STD, although one did discuss problems with vaginal infections.

While some women thought STDs were not a problem, one asserted that they could be a big problem, "because I've seen a lot of women who have very low self-esteem . . . go with anybody that will have them." It was also suggested that some women with disabilities may go through a promiscuous phase to prove they are sexually attractive. During this time, they may be at particular risk for STDs.

One woman pointed out that the barrier methods that are most effective at preventing STDs are difficult for women who lack muscle integrity in the pelvic area to use. Women with disabilities appear to be at special risk for STDs, because some women are unable to use the contraceptive methods that would afford them the most protection, while others who lack sensation are unable to detect the signs of STDs. Even more problematic is the fact that providers often do not discuss birth control and sexual issues with them.

## Aging and Menopausal Issues

Our initial questions did not specifically ask about menopausal issues, but some of the older women in our sample did raise concerns in this area. Consequently, as we proceeded through the interview process, we began asking women if they had questions about menopause. One woman with MS wondered if the steroids she had taken would increase her risk for osteoporosis. She related that her physician did not tell her to take calcium supplements; she now plans to ask her physician about doing a bone scan to look for possible bone loss. Another woman with MS pointed out that it is difficult to determine if certain symptoms are indicators of menopause, or simply occurring because of the disability. A tetraplegic woman who is an occupational therapist mentioned that kidney problems and bladder problems begin at an earlier age for people with paralysis. She also asked questions about taking hormone replacement therapy in the context of her spinal cord injury.

## Sexuality

Several of the women, including two of the experts initially interviewed, raised issues concerning sexuality and sexual health. One of the experts, who has spina bifida, stated that mothers do not talk to their disabled daughters about sex. The daughters lack important information and receive a message that women with disabilities are not desirable sexually.

The interviewees noted the reluctance providers also have in discussing sexual issues with women who are disabled. Some women interpreted this reluctance as an indicator that the providers consider women with disabilities as asexual beings. Providers, one woman said, "need to be educated and know that disabled women have sex just like nondisabled women do." The woman who works with Planned Parenthood suggested that we ask other women how they define positive sexual relationships and how they would explain that to a provider.

One married woman with MS discussed how her disability had negatively affected her sexual relationship with her husband: "My husband and I have major battles. You are tainted goods. You're used goods. There's no way our sex life is like it was before. I mean, the feeling, literally, feeling, it's not

there. I know if I were single it wouldn't be worth the effort." Another woman with cerebral palsy indicated that she has essentially given up having sex because of positioning problems.

Several women discussed the negative consequences of the low self-esteem women with disabilities tend to experience about their sexuality. It was suggested that women may become sexually promiscuous because they are so appreciative of anyone who wants them sexually, but this promiscuity can have obvious negative health consequences. In addition, women with disabilities may put up with more abuse from partners because they feel they are lucky to have anyone who wants them.

## Suggestions for Improvement

We identified two major themes from the women's comments about how reproductive health care services can be improved: suggestions for providers and suggestions for women themselves.

Women indicated that providers should be better prepared to work with women who have disabilities. Some suggested disability awareness training, with disabled women involved in the training, so that providers could become sensitive to these issues from the perspective of disabled women themselves. Better communication skills on the part of providers was identified as a major area for improvement. As one woman stated, ". . . even if they don't know, if they could ask . . . 'What can I do to make this easier for you?'"

One woman, who works with other women with disabilities, stated that providers must "purposely plan for the discussion to occur. And in a sensitive way that allows a woman to overcome what are very natural reserves about talking about that very private part of your life." She and others suggested that providers need to be prepared to spend more time with these patients, establishing rapport, providing information and individualizing care to their special needs, and giving the women—particularly those who experience spasticity—more time to relax before initiating the physical examination.

Providers must also recognize that many women with disabilities bring to the examination a history of negative health care experiences. One woman stated, "I had a lot of operations growing up. . . . I was always being poked and prodded so that really brought a whole lot of baggage into any kind of exam, like a pelvic, because it's so like being prodded." Since positioning during a pelvic examination is difficult for many women with physical disabilities, providers should be prepared to help women find positions that are most comfortable for them.

Improved accessibility, both in terms of affordable health care and physically accessible locations and equipment, was also mentioned by multiple interviewees. One woman suggested that a brochure be disseminated to health care providers outlining their responsibilities to provide accessible facilities under the American with Disabilities Act.

While most women had access to private providers, some did point out that other women with disabilities who are on Medicaid or Medicare have difficulties finding providers. A physical therapist who is tetraplegic proposed that specialty clinics be established to provide women's health care services for women with disabilities.

Interviewees also proposed interventions directed at women themselves, such as educating them about what questions to ask. One woman suggested information networks be established for women with disabilities about health issues. Women need criteria they can use in selecting a health care provider. Assertiveness training was also suggested. Two women who had been through rehab proposed that the rehab model be adapted to teach women with disabilities how to ask questions about their

reproductive health care and how to access services. Others stated that women with disabilities need to be better educated about sexuality issues, perhaps through support groups. One woman proposed that programs that individualize sexuality issues for teenage women be explored. A related suggestion was for interventions to build women's self-esteem. One woman pointed out that many women with disabilities are not comfortable with their bodies, and interventions need to be focused at enhancing their self-image in this area.

Finally, a couple of women mentioned that educational efforts should be directed at two other key groups: partners and personal attendants. One woman proposed a forum on attendant care services, related to health care issues.

## DISCUSSION

The women interviewed in this study were not representative of all women with disabilities. These women tended to be highly educated. All were either students or employed, many in professional level positions. One is a health care professional, while six others worked in disability services. Not surprisingly, financial access to health care services was not a major problem; most had private physicians. Nonetheless, these women identified a range of barriers to receiving what they considered satisfactory reproductive health care services. We can only conclude that women with more modest financial support, less education, and perhaps more limited informational resources experience even greater problems as they attempt to access reproductive health care services.

The barriers identified here can be divided into two major categories: structural barriers related to access or physical accommodation and those concerning relationships with health care providers. Inaccessible offices or equipment that did not accommodate these women's disabilities were a problem. There is obviously a need for continuing research and development of accessible examination equipment that can be made easily available to health care providers. Research should also be directed at understanding why providers do not use the modified equipment that is currently available. Do providers not use more accessible equipment because they are unaware of it, or because it is more costly? Efforts must also be directed at making providers (and their managed care organizations) understand what accommodations are required under the Americans with Disabilities Act. This includes not only building ramps, but also accessible bathrooms and examining rooms.

The second major category of barriers concerns relationships with health care providers. Providers were described as uncomfortable treating women with disabilities, insensitive to their needs, and reticent to discuss key reproductive health issues such as birth control or sexually transmitted diseases. While our respondents did not mention sexual abuse, as had some of the women interviewed by Nosek and colleagues,<sup>8</sup> we found, just as they did, that physicians' attitudes were identified as the most difficult barrier faced by the women we interviewed. The consequence of these barriers is that many women with disabilities avoid routine gynecological examinations. Since many women lack sensation in their pelvic areas, and may therefore be unable to detect signs of problems that should be treated, their avoidance of routine physical examinations is particularly troubling.

There may be several reasons why providers fail to work with these women around common women's health issues. Health care providers are well steeped in clinical training that focuses on treatment and cure of illness. When these providers treat women who have chronic and disabling conditions, they may focus on the disability and fail to see that these women

face the same, if not greater, health risks as women in the general population. Health care problems stemming from untreated infections, for example, may cause even greater problems for women with disabilities and chronic conditions than for nondisabled women.

Women interviewed in this study suggested that health care providers need to spend longer with women who are disabled during examinations. As Welner<sup>16</sup> has pointed out, however, current reimbursement mechanisms do not allow different reimbursement rates for women with disabilities. In addition, criteria used to determine what procedures will be reimbursable do not consider the special needs of women with disabilities, such as a bone scan for a relatively young woman who has been taking steroids to control arthritis or MS. Thus, providers may be unable to provide optimal levels of service, even when they recognize the need. Additional research should investigate alternative reimbursement formulas, or other creative solutions to these dilemmas.

Some of the frustrations voiced by these women point to the lack of good-quality, appropriate information for this population. Their questions reflect areas where additional research is needed. As Welner<sup>16</sup> pointed out, there is limited information about the health care needs of women during menopause or the detection and treatment of STDs for this population. The women we interviewed proposed that general information may be of limited value, unless it reflects the specific concerns of this population. One of the experts interviewed stated that many women feel like pioneers, because they are the first generation to survive into adulthood with such severe disabilities and live independently in the community. Consequently, they are frequently confronting health care providers with new issues about their health care needs.

These interviews suggest that a limited range of contraceptive options are discussed with women with disabilities. Oral contraceptives seem to be the most frequently discussed, but many women who used oral contraceptives experienced side effects or health-related concerns that made this method less desirable for them. Women whose manual dexterity is limited are unable to use various barrier methods. The problems experienced by these interviewees echo what has been previously reported in the literature<sup>8-11</sup> and further validate the need for additional research to develop acceptable and efficacious alternative contraceptive methods.

Only 3 of the 10 women interviewed had given birth, and two of them had their children before becoming disabled. Consequently, this study contributed little to our understanding of how women with disabilities experience childbirth and pregnancy. However, two issues raised by our participants have been previously reported: the discouragement women face when they want to have children and the ways pregnancy can interact with the medications women are taking to control their disability.<sup>13</sup> Clearly, additional research should be directed at how women with disabilities experience pregnancy, so that better counseling can be given to women during this critical period of their lives.

Although our study sample was small, it included women with a variety of disabling conditions and resulting functional limitations. Four of the ten were disabled from birth and approximately two-thirds had mobility impairments. However, women with other disabling conditions such as communication or cognitive impairments may face barriers to quality services not identified by these women. The study's generalizability is also limited by the fact that the sample was small and included only well-educated, Caucasian women in one geographic area. Future research should include more heterogeneous samples. As

Haight-Liotta<sup>5</sup> pointed out, too little is known about the impact of cultural differences on women's reproductive health care needs.

Although many of the themes that emerged in this study have been identified in previous research, at least one of the problems identified in earlier studies was not a major theme for the women interviewed here. Transportation to a provider's office was not a major problem. This may be because many of the women interviewed drive and therefore were not dependent on public transportation. A more heterogeneous sample might be more likely to cite transportation as a problem area.

### Implications for Training

Interventions should be directed at enhancing providers' understanding of how to work effectively with women who have physical disabilities. Just as Nosek and colleagues<sup>8</sup> reported, we found that direct communication was highly valued by the women we interviewed. Saxton<sup>17</sup> has pointed out that although women with physical disabilities and chronic illnesses are major users of medical services, few health care providers are trained to be sensitive to their specific needs. Recognizing that the quality of health care is related to the quality of patient-provider relationships, Saxton and colleagues created the Project on Women and Disability to address the health care system's treatment of women with disabilities. They found that few medical schools provide comprehensive training in disability awareness that includes social and political aspects of disability. Physicians and other health care providers tend to interact only with disabled people who are having medical difficulties. This exposure reinforces their perception of people with disabilities as patients who are passive recipients of health care services.

The fact that people with disabilities and chronic conditions cannot be "cured" is often perceived as a failure by health care professionals. Many are genuinely puzzled by the anger directed toward them by people with disabilities, who have frequently experienced well-meaning but misdirected attempts to meet their health care needs. Saxton's group has partnered with medical schools to provide disability awareness training for medical students and open communication between health care providers from various disciplines and people with disabilities. They argue that increasing the number of women with disabilities who are themselves health care providers will lead to change both within and without the traditional health care system. One of the women we interviewed has conducted training with the staff of Planned Parenthood to raise awareness of disability issues. Nosek (personal communication) has also undertaken a project that trains health care providers to work more effectively with women with disabilities. Additional interventions of this kind are warranted, both while providers are in training and on a continuing education basis for those now practicing, and should include a rigorous evaluation of their impacts.

Efforts should also be directed at preparing women with disabilities to be informed consumers about their health care needs. The women interviewed here offered several suggestions in this area. Health advocacy training and networks that link women together are ideas that merit further exploration. Informational support groups that target teenage women with disabilities could build self-efficacy for health-promoting behaviors at an early age and could also address vitally important sexual self-esteem issues. National advocacy groups could make available reproductive health care information targeted to the special needs and concerns of their female consumers. Alternative formats for information that bypass barriers should be utilized, including Braille and other nonprint media, as well as on-line health information.

Many routine prescriptions for health screening and self-care can and should be adapted for women with disabilities. For example, a woman who lacks sensation in the genital area may need to visually inspect her genitalia for signs of redness, discharge, or growth. An attendant or partner might be taught to assist in this, or other routine examinations, such as breast self-examination. Oral contraceptives might need to be repackaged so that women can self-administer these pills more easily. Additional time should be spent educating women with mobility impairments about the side effects of various contraceptive options. It is vitally important to individualize these adaptations, because as Haight-Liotta<sup>5</sup> has pointed out, not all women with disabilities are affected in the same ways or need the same accommodations.

### Implications for Rehabilitation

This study suggests a number of implications for enhancing rehabilitation health care services. At the very least, the issues raised by our interviewees point to the need for sexuality information and routine preventive health care as a part of all rehabilitation programs.

Some of our respondents clearly indicated that they felt more comfortable receiving services from rehabilitation specialists, whom they believe are more knowledgeable about their health care needs than are other health care providers. One respondent, a physical therapist, proposed that specialty clinics be established to provide women's health care services for women with disabilities. She also suggested that health care providers who undergo additional training on disability issues might then be able to market themselves more effectively in the disability community. Gans and colleagues<sup>6</sup> developed a collaborative practice model in which a multidisciplinary health care team provides patient-centered primary care under the auspices of a rehabilitation hospital. This model uses a team approach to case management to create a fully accessible care delivery system. While not all women with disabilities may choose to use such specialized services, this model merits further exploration. An alternative to such specialized clinics might be to link rehabilitation specialists as consultants to group practices, community clinics, or HMOs, so that their expertise would be available to primary care providers in community settings.

### CONCLUSIONS

While a small exploratory study is hardly definitive, our results reinforce and expand on previously reported difficulties faced by women with disabilities when they attempt to access reproductive health care services. Hopefully, future research will include women with disabilities as an integral part of the research team in addressing these issues. In short, health care providers, researchers, and women with disabilities must work together to create solutions for improving reproductive health care services.

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