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Reproductive Rights and Access to Reproductive Services for Women with Disabilities

Anita Silvers, PhD, Leslie Francis, JD, PhD, and Brittany Badesch

Are women with disabilities owed equitable access to reproductive health services, including family planning, contraception, screening for sexually transmitted infections, maternal health services, and fertility services? Or are there circumstances in which disability is a reason to deny access to such services? Conversely, should women with certain disabilities have access to procedures such as caesarean section or sterilization? May these procedures be recommended just because a woman has a disability or imposed on her if she appears reluctant or unable to consent?

Treating People with Disabilities: Equitable Access is Key

Legal and professional answers to the questions posed above have been strongly in favor of equitable access to treatment and autonomous decision making for patients with disabilities. Physicians' offices, clinics, hospitals, and other medical facilities are required by the Americans with Disabilities Act (ADA) of 1990 to provide meaningful access to the services they provide for people with disabilities who meet essential eligibility requirements, with or without accommodations. These providers may also be covered by state antidiscrimination laws.

Meaningful access is a legal standard that calls for a fact-specific inquiry into whether individuals with disabilities are afforded equitable opportunity to benefit from the provider's services [1, 2]. The focus is on whether the individual's disability has occasioned loss of equitable opportunity to receive the same quality of medical services, rather than the same resulting benefit, as that afforded to other people. A site that dispenses medical treatment would not meet this access standard if, for example, a speech-output version of the usual printed directions for taking medications was not provided to visually impaired patients, or if deaf patients could not participate with their physician in conversations about treatment choices for lack of an ASL interpreter. To use another illustration, inaccessible examination equipment continues to be a problem despite the ADA [3]. A common example is the absence of examination tables that lower to facilitate transferring from a wheelchair to the table, preventing wheelchair users from being properly examined. This subjects them to limited, substandard, noncomprehensive care [4]. As a general matter, data indicate that adults with disabilities, especially women, receive less access to needed health care even when controlling for variables such as socioeconomic status [5].

Additionally, professional organizations such as the American Society for Reproductive Medicine (ASRM) and the American Congress of Obstetricians and Gynecologists (ACOG) urge that access to medical care be available without discrimination [6-8]. As for sterilization, ACOG urges that disability is not a reason in itself for or against it and that any such decision must be made on a basis that preserves, as much as possible, the patient's autonomy [7]. This guidance is not always followed. In this paper, we explore how reproductive medicine for women with disabilities may be unfairly obstructed by this kind of laxity in guarding against discrimination and by mistaken assumptions about disabled people. We also recommend how such discrimination may be avoided.

Mistaken Assumptions about People with Disabilities

Several general assumptions commonly are made—mistakenly—about people with disabilities.

Assumptions about decision-making ability. One common mistake is to assume that a patient's having a disability necessarily affects the person's competence. Clinicians may dismiss the possibility of achieving informed consent when patients have intellectual or developmental disabilities, wrongly [equating](#) certain diagnoses with an inability to understand or communicate at the requisite level. Clinicians may be inexperienced in helping patients with disabilities understand complicated medical questions or unwilling to take the time to explain when patients have difficulties in communication. For example, they may neither realize that anyone's decision-making ability is affected by both individual capacity and social context, nor be aware that, for patients with intellectual disabilities, assessment of abilities may be improved by acknowledging positive support from family or community relationships and social services [9-12].

As a result, people with disabilities may be inappropriately subjected to paternalistic judgment, including judgments about their very ability to consent to sex or reproduction [13]. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) Article 12 requires equal legal recognition of persons with disabilities. The CRPD guidance also recommends appropriate supports for persons with disabilities in exercising their legal capacities. In line with CRPD recommendations, many jurisdictions have been exploring methods for supported decision-making—that is, methods of deciding in which persons with intellectual or psychiatric disabilities work with others to determine and pursue their goals [14, 15]. ACOG goes further, stating that it is "essential" to obtain the assistance of professionals trained in communicating with people with intellectual disabilities when ascertaining capacity to provide informed consent for any surgical procedure [7].

Assumptions about sexual and reproductive interests. Disabled people too often are stereotyped as needing special protection, including measures that curtail their ambitions for intimate relationships and family life. It is inaccurate to [assume](#) that being

disabled means having no sexual or reproductive interests or being sexually inactive, celibate, or asexual. For example, the sexual interests of people with physical disabilities such as spina bifida or cerebral palsy may be underestimated based on false assumptions about their sexual capabilities [16, 17]. People with sensory disabilities such as blindness may be burdened by others' false assumptions about their parenting abilities [18, 19]. And people with intellectual disabilities may be looked at merely as potential victims of sexual predation or exploitation, rather than as people with sexual interests or capabilities who need not only protection but also sex education and recognition of their agency [20].

Assumptions like these may be the reason that people with disabilities unjustly receive less access to medically indicated reproductive care than other people of similar age and sex. Too frequently, ordinary preventative services such as noninvasive birth control, pap smears for women who are sexually active, or mammography are not offered or are denied to women with various kinds of disabilities because they are wrongly supposed not to need them [21-23]. Mistaken assumptions about patients' abilities to use these services also reduce access to care [24]. So may concerns that these patients may require lengthier visits—for example, to navigate narrow examination rooms crowded with furniture or access equipment designed with the assumption that all patients can stand—or lack of familiarity with how the disability may affect a physical, cognitive, or communicative component of the appointment [24].

Misjudging Women with Disabilities in the Context of Reproductive Health Care

We now turn to assumptions that lead to misjudgments in reproductive care for women with disabilities.

Assumptions about risks of pregnancy. First are exaggerated or misdirected concerns about the riskiness of pregnancy when a person with a disability is involved. It is not unusual for women whose disabilities do not affect their gynecological functions to have their pregnancies labeled high-risk and to be referred for unnecessary consultations or tests by an overanxious clinician [25, 26]. Caesarean sections and induction of labor may occur more frequently in women with disabilities, even in the absence of standard medical indications [25, 26]. An illustrative example is that of a pregnant triple amputee referred to genetic counseling although her impairment was not inherited. A perinatologist to whom she also was referred denied that her pregnancy was high-risk and warned her against being talked into a caesarean section just because her absence of limbs made other physicians nervous [27]. Clinicians should take care that assumptions about risks are not prompted or exaggerated by unwarranted generalizations or stereotypes. If risk is considered per patient, and it is determined that a pregnancy would be of significant physical risk to a particular woman because of her disability, she may also achieve lower-risk parenthood by being offered access to surrogacy [12].

Assumptions about probability of treatment success. Clinicians should avoid conflating judgments that an intervention would be futile—for example, a determination that pregnancy is physiologically impossible because a patient lacks a uterus—with judgments that prognosis is poor (in which cases pregnancy would be physiologically possible, but unlikely). In cases deemed to have a low probability of pregnancy, some patients with disabilities, just like some patients without, may still wish to try to achieve pregnancy. According to the ASRM, treatment may be ethically provided in such cases if patients are fully informed about their prospects and clinics develop patient-centered, evidence-based policies about when they are willing to provide fertility services [28].

Beliefs about parenting ability. Much less clear, but not less frequent, are judgments about fitness to parent that motivate reluctance to provide fertility services. Mistaken assumptions about parenting ability may discourage referrals for fertility therapy [29, 30]. People with disabilities who reproduce are sometimes condemned as posing risks to or imposing burdens on society. Women with disabilities who have experienced pregnancy frequently report being targeted by complaints about their selfishness, based on the assumption that their relatives will have to raise their children or that their children will become burdens to taxpayers [12, 27].

Despite increased understanding of heritability, disabled women may also be discouraged from pregnancy out of misplaced fear that their children will in turn have disabilities [27]. As legal history underlines, people with disabilities have been subject to forced sterilization for precisely these reasons [31, 32]. The US Supreme Court's 1927 decision in *Buck v. Bell* upheld involuntary sterilization on the grounds that it was necessary "to prevent our being swamped with incompetence. It is better for all the world if...society can prevent those who are manifestly unfit from continuing their kind" [33]. This reasoning is both misleading, as many disabilities are not heritable, and profoundly biased, as it expresses the idea that the existence of disabled people impedes or otherwise harms everyone else.

Whether withholding reproductive services from patients is discriminatory depends on the beliefs that prompt it: are all prospective parents vetted to discover whether they are likely to raise children safely and well—or has stereotyping made disability a trigger for withholding services? The ASRM opines that fertility programs may withhold services to prospective parents—but only on the basis of "well-substantiated judgments that those patients will be unable to provide minimally adequate or safe care for offspring" [34]. The ASRM cautions clinicians to "pay special attention to treating equally persons with disabilities who request fertility services" [35] and notes that children thrive within a wide range of "parenting approaches or homes" [35]. Especially noteworthy is the ASRM stricture that scrutiny of potential parenting ability should not be applied to persons with disabilities unless applied to persons generally [6]. The ASRM is explicit that this

antidiscrimination provision applies to both potential parents with intellectual disabilities and mental illness and those with physical disabilities.

This advice—to respond to patients with disabilities with respect—requires attention to individual differences, language and culture, counseling settings, stressors, and medications [7]. It may be generalized to all areas of medicine and to all disabilities as good guidance for acting ethically by avoiding discrimination.

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