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# The Importance of Preconception Care for Women With Disabilities

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Overall estimates of the number of women with disabilities in the United States range from 16.8 to 28.6 million, or approximately one in every five women [1–3]. A large percentage of these women are in their reproductive years, and they often encounter greater obstacles to receiving health care than women without disabilities [4]. Some disabling conditions, such as spinal cord injury (SCI) and multiple sclerosis (MS), have low prevalence rates but are more common in the reproductive age group. Such conditions are often associated with a greater severity of disability and increased need for specialized services, including prenatal care [5]. Health care professionals need to be aware of the reproductive health care issues facing women with disabilities and take every opportunity to address them.

Sexuality and reproductive health issues have received inadequate attention for women with disabilities. Many women with disabilities desire children and are capable of conceiving, but face considerable pressure not to reproduce [6, 7]. Although a growing number of women with disabilities are becoming pregnant, anecdotal evidence suggests that many of these women encounter negative attitudes towards their pregnancies and report difficulty receiving comprehensive prenatal care [6].

Women with disabilities who become pregnant face similar issues and concerns as pregnant women without disabilities. Although many pregnant women experience problems with weight gain, fatigue, fluid retention, bladder dysfunction, and urinary tract infections, these problems may be more serious in women with disabilities [8]. All women are concerned about the health of their unborn child. Like other women, women with disabilities express concern about the possibility of giving birth to a child with disabilities and may seek genetic counseling. On the other hand, not all disabled women embrace the idea of genetic testing. To these women the idea of genetic counseling raises psychosocial issues that may be difficult for them to consider [6].

Some disabling conditions pose unique problems during or after pregnancy. Complications associated with specific conditions, such as systemic lupus erythematosus (SLE), SCI, or MS, can affect pregnancy and should be evaluated prior to conception [8–12]. For example, an increased risk of fetal loss, growth retardation, premature placental aging with thrombosis, and preeclampsia are described in women with lupus [9]. Given the seriousness of these complications, ongoing monitoring and interventions to reduce them are critical. Pregnant women with SCI above the level of T6 also require special attention [7, 8, 10, 11]. Such women have an increased risk of autonomic dysreflexia during all stages of pregnancy and, if it is not recognized and treated, autonomic dysreflexia can be fatal [8, 11]. Although women with stable MS can safely carry a pregnancy to term, postpartum exacerbations of MS are quite common and occur in up to 30% of women within one month of delivery [11, 12]. Pregnancy management in women with disabilities should therefore include preconception counseling and evaluation to identify these and other potential problems that can occur throughout the course of the pregnancy.

Health care professionals need to know that physical barriers, such as the lack of accessible scales or examination tables, present enormous and recurring obstacles to

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obtaining adequate prenatal care. Also, communication barriers, particularly for those who are deaf or hard of hearing, affect a women's ability to receive appropriate medical care. In addition, there are some aspects of gynecologic health care such as informed consent, sedation, and contraceptive issues that are unique for women with developmental disabilities. A recent publication from the American College of Obstetricians and Gynecologists highlights ways to improve care for this group of women [7].

Preconception care is associated with improved pregnancy outcomes. It is recommended that primary care providers assess all women of reproductive age for their preconception risk conditions and provide or refer individuals for interventions as appropriate [13]. When caring for a woman with a disability, a team approach involving the primary physician, obstetrician, anesthesiologist, neurologist, physiatrist, and other allied health professionals such as occupational and physical therapists, is recommended [6–8, 11]. This is particularly important, as many obstetricians are unfamiliar with disability-related complications. A multidisciplinary approach, which involves nursing and social work, can further improve pregnancy outcomes. This shared approach to pregnancy management can also increase the level of comfort for women with disabilities, by knowing that more than one health care provider is looking out for their well-being.

Preconception counseling for women with disabilities should address the medical, psychological, and social impact of a pregnancy [10]. During preconception counseling, it is particularly important to evaluate the prenatal and postpartum social support systems available to women with disabilities. Body changes such as decreased mobility or bladder dysfunction increase the need for personal assistance with routine activities of daily living. Many women with disabilities also benefit from an occupational therapy evaluation to assess environmental barriers and explore adaptive equipment and techniques that facilitate breast feeding and infant care. Health care providers might want to recommend that women with disabilities explore creative parenting strategies such as those offered by *Through the Looking Glass*, a national resource center on parenting with a disability, located in Berkeley, California [6, 14].

An increasing number of women with disabilities are becoming pregnant. Despite this little is known about the reproductive experiences of these women. Population-based data describing the reproductive experiences of women with disabilities is virtually non-existent. Currently, disability is not regularly included in national or statewide surveys and surveillance tools related to pregnancy. Consequently, the true magnitude of health concerns, including reproductive issues, facing women with disabilities is largely unknown. To improve our understanding of these issues, disability should be included as a demographic variable in all national and state-level surveys addressing reproductive health issues.

All women of childbearing age, including women with disabilities, should have access to preconception care that addresses the medical, psychological and social impacts of pregnancy. Women with disabilities can and do have healthy pregnancies. Accurate knowledge of disabling conditions and a shared multidisciplinary approach to pregnancy management are critical components for good pregnancy outcomes among women with disabilities.

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