



# Perinatal Care for Women With Disabilities: Clinical Considerations

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## ABSTRACT

Approximately 11% of women in their childbearing years are disabled. A disability is a physical or mental impairment that substantially limits 1 or more major life activities, is not regarded as transitory, and is documented in a medical or legal record. Many women who are disabled would like to have children. Nurse practitioners and midwives must have the knowledge and skills to provide perinatal care to women with disabilities. In this study we present what is known about the perinatal experience of women who experience physical, sensory, and neurologic disabilities and how health care providers can deliver competent care to disabled women. Recommendations for education and research are also made.

**Keywords:** disabilities, physical disability, perinatal care, pregnancy, sensory disability, women with disabilities, women's health

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## INTRODUCTION

It is estimated that approximately 11% of women in their childbearing years, ages 15–44, have a disability that affects activities of daily living and quality of life.<sup>1,2</sup> Although there are no population-based studies on incidence and prevalence of pregnancy and birth among women with disabilities, smaller studies have shown that many women with disabilities desire and are able to have children.<sup>3,4</sup> Of

the total population of 91 million American women aged 16–64, 11 million were identified as having a physical (51%), mental (30%), or sensory (19%) disability.<sup>2</sup> In this study we explore the unique needs of women with disabilities in relation to pregnancy and perinatal care based on published evidence. Care recommendations are made to improve the physical and psychological experience of pregnancy for disabled women.

This CE learning activity is designed to augment the knowledge, skills, and attitudes of nurse practitioners and assist in their understanding of caring for pregnant women with disabilities.

**At the conclusion of this activity, the participant will be able to:**

- Describe the incidence and prevalence of disabilities in women
- Discuss the impact of a disability on access to and utilization of healthcare during the perinatal period
- Identify evidence-based interventions to promote positive outcomes

The authors, reviewers, editors, and nurse planners all report no financial relationships that would pose a conflict of interest.

The authors do not present any off-label or non-FDA-approved recommendations for treatment.

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Disabilities are defined from medical, legal, and social perspectives, which can allow for different interpretations of the impact of a disability. Health care providers (HCPs) may utilize the medical definition as a frame of reference when providing care to patients who are disabled; however, it is equally important for HCPs to understand the legal and social definitions and implications of disabilities.

### **MEDICAL DEFINITION**

The United States Centers for Disease Control and Prevention defines disability as a condition that impedes activity and the ability to interact in daily activities.<sup>2</sup> The World Health Organization defines disability as a complex phenomenon that includes impairments, activity limitations, and restrictions on participating in daily life, due to body function or structure.<sup>5</sup> Disabilities can be further classified as physical, sensory, neurologic, and developmental. It is not unusual for a person with a disability to have related comorbid conditions.

Physical disabilities include those from birth (eg, spina bifida or cerebral palsy), those related to trauma (eg, spinal cord injury), and those related to a medical condition (eg, amputation related to disease, such as cancer).

Sensory disabilities include those related to the senses of hearing and sight, such as deafness or blindness.

Neurologic and developmental disabilities include those that occur during fetal development (eg, microcephaly), birth (eg, anoxia), and exposure to toxic substances (eg, alcohol and lead). Other disabilities include disorders on the spectrum (eg, autism and pervasive developmental disability) and mental/intellectual disabilities.

### **LEGAL DEFINITION**

The Americans with Disabilities Act (ADA) defines disability as “a physical or mental impairment that substantially limits one or more major life activities of such individual, a record of such an impairment and being regarded as having such an impairment.”<sup>6</sup> The ADA prohibits discrimination of persons with disabilities and was built on the Civil Rights Act of 1964. The ADA was signed into law in 1990 and requires employers to provide reasonable

accommodations for employees with disabilities and accessibility on public accommodations, including transportation, recreation, education, dining, and health care services.<sup>6</sup> Therefore, it is critical for health care providers to not only have the necessary physical accommodations in place for patients with disabilities, but to have extensive knowledge about how each disability has the potential to impact health.

### **SOCIAL DEFINITION**

The social model of disability, which originated in the United Kingdom, posits that disabilities are caused by the manner in which they are viewed by nondisabled persons in society and are based in attitude as opposed to the experience of the disabled individual.<sup>7,8</sup> The social model explores the needs of persons with disabilities, as opposed to being grounded in what is wrong with a person with a disability. The social definition of disability is not based on medical or legal terms, but instead relies on an attitudinal construct. Many women with disabilities consider themselves healthy and wish to be viewed holistically. According to this model, women with disabilities want the assistance of the health care community in advancing their health goals, including having healthy pregnancies and children. Health care providers should consider how incorporating the social model of disability into their practice can enhance the provision of care by supporting the strengths of disabled women and partnering with them to develop plans of care that are mutually satisfactory.

### **BACKGROUND AND SIGNIFICANCE**

Women living with disabilities struggle with social and environmental barriers related to maintaining health and well-being when compared with women who are not disabled.<sup>4</sup> They are at greater risk for experiencing health disparities, including decreased access to quality care and lower rates of screening for both cervical and breast cancer, and are more likely to have unmet sexual and reproductive health needs.<sup>9</sup> A qualitative study conducted by Walsh-Gallagher and colleagues showed that participants (n = 17) with disabilities perceived the experience of pregnancy and motherhood as one to celebrate, considered pregnancy an achievement, and felt that pregnancy

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