

Providing Perinatal Care for Women with Developmental Disabilities

Women with intellectual and developmental disabilities (IDD) encounter numerous barriers to healthcare services, including environmental, physical, informational, attitudinal and others.^{1, 2, 3} As the number of women with IDD reaching reproductive age grows, healthcare systems and providers need to be prepared to provide quality care for these women. “The information needed by clinicians to provide high quality care to women with physical disabilities and chronic health conditions can be summarized simply: most women with disabilities have the same health care needs as women without disabilities, but may also have additional unique health needs.”¹

Due to existing healthcare and socio-economic disparities, women with IDD are at higher risk for smoking, obesity, and co-morbid chronic health conditions. Women with disabilities represent a heterogeneous group of individuals who, in addition to their disability, may face other cultural barriers. These may include diverse sexual orientations, gender identities, racial and ethnic backgrounds, and religious affiliations. It is important for providers to keep these cultural considerations in mind.



MYTH vs FACT¹

MYTH: Women with IDD are infertile
FACT: Fertility rates are comparable to the general population

MYTH: Women with IDD have no interest in sex
FACT: Women with IDD are sexual beings

MYTH: Women with IDD cannot deliver vaginally
FACT: The majority of developmental disabilities do not impact vaginal delivery

MYTH: Women with IDD are unfit to be mothers
FACT: Women with IDD can become confident and successful parents; some may need additional supports, education, and/or accommodations

QUICK FACTS⁵

When compared to women without disabilities, women with IDD are

-  16% more likely to have a cesarean section
-  6% less likely to access prenatal care in the first trimester
-  5% less likely to breastfeed
-  4% more likely to give birth prematurely
-  3% more likely to deliver infants of low weight

“The expectation that a cesarean section is necessary needs to be dispelled and each patient’s needs individually assessed. I have assisted many patients, even women with involved physical conditions, through a successful vaginal delivery.”

- Dr. William Schnettler, board certified Maternal-Fetal Medicine physician



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Excellence in Developmental Disabilities
Leadership Education in Neurodevelopmental
and related Disabilities

Best Practices for Care¹



Resources

A provider's guide for the care of women with physical disabilities and chronic health conditions¹: Includes lists for equipment resources, books, and disability-specific recommendations



Websites

[ACOG – Physician Information on Women with Disabilities](#)

[Disabled Parenting Project](#)

[ADA Guidelines for Accessible Medical Facilities](#)

[NIH Clear Communication Guidelines](#)

[National Research Center for Parents with Disabilities](#)



Contact Us

ucucedd@cchmc.org
513-803-3627

Before the initial visit:

- Ask all patients if they require any accommodations and prepare accordingly
- Schedule more time for the visit to allow for needs (e.g. transfers)
- Assess the office space for accessibility utilizing [ADA guidelines](#)
- Offer accessible exam tables that can be lowered and scales to weigh women in wheelchairs
- Encourage the patient to bring her medical records and a written list of medications

During outpatient care:

- Have staff and equipment available to assist with safe transfers
- View the woman with IDD first as a woman and avoid common stereotypes of persons with disabilities
- Utilize person-first language
- Orient the patient by explaining all procedures
- Offer nonjudgmental acceptance of the woman's choice about pregnancy/parenting
- Recognize that the woman is the expert on her body and disability and should be treated as a partner in decisions
- Reinforce the patient's positive qualities
- When a support person is present, address the patient directly and ask how she would like this person to be involved
- Offer healthcare information in a variety of alternative formats (braille, audio, video, web and phone)
- Whenever possible, provide both written and verbal instruction
- Use simple, direct language and ensure that written information is provided at a 6th grade reading level in accordance with [NIH and AMA guidelines](#)
- Use the "teach back" method to ensure instructions are understood by having the patient explain to you in her own words the recommendations you provide

During the hospital stay and postpartum period:

- Collaborate with the woman's existing care team
- Inform birthing team of the patient's accommodations and ensure supports will bridge to inpatient stay
- Provide equal access to lactation consults and other specialists
- Provide resources for adaptive parenting equipment as needed



"When my husband and I spoke to my doctors, none of them had any direct experience with assisting a woman with spina bifida through a pregnancy."

- Amy Blanchard, Sweetie & Me blogger

¹ Smeltzer, S. C. & Sharts-Hopko, N. C. (2005). A provider's guide for the care of women with physical disabilities and chronic health conditions. CDC.

² Stockburger, S. & Omar, H. A. (2015). Women with disabilities: reproductive care and women's health. Pediatrics Faculty Publications, 8(4), 429-447.

³ Greenwood, N. W., & Wilkinson, J. (2013). Sexual and reproductive health care for women with intellectual disabilities. International Journal of Family Medicine, 2013, 1-8.

⁴ Parish, S. L. et al (2015). Pregnancy outcomes among U.S. women with intellectual and developmental disabilities. American Journal on Intellectual and Developmental Disabilities, 120(5), 433-443.

⁵ Darnay, Blair G., Frances M. Biel, Brian P. Quigley, Aaron B. Caughey, Willi Horner-Johnson (2016). Primary Cesarean Delivery Patterns among Women with Physical, Sensory, or Intellectual Disabilities, *Women's Health Issues 27-3 (2017) 336-344*