So You Are Going to Have a Baby: A Guide for Women with Developmental Disabilities

Whether you are planning a pregnancy or already pregnant, becoming a mom can be an exciting and challenging time. When it comes to pregnancy, women with disabilities have the same needs as other women including being treated with dignity and respect. In this resource, you will find information related to:

- Preparing for childbirth
- Finding an accessible provider
- Building your support network
- Advocating at your medical appointments

Women with disabilities have many things to consider related to pregnancy. It can be difficult to determine which issues are disability-related and which are pregnancy-related. Your disability may or may not affect the way your baby develops. To find these answers:

- Work as a team with your OB/GYN and doctors who know your disability
- Connect with other mothers with disabilities to learn strategies to cope with pregnancy and beyond

Healthy Habits for Pregnancy

- Make your home safe so you won’t have accidents
- Get regular checkups with your doctor
- Don’t drink, smoke, or take drugs
- If you take medication, talk to your doctor because some medications may not be safe during pregnancy
- Eat plenty of fruits and vegetables, exercise regularly, take a multivitamin every day, and get enough sleep

“You are the expert on what you need and what your challenges are. So whether or not a doctor has previous experience working with your specific challenges doesn't really matter, as long as they are willing to listen, research, help and advise YOU in the best ways possible.”

- Amy Blanchard, Sweetie and Me blogger and mother with a disability

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Pregnancy & Parenting

Building a Support Network
When expecting and caring for a baby, you may find you need a little more help than before. Asking for the support of a trusted family member, community organization, or disability agency can make a big difference. It is up to you to decide what role each support will play and discuss this role with him or her and your health care provider before you go to a medical appointment.

Types of Supports

Natural
Family
Friends
Partner

Disability-specific
Medicaid
Social Security
Peer Support

Community
Public Transportation
YMCA
Library

Assistive
Wheelchair
Communication Device
Interpreter

Finding Accessible Providers
There is a lot to think about when searching for a new obstetrician/gynecologist (OB/GYN) or pediatrician. Consider asking your support system, your current doctor, or insurance company for recommendations. Once you’ve selected a potential provider, it is important to ask questions to make sure they meet your needs.

Before the visit: ask the office about accepted insurance providers, office accessibility, office hours (including after-hours and weekends), and willingness to meet your need for accommodations.

During the visit: ask the doctor if he/she has experience with patients similar to you and if they are willing to collaborate with your other doctors. If it is a practice with several providers, make sure everyone is comfortable working with/supporting you.

After the visit: ask yourself if the doctor treated you with respect, listened to you, spent enough time with you, and explained information in a way that was understandable. Remember, if you are not happy with the first doctor you select, it is okay to try another doctor before picking one!
Advocating for your Birth Plan

Talk with your doctor and the hospital staff about reasonable accommodations and your preferences:

- During Labor
- During Birth
- After Birth
- For Your Baby
- In Case of C-Section Birth
- In Case of an Unexpected Event
- Your Plan to Go Home

Information about Your Rights:

- Women with genetic disabilities can still choose to have children.
- Most disabilities do not affect a woman’s ability to have a vaginal delivery and to breastfeed.
- Women with disabilities cannot be made to do things that other women are not asked to do, such as a parenting assessment before discharge from the hospital.
- Like any mom, you have the right to help from others to provide loving and safe care to your child.
- Many states do not allow women to use their state-funded personal attendant to assist with parenting tasks.
- Having a disability might change your birth plan. Planning ahead can prepare everyone for your big day!
- Learn about adaptive parenting equipment and connect with other moms with disabilities through the Disabled Parenting Project.

Self-Advocacy at Healthcare Appointments:

- Know your needs and your learning style and share these with your doctor.
- Talk to your doctor’s office before the visit about accommodations you need, such as wheelchair access, help with transfers, an interpreter, or extra time.
- Write down things you want to talk to your doctor about ahead of time. It may be helpful to use a worksheet.
- Ask questions if there is something you do not understand.
- If you want, bring someone with you who can help by taking notes or providing other supports.
- Call your doctor if you think of questions after the visit.

Self-Advocacy Phrases to Use

- “Please slow down.”
- “Please repeat what you just said.”
- “I don’t understand that word.”
- “I have more questions.”
- “You’re not listening to me.”
- “Please write down these instructions for me.”

Adapted from “Take Charge!”