

Pregnancy Care for Women with Intellectual Disabilities

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Introduction

Pregnant women with disabilities can have a lot of challenges with their pregnancies. This is especially true for women with intellectual disabilities. Pregnancy care often does not meet the needs of women with intellectual disabilities.

We asked doctors about providing pregnancy care to women with intellectual disabilities. We looked what the doctors told us about why it is sometimes hard to provide good care for women with intellectual disabilities.

How did we do the research study?

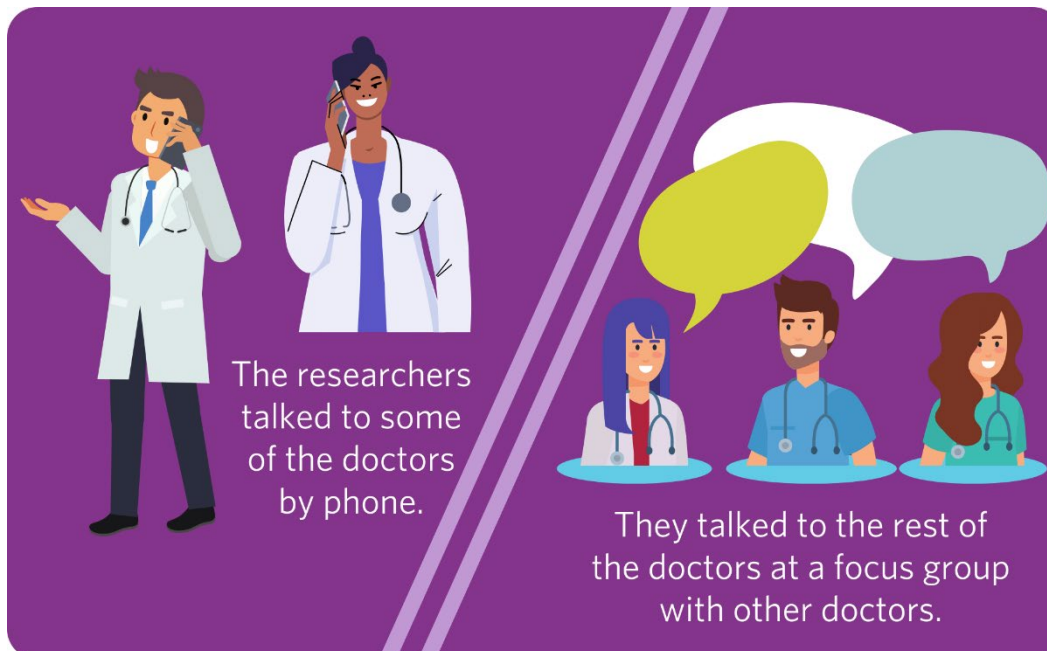
We interviewed 17 doctors who provide care to pregnant women with intellectual disabilities. We spoke with some of the doctors over the phone and we spoke to the others in a focus group with other doctors. The researchers looked at what the doctors said in the interviews.



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What Did We Learn About the Barriers for Doctors?

We found there were many barriers that make it harder for doctors to give good care to pregnant people with intellectual disabilities. Here are the barriers we learned about:

- ▶ *Doctors don't always know how to communicate well with patients with intellectual disabilities*

Pregnancy can be really confusing and complicated. It can be hard for doctors to explain things in ways that everyone can understand. Some doctors feel like they don't know how to provide good care to pregnant women with intellectual disabilities because nobody ever taught them. This means that sometimes women are sent to a special doctor to get care, even if they don't need it.

- ▶ *Doctors don't always know how a support person should be involved*

A lot of people with intellectual disabilities have a family member or Direct Support Professional (staff) who supports them. These people may come

with them to their doctor's appointments. Doctors may be confused about the role of the family member or support person. They aren't always sure if they should involve this person in decisions or how that person should be involved.

The doctor also doesn't always know if someone has a legal guardian. If the pregnant woman and her guardian or support person have *different* opinions, the doctor needs to figure out who makes the decision. Sometimes the doctor needs to talk with someone else (such as a lawyer or hospital staff) to help figure out who can make a decision.

► *Doctors often do not know ahead of time that the pregnant person has an intellectual disability*

A doctor may not be sure whether their patient has an intellectual disability. The file they keep about the patient doesn't say if someone has an intellectual disability. This problem can make it hard to provide the best care for the pregnant woman.

► *It can be difficult for pregnant people with intellectual disabilities to manage their appointments and tests*

During pregnancy, a pregnant woman must often set up appointments for visits or special tests at a different office from their regular doctor's office. Doctors' offices do not always have office staff to help with booking additional tests and appointments. Sometimes women with intellectual disabilities miss appointments or tests they need.

► *Doctors don't have enough training*

Doctors don't have enough training about providing care for pregnant women with intellectual disabilities. If a doctor wants to learn more, they

must teach themselves. There aren't many classes about pregnancy care for women with intellectual disabilities.

► *Doctors need guidelines*

Doctors may use practice guidelines to provide the best care for their patients. Practice guidelines are written instructions for doctors about how to care for different groups of people or different health conditions. In the United States, there aren't any practice guidelines for doctors who provide pregnancy care for women with intellectual disabilities. Doctors want to have guidelines so they can do a better job.

► *Doctors need plain-language, written pregnancy information to give to patients*

Information about pregnancy is often not available in plain language. Doctors want to give out reading materials about pregnancy to their patients. These reading materials may not be accessible to everyone. There needs to be more health information in words that people with intellectual disabilities can understand.

► *Pregnant people with intellectual disabilities need services and supports*

More services and supports are needed for people with intellectual disabilities. Some places have a lot of services but other places do not. These services and supports should help with preparing for pregnancy and taking care of the baby.

► *Pregnant people with intellectual disabilities need longer visits and may need visits more often*

Pregnant women with intellectual disabilities may need to go to the doctor more often. Doctors want to make sure that a woman with an intellectual

disability understands what is happening during the pregnancy and answers her questions. However, doctors have lots of patients and may not have extra time to spend with one patient. Also, they may not get paid for longer visits or more visits. This makes it hard to provide the best possible care.

Why This Matters

The study shows a need for:

1. more doctor training



2. guidelines for doctors about pregnancy and intellectual disability



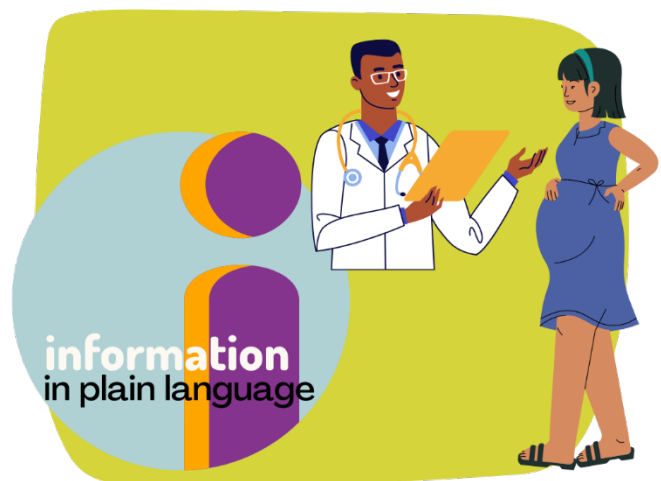
3. more time and visits with the doctor



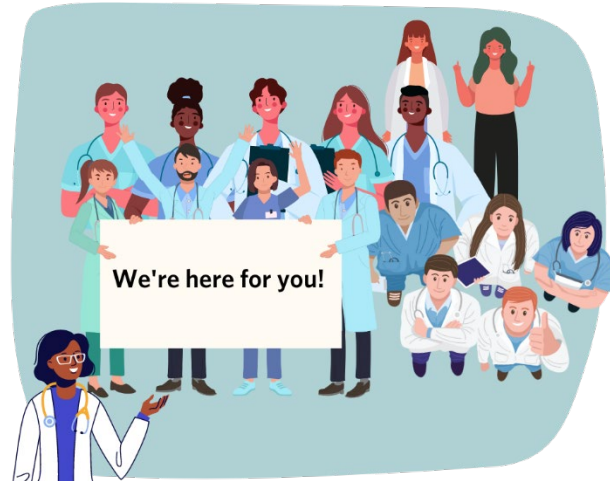
4. a process at doctors' offices to ask about disability, accommodations, and guardianship



5. information about pregnancy available in plain language



6. services and supports for
pregnant women with intellectual
disabilities



Credit

Adapted from “Clinician-Reported Barriers to Providing Perinatal Care to Women with Intellectual and Developmental Disabilities,” by L. D. Smith, A. Valentine, T. A. Moore Simas, S. L. Parish, A. Levy, and M. Mitra, 2023, *Journal of Intellectual & Developmental Disability*, 48(1), pp. 12–22.

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How to Cite This Brief

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