Supporting People with Disabilities in Pregnancy, Labour and Delivery, and Postpartum: Resources for Public Health Nurses

This resource provides current evidence about the perinatal health and health care experiences of people with physical, sensory, and intellectual/developmental disabilities and guidance on supporting them during the perinatal period.

Disability is common, **impacting nearly 15% of reproductive-aged people.**[1] The World Health Organization defines disability by the interaction between a person's health condition and environmental barriers to full participation in society.[2] Disabilities can be physical, impacting mobility; sensory, impacting vision or hearing; and intellectual or developmental, impacting learning, practical or social skills, or communication.

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The pregnancy-related needs of people with disabilities have often been overlooked, in part because of negative societal assumptions about disability, sexuality, and parenting. The 2006 United Nations Convention on the Rights of Persons with Disabilities protects the rights of people with disabilities to decide the number and spacing of their children and to found a family.[3] Data from Ontario suggests that **one in eight pregnancies in 2017 were people with a disability.**[4]

To support people with disabilities in pregnancy it is important to keep in mind that reproductive-aged people with disabilities are more likely than those without disabilities to experience preconception health disparities,[5] including:

- poverty;
- chronic medical conditions, such as diabetes, hypertension, asthma, and depression;
- prescribed medications that are potentially teratogenic;
- history of assault; and
- barriers to accessing health care and negative health care experiences.

These disparities are known risk factors for maternal and newborn complications and need to be addressed before and during pregnancy.

Most people with disabilities have healthy pregnancies. However, compared to those without disabilities, they can experience higher rates of certain maternal and newborn complications,[6-8] which can be prevented with good prenatal care. These include:

- common complications like gestational diabetes, gestational hypertension, and cesarean section;
- rare but serious complications like hemorrhage in pregnancy or postpartum;
- newborn complications like preterm birth and small for gestational age; and
- postpartum depression and anxiety.

These disparities show how important it is to provide accessible perinatal health supports to people with disabilities that are responsive to their needs.

Public health nurses play a key role in providing care to pregnant and parenting people with disabilities and their newborns, and may spend more time interacting with them than other health care providers (e.g., in prenatal classes, postpartum home visits, lactation consultations).

Public health nurses are therefore instrumental in building relationships with clients with disabilities and ensuring their perinatal health care needs are met. Nurse managers and other administrators also play a role in making sure public health nurses have enough time with their clients to accommodate their needs.

Quality care essentials

Do the research: Take time to learn more about your client's disability, including how it may impact their pregnancy and how their pregnancy may impact their disability.	*"It would help if nurses and doctors find out that a person has disability, to **learn a bit more about the disability**. How it manifests … how can that affect the pregnancy?"*
Just ask: Ask people with disabilities how disability shapes their everyday lives, what they need to feel informed and supported, and who can provide that to them. Ask them what other providers are already involved in their care.	*"Not every disability is the same so you can't just treat it as an umbrella. You have to get to know the client that you're working with and what their needs are and like **it's OK to ask**."*
Be proactive: Start planning resources and supports early so that you are creating an accessible and supportive environment (e.g., in prenatal classes, hospital, early parenting programs) rather than reacting to crises.	*"**Getting the interpreter in the first place** so you're preventing any of the miscommunications and misunderstandings that could happen in the future."*
Meet them where they are: Home visits may be particularly useful because they help to eliminate accessibility barriers many people with disabilities experience.	*"It [**being at home] just automatically covers many accommodations**. There's also automatically more time to do any of that learning or asking questions."*
Communicate: Talk directly to people with disabilities, and make sure that all providers involved in their care are informed about their wishes and their needs. This includes making sure everyone is on the same page about what services and supports should be in place to support them when they are home with their new baby.	*"**Make sure you're talking to the patient and not about the patient**. … And whenever it will be possible to have … somebody who kind of follows your case throughout … so that you don't have to keep on reiterating the same information again and again. Somebody who can maybe be your advocate sometimes if that's needed, just so that all your medical professionals will be on the same page."*

Get creative: Consider what adaptations and accommodations are needed to meet clients' physical, sensory, and learning needs related to pregnancy and newborn care (e.g., wheelchair-accessible spaces, hoyer lifts, accessible cribs, different breastfeeding positions, tactile resources, ASL interpreters, visual aids, avoiding medical jargon).	*"Just to be aware of how welcoming it [the office] is to a disabled person. Even just little things like in the waiting room,* ***is there a place to wait with a wheelchair****, … When people actually listen, you'll hear them say, 'Oh, I'm glad you said that because now it's so much easier to transfer you this way,' or whatever it was."*
Think outside the health care box: Work with people with disabilities, their partners or families, and other providers to ensure that resources and services related to the disability and other life circumstances, such as those related to the social determinants of health, are in place. This might include working with disability community agencies, accessible transportation services, financial aid, housing services, child protection, occupational therapy, and nurturing assistance	*"****Access to the supports is huge****. … Listen to the people [with disabilities] about what their particular needs are. … There may have been supports available to me and I didn't know about them."* *"They [health care providers] should be oriented to work with the society, the community. … so* ***they should be also working with the [disability] community*** *so that they can know about these things [resources]."*
It takes a team: Ask people with disabilities what care they are receiving from other providers, especially if they have multiple disabilities or chronic medical conditions like diabetes. It may be helpful to connect with other providers involved in their care by writing a note to communicate care needs.	*"I just wish there was a* ***true multidisciplinary team … a truly cohesive circle of care,*** *that if this person is pregnant and she has a chronic illness or disability, 'Okay I'm going to send her to this person, this person, that person,' and they would all kind of know about you."*
Take the time: Provide more frequent and/or longer visits or sessions (e.g., during home visits, lactation consultations) to facilitate delivering the aspects of support above.	*"Be more open. Listen to the client. It's not easy to have a disability nor is it easy to go in it and facing it alone. …* ***more support, someone to talk to and not so rushy-rushy.****"*

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