

Improving Accessibility of Pregnancy Care for People with Disabilities Resource for Healthcare Administrators

Nearly 15 percent of reproductive-aged people have a physical, hearing, vision or intellectual disability. The 2006 United Nations Convention on the Rights of Persons with Disabilities recognizes the reproductive rights of disabled people, including the right to have a family and to decide the timing and spacing of their children.² **In 2017, nearly one in eight pregnancies in Ontario were to people with a disability.**³ However, pregnancy care has typically not been structured with the needs of disabled people in mind.⁴

This resource describes current evidence about the pregnancy, birth and postpartum health outcomes and healthcare experiences of people with disabilities. It also provides advice for healthcare administrators on improving the accessibility of care.

Improving the accessibility of care requires an understanding of the **preconception social and health disparities** experienced by people with disabilities.⁵ These include elevated rates of:

- Poverty, unstable housing and food insecurity
- Chronic conditions such as diabetes, hypertension, asthma and mental illness
- Prescribed medications that are potentially teratogenic
- Histories of experiencing violence and other forms of trauma, and
- Negative healthcare experiences, including physical and communication barriers to care.

These factors are established predictors of pregnancy complications and need to be addressed through high-quality, accessible preconception and pregnancy care.

Improving the accessibility of care also requires an understanding of the **disparities in pregnancy outcomes** experienced by disabled people.

Most people with disabilities have healthy pregnancies. However, compared to people without disabilities, they do have slightly elevated risks of some pregnancy complications (*described below*) that might be prevented through more accessible pregnancy care.⁶⁻¹¹

Potential Complications:

- Emergency department visits and hospital admissions in pregnancy and postpartum⁶
- Common pregnancy complications like gestational hypertension and gestational diabetes⁷
- Rare but significant pregnancy complications like hemorrhage⁸
- Other adverse outcomes like postpartum depression and intimate partner violence^{9,10}
- Newborn complications like preterm birth¹¹

Health outcomes among people with disabilities can be improved by providing accessible pregnancy care.

Finally, improving the accessibility of care requires an understanding of the **barriers to and facilitators of healthcare** experienced by pregnant and postpartum people with disabilities.

Facilitators

- Advocacy by the disabled person and their family, friends, and providers¹²
- Adapted strategies and hands-on help (e.g., with infant feeding, newborn care)
- Help at home (e.g., midwifery and public health nurse visits)
- Holistic care (e.g., integrated medical, social, human services)
- Financial, housing, mental health supports

Barriers

- Ableism, including negative provider attitudes toward disability and parenting¹²
- Physically inaccessible healthcare spaces

- Barriers to communication (e.g., lack of ASL interpreters, accessible documents)¹³
- Lack of coordination across providers¹²
- Lack of information about disability and pregnancy
- Social determinants of health like poverty

These barriers to and facilitators of care show areas where the accessibility of pregnancy care could be improved.

Healthcare administrators are critical for establishing the structures necessary for developing and delivering accessible pregnancy care to people with disabilities. The following recommendations are accompanied by quotes from people with disabilities and healthcare providers in Ontario.

Recommendation 1: Set up care pathways to ensure continuity

- **Set up patient-centred structures**, such as patient care conferences, to ensure that pregnancy and disability-related specialists are able to communicate directly.
- **Consider the use of patient navigators** or others who can act in a coordination role to assist patients, clinical staff, and office staff with communication and planning across multiple providers.
- **Look beyond healthcare** to ensure that appropriate disability-related services (e.g., occupational therapy) and social services (e.g., housing services) are in place to provide continuity across transitions after delivery and after the final postpartum visit.

“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.” – disabled parent

“Maternity care is not about just checking on the heartbeat, blood pressure, they’re fine and they’re out the door. I think you need to think about the whole

person, about their social situation, what's happening, how is it going to look after they have their baby and anticipate certain things.” – family physician

Recommendation 2: Provide staff with required resources

- **Provide disability and empathy training** to clinical and office staff to build competency.
- **Address environmental needs** by ensuring spaces and equipment (e.g., examination tables, ultrasound machines, weigh scales, washrooms) are accessible for people with mobility-related disabilities.
- **Develop relationships with community agencies** that can address disability accommodation requests (e.g., ASL interpreters, accessible documents, plain language resources).

“I think [healthcare providers] need to demonstrate they've done some training... If there were certification training programs out there, then people within the Deaf or disabled communities would be able to say, 'Ah, this person's done some training'.” – midwife

“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?” – parent with a disability

Recommendation 3: Push existing structural boundaries

- **Recognize structural changes** that need to occur to provide more accessible care (e.g., time for longer or more frequent visits).
- **Identify champions** in your institution who can advocate for change.
- **Engage disabled people** by involving them in identifying improvements.

“There has to be some sort of recognition of funding for that as well. It's not a five-minute assessment...” – obstetrician

“[Identify] someone who's definitely not complacent to the systems that they interact with, but someone who really pushes against those preconceived notions.” – physician

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Resources

Clinical guidelines

- Berndt A, Ladhani N, Wilson RD, et al. [Guideline No. 416: Labour, Delivery, and Postpartum Care for People with Physical Disabilities](#). *J Obstet Gynaecol Can* 2021;43(6):769-80.
- American College of Obstetricians and Gynecologists Committee on Obstetric Practice. [Committee Opinion No. 808: Obstetric management of patients with spinal cord injuries](#). *Obstet Gynecol* 2020;135(5):e230-6.
- Sullivan WF, Diepstra H, Heng J, et al. [Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines](#). *Can Fam Physician* 2018;64(4):254-79.

Centres with expertise

- [Accessible Care Pregnancy Clinic](#), Sunnybrook Health Sciences Centre, Toronto, ON: Specialized clinic that provides care for people with physical disabilities who are pregnant or are contemplating a pregnancy.

Provider training resources

- [Caring for Pregnant and New Parents with Physical Disabilities](#), BC Provincial Health Services Authority, Vancouver, BC: eLearning Course on health and infant feeding considerations for pregnant and postpartum people with physical disabilities
- [The Advancing Care Excellence for Persons with Disabilities \(ACE.D\) Program](#), National League for Nursing, USA: Resources and teaching strategies for nurses working with disabled people
- [The National Research Center for Parents with Disabilities](#), Heller School for Social Policy and Management, Brandeis University, USA: Research, training, and technical assistance to improve the lives of parents with disabilities and their families

Resources to assist with care delivery

- [Childbirth Preparation and Support Tool](#), Health Nexus, ON: A tool for healthcare providers to use with patients with fetal alcohol spectrum disorder and related disabilities who may need extra support in pregnancy
- [Parenting with a Disability Network](#), Centre for Independent Living Toronto, Toronto, ON: Cross-disability network for parents and prospective parents with disabilities
- [Pregnancy and Spinal Cord Injury: An information booklet for women with SCI](#), Vancouver Coastal Health's Sexual Health Rehabilitation Service, BC Women's Hospital and Health Centre's Maternal Fetal Medicine Service, Rick Hansen Institute, Spinal Cord Injury BC, Vancouver, BC: Resource for parents with spinal cord injuries
- [Resources for Patients by Patients](#), Canadian Arthritis Patient Alliance, Ottawa, ON: Resources on sexuality, family planning, pregnancy, and birth created by people with arthritis for people with arthritis

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A note about language: This resource uses the language of "disabled people" and "people with disabilities" interchangeably, recognizing that different individuals have different preferences.