

Pregnancy and Postpartum Care Resource for Parents with Disabilities

Whether you are thinking about becoming pregnant or are pregnant right now, this is an exciting time! You can find a lot of useful information by talking to your healthcare provider, looking at recommended pregnancy websites, and talking to other parents with disabilities. However, although **one in eight pregnancies in Ontario are to people with a physical, hearing, vision, or intellectual disability**¹ it can be difficult to find information specifically on disability and pregnancy.

This resource describes research about the pregnancy, birth, and postpartum health and healthcare experiences of people with disabilities. The resource also provides advice for prospective and new parents on accessing pregnancy and postpartum care.

Research with people with disabilities shows a variety of experiences in pregnancy and postpartum care. People identified a number of things that helped them when they were accessing pregnancy-related care, and some things that they found to be challenging.

Things that helped

- Advocating for themselves and having advocacy from family, friends and providers²
- Adapted ways of doing parenting tasks 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., medical, and social services)

“When you’re home with the midwives, you’re totally levelling the playing field. I’m in my own space so I know where everything is. I needed so many fewer accommodations. In my own home, no one has to tell me how I can find the washroom... I loved that the midwives do home visits, the first three or four visits at home. I loved anytime I could get home visits, so helpful... There’s also automatically more time to do any of that learning or asking questions.”

Things that were challenging

- Negative healthcare provider attitudes toward disability and parenting²

- Physically inaccessible healthcare spaces
- Barriers to communication (e.g., lack of ASL interpreters, plain language resources)³
- Lack of coordination across providers²
- Lack of information about disability and pregnancy

“When they give information to parents, they give you a bunch of pamphlets, right? ... ‘Here’s a bunch of mysterious papers,’ you know? And usually [I] just have to recycle it because I don’t know what this is so I do really appreciate anytime someone can email me that, as a PDF or anything. Or even just tell me the key [information], so it is helpful... So just making that information a bit more accessible is helpful.”

These findings show the importance of accessing the right services and resources to support you throughout your pregnancy. On the last page of this document, there are links to several resources that may be helpful.

Parents with disabilities often report looking for information about how pregnancy might impact their disability and health and vice versa. Until recently, there was not a lot of data on this topic.

New research shows that **most people with disabilities have healthy pregnancies**. However, compared to people without disabilities, they do experience small risks of some health complications.

These health complications are often preventable through access to high-quality pregnancy care.

Potential complications

- Emergency department visits and hospital admissions in pregnancy and postpartum⁴
- Common pregnancy complications such as gestational hypertension and gestational diabetes⁵
- Rare but important pregnancy complications like significant bleeding⁶
- Other important outcomes like postpartum depression and experiences of intimate partner violence^{7,8}
- Newborn medical complications like preterm (premature) birth⁹

Remember that most disabled people have healthy pregnancies. However, high-quality pregnancy care is important for reducing the risks of any potential health complications.

Many changes need to happen to the healthcare system to make pregnancy and postpartum care more accessible for people with disabilities.

In separate resources, we give recommendations for [healthcare providers](#) and [administrators](#) about these changes.

Below, we list recommendations from other parents with disabilities that may help you advocate for supports and resources during your pregnancy and postpartum journey.

- **Think ahead:** Thinking ahead about your pregnancy plans can be helpful for having conversations with your doctor early (e.g., if you need to make changes to medications when you are pregnant).

“I went to see all my doctors before we decided to get pregnant and we made sure that, you know, it was safe for me, it was safe for the baby, and all of them gave us the green light so we felt comfortable moving forward with that.”

- **Find a navigator:** Be aware that there may be many providers involved in your pregnancy care (e.g., obstetrician, disability-related specialist). Often, pregnant people act as the “go between”, but, if available, it can be useful to have a social worker or “navigator” who can help coordinate your care.

“[Hospital] organized everything so I had like a million people. I had a respirologist and anesthesiologist, neurologist. I went back to see my [occupational therapist] that I already had there to do some pregnancy stuff. I saw a... physiatrist there who I consulted with... [Doctor] I think just used her magic so I would get in... Every time, they would just fit me in.”

- **Find a community:** Connect with parenting groups and other community resources that can give you social support and a person to talk to about your experiences.

“The community part is really important and also talking to people about how hard it is.... And listening to people talking about their experiences is really helpful too. Everybody’s different.”

- **Have a birth plan:** Think ahead with your providers about your birth plan. Sometimes emergencies can happen, and things change but discussing your wishes and needs ahead of time can be helpful. This way, you know what to expect and can consider what to do if plans do change.

“I was concerned about the day of [delivery]. I have osteoporosis and really bad contractures and I can't lay flat on my back, and I was just picturing everybody putting me under and then just fracturing me because they didn't understand my body. And so I made them go through it multiple times like, ‘How am I going to be transferred? Who's going to be doing it?’”

- **Request accommodations:** Parents with physical, hearing, and vision disabilities in particular often find there are gaps in accommodations, especially when giving birth in a hospital. Speak to your healthcare provider ahead of time to ensure your required accommodations are in place.

“I only had the interpreter for the delivery and then that was it... And the nurses come, they come in a lot when you're in the hospital. They're doing bloodwork... and there was no interpreter for that... As long as the patient's in the hospital, they should have someone on hand from 8 to 5, at least. So that if they have questions, they can talk to the nurse.”

- **Think about mental health:** The postpartum period is a difficult time for all new parents. Consider seeking out mental health supports in addition to medical care.

“It would have been helpful to have some sort of mental health support or support from other disabled people. Because I remember feeling very isolated and all the people I was seeing, they didn't get it. And I also was wary of appearing to struggle too much.”

- **Seek out resources:** Parenting groups and occupational therapists can be great sources of information on adapted devices and other practical

resources that can help with infant feeding and newborn care.

“If there’s something, just get it. So, there is a Well Baby [public health] program. If you want support, that is a thing that’s out there. Build a village. Don’t reinvent the wheel. Don’t problem-solve something 50 of us have problem-solved, just ask.”

References

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Resources

Resources for pregnancy

- [Childbirth Preparation and Support Tool](#), Health Nexus, ON: A tool for patients with fetal alcohol spectrum disorder and related disabilities to communicate support needs in pregnancy
- [Having a Baby](#), Books Beyond Words, London, UK: Stories for people with intellectual and developmental disabilities about what is involved in being pregnant, becoming a parent, and caring for a baby
- [Mamas Facing Forward](#): Private Facebook group designed to help women with chronic illness move forward with motherhood, whether you already have kids, are pregnant, are trying to conceive, are looking to adopt, or are just considering motherhood someday – we can find ways to support each other!
- [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
- [The National Center for Disability and Pregnancy Research](#), Heller School for Social Policy and Management, Brandeis University, USA: Research and resources to improve the pregnancy experiences and outcomes of parents with disabilities

Resources for early parenting

- [Disabled Parents Network](#), London, UK: A national organization for disabled people who are parents or hope to become parents, and their families, friends, and supporters
- [Mom on Wheels: The Power of Purpose for a Parent with Paraplegia](#), Ingenium Books, Toronto, ON: Biography of a parent with paraplegia
- [Parenting with a Disability Network](#), Centre for Independent Living Toronto, Toronto, ON: Cross-disability network for parents and prospective parents

with disabilities

- [The National Research Center for Parents with Disabilities](#), Heller School for Social Policy and Management, Brandeis University, USA: Research and resources to improve the lives of parents with disabilities and their families

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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.