



TAILORING PREGNANCY CARE FOR PEOPLE WITH DISABILITIES



Resource for Healthcare Providers

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, healthcare providers frequently report not having the resources and training they need to support people with disabilities in pregnancy and postpartum.⁴

This resource describes evidence about the pregnancy, birth, and postpartum health outcomes and healthcare experiences of people with disabilities. It also provides advice for healthcare providers on tailoring care to the needs of disabled people.

Tailoring care for people with disabilities 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, tailored preconception and pregnancy care.

Tailoring care for people with disabilities 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 on the right***)

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}

that might be prevented through tailored pregnancy care.⁶⁻¹¹

- Newborn complications like preterm birth¹¹

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

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

 Facilitators	Barriers
<p>Advocacy by the disabled person and their family, friends, and providers¹²</p> <p>Adapted strategies and hands-on help (e.g., with infant feeding, newborn care)</p> <p>Help at home (e.g., midwifery and public health nurse visits)</p> <p>Holistic care (e.g., integrated medical, social, human services)</p> <p>Financial, housing, mental health supports</p>	<p>Ableism, including negative provider attitudes toward disability and parenting¹²</p> <p>Physically inaccessible healthcare spaces</p> <p>Barriers to communication (e.g., lack of ASL interpreters, accessible documents)¹³</p> <p>Lack of coordination across providers¹²</p> <p>Lack of information about disability and pregnancy</p> <p>Social determinants of health like poverty</p>

Barriers to and facilitators of care show areas of care that could be tailored to be more inclusive and accessible.



Physicians, midwives, and nurses have an important role to play in tailoring pregnancy care to the needs of people with disabilities. The following

recommendations for care are accompanied by quotes from people with disabilities and healthcare providers in Ontario.

RECOMMENDATION 1: Provide coordinated multidisciplinary care

- ✓ **Engage a multidisciplinary medical team** (e.g., pregnancy and disability specialists) that includes someone in a coordination role who can assist with communication.
- ✓ **Work with the disability sector** to engage disability-related supports (e.g., accessible transportation services, occupational therapy and peer and parenting supports).
- ✓ **Work with social services** (e.g., financial aid, housing services) to address social determinants of health (e.g., poverty) that disproportionately affect disabled people.
- ✓ **Make a plan** that is put on file and is accessible to everyone on the care team.

“I think we need to sort of have more holistic care. 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

“[Healthcare 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].” –disabled parent

RECOMMENDATION 2: Organize required disability accommodations

- ✓ **Address communication barriers**, especially for patients with sensory and intellectual disabilities (e.g., by using ASL interpreters, accessible documents and visuals).

“Stop talking doctor terms. ...because not everyone’s going to understand what ‘hemorrhaging’ is.” – parent with a disability

- ✓ **Address physical barriers**, particularly for patients with mobility-related disabilities (e.g., by having accessible examination tables, weighing scales and washrooms).

“Just 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?” – disabled parent

RECOMMENDATION 3: Promote delivery of respectful maternity care

- ✓ **Actively ask patients** what they need, listen and involve them in decision-making, recognizing that disabled people are experts in their own lives and what works for them.
- ✓ **Engage in empathy training** and build trusting relationships with patients, recognizing that many disabled people have had negative healthcare experiences.
- ✓ **Engage in disability training** and seek out resources to understand how a disability might impact pregnancy and vice versa.

“I think it’s so important to look for like what people are able to do, as opposed to what they’re lacking and to try to really explore their support systems and then try to be creative in what can work.” –nurse

“I declined a public health nurse visit because of my disability and fear of lack of understanding from their part. ... I don’t think I would’ve disclosed any problems to them, because I don’t know who they are. They don’t know who I am.” –disabled parent

References

1. Burlock A. [Women with Disabilities](#). Women in Canada: A Gender-based Statistical Report. Catalogue no. 89-503-X. Ottawa: Statistics Canada; 2017.
2. United Nations. [Convention on the Rights of Persons with Disabilities](#). United Nations; 2016.
3. Brown HK, Chen S, Guttman A, et al. [Rates of recognized pregnancy in women with disabilities in Ontario, Canada](#). *Am J Obstet Gynecol* 2020;222(2):189-92.
4. Tarasoff LA. [“We don’t know. We’ve never had anybody like you before”: Barriers to perinatal care for women with physical disabilities](#). *Disabil Health J* 2017 Jul;10(3):426-33.
5. Tarasoff LA, Lunsky Y, Chen S, et al. [Preconception health characteristics of women with disabilities in Ontario: A population-based, cross-sectional study](#). *J Women’s Health* 2020;29(12):1564-75.

6. Brown HK, Chen S, Vigod SN, et al. [A population-based analysis of postpartum acute care use among women with disabilities](#). *Am J Obstet Gynecol MFM* 2022;4(3):100607.
7. Tarasoff LA, Salaeva D, Ravindran S, Malik H, Brown HK. [Maternal disability and risk for pregnancy, delivery, and postpartum complications: A systematic review and meta-analysis](#). *Am J Obstet Gynecol* 2020;222(1):27-40.
8. Brown HK, Ray J, Chen S, et al. [Association of pre-existing disability with severe maternal morbidity or maternal mortality in Ontario, Canada](#). *JAMA Netw Open* 2021;4(2):e2034993.
9. Brown HK, Vigod SN, Fung K, et al. [Perinatal mental illness among women with disabilities: A population-based cohort study](#). *Soc Psychiatry Psychiatr Epidemiol* 2022; in press.
10. Brown HK, Saunders N, Chen S, et al. Disability and interpersonal violence in the perinatal period. *Obstet Gynecol* 2022; in press.
11. Brown HK, Chen S, Guttman A, et al. [Neonatal outcomes of mothers with a disability](#). *Pediatrics* 2022;e2021055318.
12. Saeed G, Brown HK, Lunskey Y, et al. [Barriers to and facilitators of effective communication in perinatal care: A qualitative study of the experiences of birthing people with sensory, intellectual, and/or developmental disabilities](#). *BMC Pregnancy Childbirth* 2022;22(1):364.
13. Khan M, Brown HK, Lunskey Y et al. [A socio-ecological approach to understanding the perinatal care experiences of people with intellectual and/or developmental disabilities in Ontario, Canada](#). *Womens Health Issues* 2021;31(6):550-59.

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.

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 share with parents**
- [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
 - [Having a Baby](#), Books Beyond Words, London, UK: Plain language 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
 - [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

Citation: Brown HK, Tarasoff LA, Welsh K, Proulx L, and Lunskey Y, on behalf of the Disability and Pregnancy Study and in collaboration with the Provincial Council for Maternal and Child Health. [Tailoring Pregnancy Care for People with Disabilities: Resource for Healthcare Providers.](#)

This resource was created by researchers at the University of Toronto and the Centre for Addiction and Mental Health, based on findings from a National Institutes of Health-funded study on the perinatal health and healthcare experiences of women with disabilities in Ontario, Canada (Award No. 5R01HD092326). The study included health data on over 1.8 million births in Ontario, as well as interviews with 62 women with disabilities, service-providers, and administrators. The study advisory committee, which includes women and parents with disabilities, provided feedback on this resource.

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