

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 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."

"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

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

- 1. Brown HK, Chen S, Guttmann A, et al. <u>Rates of recognized pregnancy in women with disabilities in Ontario, Canada</u>. *Am J Obstet Gynecol* 2020;222(2):189-92.
- 2. Saeed G, Brown HK, Lunsky Y, et al. <u>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.</u>
- 3. Khan M, Brown HK, Lunsky Y et al. <u>A socio-ecological approach to understanding the perinatal care experiences of people with intellectual and/or developmental disabilities in Ontario, Canada</u>. *Womens Health Issues* 2021;31(6):550-59.
- 4. Brown HK, Chen S, Vigod SN, et al. <u>A population-based analysis of postpartum acute care</u> use among women with disabilities. *Am J Obstet Gynecol MFM* 2022;4(3):100607.
- 5. Tarasoff LA, Salaeva D, Ravindran S, Malik H, Brown HK. <u>Maternal disability and risk for pregnancy, delivery, and postpartum complications: A systematic review and meta-analysis.</u> *Am J Obstet Gynecol* 2020;222(1):27-40.
- 6. Brown HK, Ray J, Chen S, et al. <u>Association of pre-existing disability with severe maternal morbidity or maternal mortality in Ontario, Canada</u>. *JAMA Netw Open* 2021;4(2):e2034993.

- 7. Brown HK, Vigod SN, Fung K, et al. <u>Perinatal mental illness among women with disabilities:</u>
 <u>A population-based cohort study</u>. *Soc Psychiatry Psychiatr Epidemiol* 2022; in press.
- 8. Brown HK, Saunders N, Chen S, et al. Disability and interpersonal violence in the perinatal period. *Obstet Gynecol* 2022; in press.
- 9. Brown HK, Chen S, Guttmann A, et al. <u>Neonatal outcomes of mothers with a disability</u>. *Pediatrics* 2022;e2021055318.

Resources

Resources • for pregnancy

- <u>Childbirth Preparation and Support Tool</u>, Health Nexus, ON: A tool for patients with fetal alcohol spectrum disorder and related disabilities to communicate support needs in pregnancy
- <u>Having a Baby</u>, 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 out comes of parents with disabilities

Resources • for early parenting

- <u>Disabled Parents Network</u>, 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
- <u>Parenting with a Disability Network</u>, 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

Citation: Brown HK, Tarasoff LA, Welsh K, Proulx L, and Lunsky Y, on behalf of the Disability and Pregnancy Study and in collaboration with the Provincial Council for Maternal and Child Health. Pregnancy and Postpartum Care: Resource for Parents with Disabilities.

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.



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

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

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 mobilityrelated 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

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- 1. Burlock A. <u>Women with Disabilities</u>. 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.
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Resources

Clinical guidelines

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

Provider training resources

- <u>Caring for Pregnant and New Parents with Physical Disabilities</u>, 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 •

- <u>Childbirth Preparation and Support Tool</u>, 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
- <u>Having a Baby</u>, 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
- <u>Mamas Facing Forward</u>: Private Facebook group designed to help women with chronic illness move forward with motherhood
- <u>Parenting with a Disability Network</u>, 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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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 on the right*) 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 disabilityrelated 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,

"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

- 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).

"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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- Sullivan WF, Diepstra H, Heng J, et al. <u>Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. Can Fam Physician 2018;64(4):254-79.</u>

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

<u>Caring for Pregnant and New Parents with Physical Disabilities</u>, 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

- <u>Childbirth Preparation and Support Tool</u>, 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
- <u>Parenting with a Disability Network</u>, 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 Lunsky Y, on behalf of the Disability and Pregnancy Study and in collaboration with the Provincial Council for Maternal and Child Health. <u>Improving Accessibility of Pregnancy Care for People with Disabilities: Resource for Healthcare Administrators.</u>

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.