

# Equity and Inclusion in Pregnancy Care:

Report on the Pregnancy Outcomes  
and Health Care Experiences of People  
with Disabilities in Ontario

## EXECUTIVE SUMMARY



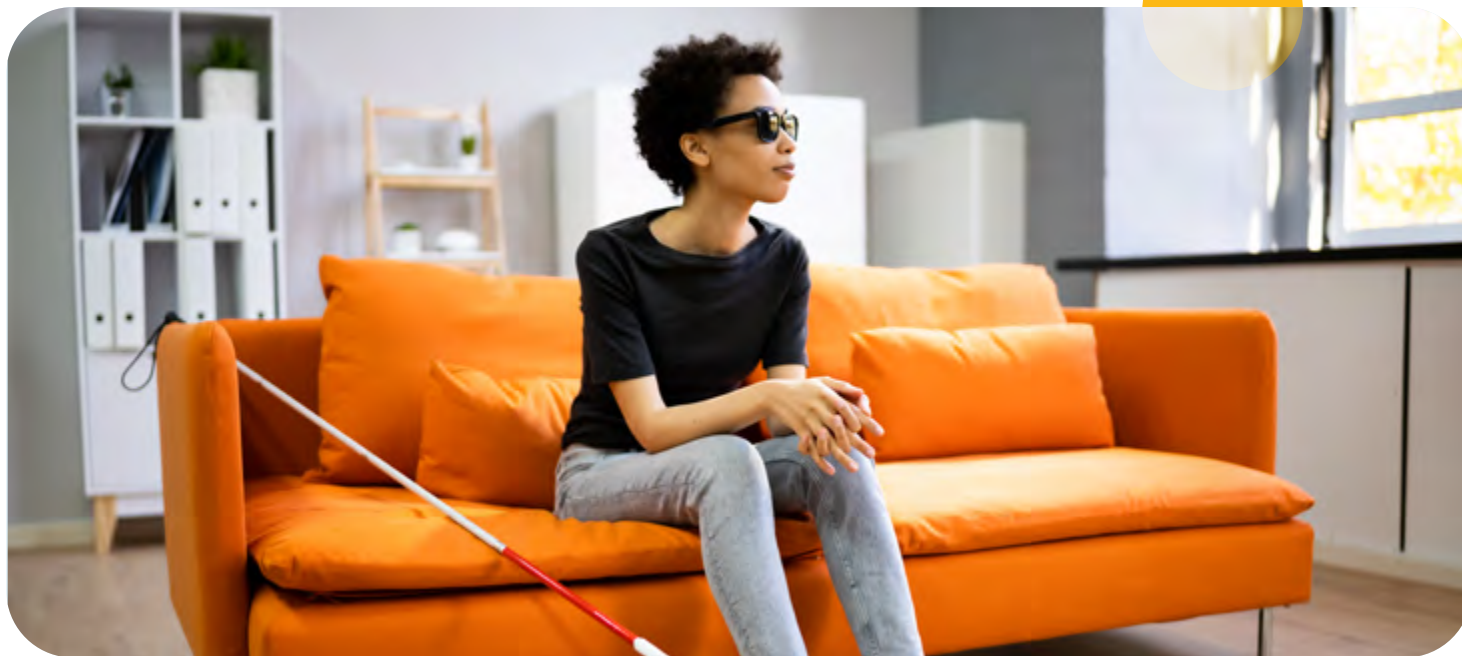




## Executive Summary

# The Issue

**High-quality pregnancy care is defined by the provision of timely, accessible, respectful, family-centred and evidence-based care across the pregnancy period, from preconception to postpartum and newborn care. Yet, despite policy and clinical efforts, equity and inclusion in high-quality pregnancy care is not guaranteed for all families in Canada. One group consistently reporting unmet pregnancy care needs is people with disabilities.<sup>1</sup>**



<sup>1</sup> The language used to refer to disability is critical to ensure individuals' dignity and respect their preferences. We use person-first and identity-first language to acknowledge the diverse ways in which people prefer to speak about their disability.

## THE STUDY

“Equity and Inclusion in Pregnancy Care: Report on the Pregnancy Outcomes and Health Care Experiences of People with Disabilities in Ontario” describes the results of the Disability and Pregnancy Study. Funded by the US National Institutes of Health, the Disability and Pregnancy Study was a landmark study that used parallel evidence from health administrative data on nearly 150,000 births to people with disabilities and qualitative interview data from key informants to examine the preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes and health care experiences of people with physical, sensory, developmental and multiple disabilities in Ontario, Canada. This initiative was led by a multidisciplinary team with expertise in epidemiology, qualitative methods, maternal-fetal medicine, paediatrics, psychology, psychiatry and disability, including lived experience of disability, and was further informed by an Advisory Committee of people with disabilities, service-providers and decision-makers. The Disability and Pregnancy Study gathered evidence supporting the need for a more equitable and inclusive approach to pregnancy care that addresses the needs of disabled people.

### The goals of this Report are to:

1. Describe the preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes of people with disabilities in Ontario;
2. Highlight the pregnancy care experiences of people with disabilities, from the perspectives of people with disabilities, service-providers and decision-makers; and
3. Provide policy and clinical recommendations to improve pregnancy care for people with disabilities.



## Executive Summary

# KEY FINDINGS

## PRECONCEPTION HEALTH AND PREGNANCY RATES

- Sixteen percent of 15 to 49-year-old females<sup>2</sup> in Ontario had a physical, sensory or developmental disability, or multiple disabilities.
- Most females in Ontario experienced adequate preconception health. Even so, there were important disparities between those with and without a disability related to the social determinants of health, physical health, mental health, medication use and experiences of interpersonal violence.
- Females with disabilities had lower pregnancy rates than those without a disability.
- Overall, one in eight pregnancies were to females with a disability.

## PREGNANCY OUTCOMES

- Most females in Ontario first received prenatal care within the first trimester and received the recommended number of prenatal care visits. However, females with developmental disabilities tended to have access to prenatal care later and received fewer prenatal care visits than those without disabilities.
- Notably, females with disabilities were more likely than those without a disability to have an emergency department visit or hospital admission during pregnancy.
- Females with disabilities were also more likely to experience rare but serious physical health complications, as well as mental health conditions and interpersonal violence during pregnancy.

## LABOUR AND BIRTH OUTCOMES

- Labour induction and Caesarean delivery were more common in females with multiple disabilities than those without a disability.
- Newborns of females with developmental and multiple disabilities were more likely than those of females without a disability to be born preterm, and newborns of females with developmental disabilities were also more likely to be small for their gestational age.
- Females with developmental and multiple disabilities and their newborns had longer birth hospital stays than those without a disability.
- Breastfeeding initiation and support during the birth hospital stay were generally high in all groups, but there were important disparities in these indicators for females with developmental and multiple disabilities.

<sup>2</sup> Only information on biological sex, based on individuals' provincial health insurance cards, is available in Ontario health administrative data. This Report uses the language of "females" to describe findings from health administrative data, and gender-inclusive language to describe policy and clinical recommendations.







## Executive Summary

# KEY FINDINGS

## POSTPARTUM AND NEWBORN OUTCOMES

- Most females in Ontario received a standard postpartum outpatient visit at six weeks after childbirth.
- However, females with disabilities were more likely than those without a disability to have an emergency department visit or hospital admission in the postpartum period.
- Females with disabilities were also more likely to experience rare but serious physical health complications, as well as mental health conditions and interpersonal violence in the postpartum period.
- Though rare overall, rates of neonatal intensive care unit admission were higher in newborns of females with developmental and multiple disabilities than in newborns of those without disabilities.

## PREGNANCY CARE EXPERIENCES

- Interviews with people with disabilities, their service-providers and decision-makers revealed challenges in, and facilitators of, pregnancy care for people with disabilities in Ontario.
- People with disabilities identified many challenges in pregnancy care, including physical and communication accessibility barriers in health care settings; fragmented care across services; poor service-provider knowledge about disability; lack of respect from service-providers; ableist service-provider assumptions about pregnancy and parenting; and inadequate information and decision-making autonomy.
- Facilitators of high-quality pregnancy care identified by people with disabilities included advocacy from individual service-providers, family and friends, and self-advocacy; flexible care strategies, including care delivered at home; and adapted and hands-on help, particularly related to breastfeeding and newborn care.
- Service-providers and decision-makers also identified many challenges in pregnancy care for people with disabilities, including inflexible fee-for-service remuneration policies; inadequate service-provider education and training about disability; and limited resources to support their delivery of care.
- Facilitators of high-quality pregnancy care for people with disabilities identified by service-providers and decision-makers included policy changes to improve access; service-provider advocacy for their patients concerning existing barriers to care; holistic care that addresses both medical and social needs; and tailored care that meets patients' unique needs.





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# RECOMMENDATIONS

The Disability and Pregnancy Study identified important preconception, pregnancy, labour and birth, and postpartum and newborn health disparities in people with versus without disabilities in Ontario, and significant gaps in the quality of their pregnancy care. Together, these findings signal the need to improve equity and inclusion in pregnancy care for people with disabilities, through the following actions:

1. **Modify health care system structures and processes;**
2. **Increase service-provider knowledge and resources;**
3. **Develop accessible patient supports; and**
4. **Strengthen the scientific evidence base.**

## MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

The findings of the Disability and Pregnancy Study identified a pregnancy care system that can be fragmented and inaccessible for many people with disabilities. There is a need to modify the structures and processes of pregnancy care so that care is responsive to the needs of all people with disabilities.

### We recommend that:

- All pregnancy care spaces, resources and related technology devices should be accessible for the mobility, communication, sensory and learning needs of disabled people.
- Pregnancy care guidelines and physician remuneration policies should be adapted to allow longer pregnancy care visits for people with disabilities, and with greater frequency during critical periods, as needed.
- Person-centred multidisciplinary pregnancy care should be available to people with disabilities, as needed, with systems in place to coordinate such care.
- Pregnancy care should be affirming of people with disabilities.
- Broader health care services for people with disabilities should take a life course perspective that considers their reproductive health needs, including through enhanced preconception care.
- People with disabilities should be engaged in health care system changes through ongoing consultation.







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# RECOMMENDATIONS

## INCREASE HEALTH CARE PROVIDER KNOWLEDGE AND RESOURCES

System-level changes require service-providers who are equipped to deliver high-quality pregnancy care to people with disabilities. However, inadequate service-provider education and training was a significant gap identified in the Disability and Pregnancy Study.

### We recommend that:

- All health and social service-providers should receive education and training about disability, disability-related accessibility needs and pregnancy care needs.
- Service-provider education should address ableism and delivery of respectful pregnancy care, including training on the rights of disabled people to dignity, information and bodily and decision-making autonomy.
- Clinical guidelines and other resources that address diverse disabilities and all pregnancy care stages should be developed to support service-providers' delivery of pregnancy care to people with disabilities.
- People with disabilities should be actively involved in the creation of service-provider resources and the delivery of training.

## DEVELOP ACCESSIBLE PATIENT SUPPORTS

Actions at the system and service-provider levels should, ultimately, be aimed at improving direct patient supports to reduce health disparities.

### We recommend that:

- Evidence-based resources related to disability and pregnancy, including resources for people planning a pregnancy and who are pregnant or postpartum, should be developed to meet patient-identified needs for information.
- Routine pregnancy-related education, including prenatal, breastfeeding and newborn care classes, should be accessible to people with disabilities and address their needs.
- Community organizations should be supported to provide resources to people with disabilities planning a pregnancy, and in pregnancy and postpartum.
- Patient supports should be developed in direct consultation with people with disabilities.

## STRENGTHEN THE SCIENTIFIC EVIDENCE BASE

Underlying these efforts is a need to continue to strengthen the scientific evidence base to inform pregnancy care delivery, facilitate evaluation of new initiatives and ultimately hold health care systems accountable for the quality of pregnancy care delivered to people with disabilities.

### We recommend that:

- Disability indicators should be routinely included in health administrative data so that pregnancy-related health outcomes for people with disabilities can be monitored at a population level.
- Patient-related outcome and experience measures should be developed in consultation with people with disabilities and used to ensure that efforts to improve pregnancy care meet their needs.
- A national funding strategy should be developed that supports research on disability and health equity, including research on pregnancy-related health disparities in people with disabilities.





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# Conclusion

Data from the Disability and Pregnancy Study show that many people with disabilities in Ontario experience pregnancy. People with disabilities have a right to high-quality pregnancy care that is timely, accessible, respectful, family-centred and evidence-based. However, our health administrative data showed consistent health disparities for people with disabilities at every stage of the pregnancy journey, and our qualitative interview data identified a pregnancy care system that is inaccessible to many people with disabilities. These findings show that it is time for action, where data can come together with policy and clinical practice leaders as well as people with disabilities, to ensure that pregnancy care is inclusive of and equitable for all people with disabilities.







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