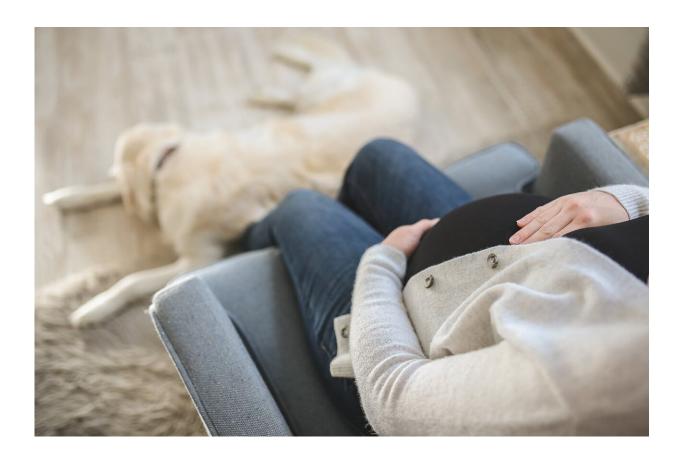


One in eight pregnant people have a disability, but report shows gaps exist in the provision of accessible care

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People with disabilities account for 13% of all pregnancies in Ontario, but a new report shows that this population was more likely to



experience pregnancy complications such as emergency department visits, hospitalizations, and preterm birth.

Researchers from ICES, the University of Toronto Scarborough, and the Centre for Addiction and Mental Health (CAMH) have released a landmark report detailing findings from one of the largest studies to date on disability and pregnancy.

The Disability and Pregnancy Study used health care data on nearly 150,000 births to people with disabilities and interview data to examine the preconception, pregnancy, labor and birth, and postpartum and newborn health outcomes and health care experiences of people with physical, sensory, developmental and multiple disabilities in Ontario, Canada.

"In our in-depth interviews with over sixty people with disabilities, service-providers, and policymakers, we certainly found examples of positive pregnancy care experiences," says lead author Hilary Brown, Adjunct Scientist at ICES and Associate Professor in the Department of Health and Society at the University of Toronto Scarborough. "But we also heard just how inaccessible pregnancy care can be for people with disabilities."

Pregnancy care experiences

Interviews with people with disabilities revealed challenges that many face in the pregnancy care system, including barriers to accessibility, fragmented care, poor health care provider knowledge about disability, and disrespectful and ableist assumptions.

One participant shared, "I met [the doctor] for the first time when I went in to confirm the pregnancy. He was like 'What brings you here?' 'Oh, I just found out that I'm pregnant.' And he looked down at my wheelchair



for a second, and he looked at me, and he said, 'Are you here to get an abortion?' And I was absolutely stunned. 'No, we've been trying for a year and we're really excited,' and that was a really weird and terrible experience."

Other participants reported difficulties in using equipment such as exam tables, communication challenges, judgment from <u>health care providers</u>, and a lack of coordinated care from <u>social services</u> and the health system.

Service-providers and policymakers shared their thoughts on structural barriers to accessible pregnancy care, including a lack of time during appointments to address patients' needs—often cited as a consequence of Ontario's fee-for-service remuneration system. Other barriers included insufficient funding for accessible equipment, inadequate disability-related training, and few clinical guidelines to support the delivery of care.

"There is a lot of evidence showing that higher rates of mental health concerns and mental health service utilization are seen in disabled people than non-disabled people accessing pregnancy care. Inaccessible care has significant impacts on mental health during pregnancy as well as postpartum," says Yona Lunsky, report co-lead, Adjunct Scientist at ICES and Scientific Director of the Azrieli Adult Neurodevelopmental Centre at CAMH.

"We learned from our study that the experience can be isolating, frightening, and challenging when supports are not in place. When we think about how to make our pregnancy care as good as possible, we need a mental health lens to fully support people."

Key data findings:



- Overall, 16.3% of 15 to 49-year-old females in Ontario had a recorded disability. The most common disabilities were <u>physical disabilities</u> (11%), followed by sensory (4%), multiple (1%) and developmental (0.4%) disabilities.
- Emergency department visits for obstetric reasons in pregnancy were more common in females with physical (20%), developmental (27%), and multiple disabilities (25%) than in those without a disability (15%). Hospital admissions and mental health conditions were also more common for these groups.
- Newborns of females with developmental (9%) and multiple (10%) disabilities were more likely than newborns of females without a disability (6%) to be born premature (less than 37 weeks' gestation).

Time for change

"The time to act is now," says Brown. "We need to put a greater focus on accessibility, and this includes modifying the structures and processes of pregnancy care, so that we're meeting the full range of needs of people with disabilities."

The authors recommend that all pregnancy care spaces should be adapted for the mobility, communication, sensory and learning needs of people with disabilities. Further, health care provider remuneration policies should be flexible to allow for longer and more frequent appointments.

Health care providers themselves need better training related to disability and accessibility. A <u>holistic approach</u> needs to attend to both physical and mental health needs.

"Most importantly, we need to be offering person-centered care," Brown adds. "This means we need to listen to and affirm what people with



disabilities are telling us they need—without this, we risk making changes that cause further harm."

The report, "Equity and Inclusion in Pregnancy Care: Report on the Pregnancy Outcomes and Health Care Experiences of People with Disabilities in Ontario," was published by ICES.

More information: Report: Equity and Inclusion in Pregnancy Care: Report on the Pregnancy Outcomes and Health Care Experiences of People with Disabilities in Ontario.

Provided by ICES

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