

Health care system often fails people with disabilities who give birth in Ontario, finds research

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The day Alyssa told her doctor she was pregnant, the doctor looked at her wheelchair and asked if she had come to terminate the pregnancy.

Alyssa had been trying to get pregnant for a year.

Alyssa, who uses a pseudonym for privacy, is one of 31 people interviewed for two new studies on the health care experiences of people with [disabilities](#) who gave birth in Ontario.

One study, published in the *Journal of Obstetric, Gynecologic & Neonatal Nursing*, looked at care during pregnancy, while the other, published in the *Journal of Advanced Nursing*, asked people with different disabilities about multiple forms of postpartum care. Their stories illustrate a [health care system](#) entrenched in ableism, from infrastructure to interactions.

"Nearly one in eight pregnancies in Ontario are to someone with a disability, so inadequate care is an issue that affects a large proportion of the population," says Hilary Brown, an assistant professor in the department of health and society at U of T Scarborough and co-author of the study.

Four themes emerged in participants' stories during pregnancy: their care needs were unmet; there was a lack of coordination between health care providers; they faced frequent ableism; and advocacy played a key role in getting the care they needed. The postpartum period was characterized by needs remaining unmet, health care providers lacking knowledge of disabilities, and a fear of judgment, discrimination and intrusive surveillance.

Study participants had given birth in the last five years and have a physical, sensory or intellectual or developmental disability, or multiple disabilities. Participants with all disability types noted a gap in communication between different care providers, leaving many responsible for coordinating their care during pregnancy.

There was also a steep drop-off in services after giving birth, when

attention largely shifted to newborn care despite parents still dealing with injuries such as tearing and hemorrhaging.

Throughout their care, disability-specific education, equipment and providers were noted as difficult to find and afford. Facilities such as bathrooms and neonatal intensive care wings couldn't accommodate mobility devices, and one participant had to be weighed by having their husband pick them up and step on the scale.

Another parent who was deaf was not provided an American Sign Language interpreter at their pediatrician appointments—a common occurrence for those with sensory disabilities—and believed the lack of communication contributed to the doctor's eventual decision to call child protective services.

Both during and after pregnancy, participants recounted experiences with providers that had negative attitudes toward disabilities. A common assumption observed during pregnancy was that participants were unfit to be parents due to their disabilities, and some later hesitated to seek [mental health care](#) because they felt they had to prove themselves as parents. Others reported [social workers](#) were judgmental and intrusive, and participants from all disability groups had a strong desire to avoid child protective services as much as possible.

"Negative attitudes and not having knowledge about disability unfairly burdens patients and their [family members](#) with having to advocate to have their needs met," says Lesley Tarasoff, a postdoctoral research fellow in the department of health and society at U of T Scarborough, who co-authored the study and conducted the interviews.

Participants reported that positive relationships with providers who were knowledgeable about disabilities was helpful, and the study calls for proactive, multidisciplinary care for people with disabilities. For

instance, several participants began breastfeeding in ways that accommodated their disability but were told by nurses and lactation consultants that they were doing it wrong.

"We need to be integrating disability into training early for [medical students](#) and adding continuing education on disability for providers currently practicing," says Tarasoff. "And we need to be including people with disabilities in developing the curriculum and delivering it."

Brown and Tarasoff recently collaborated with the Provincial Council for Maternal and Child Health to turn their data into action. They created [tip sheets](#) to help people with disabilities navigate childbearing, and also to help [health care providers](#) and administrators address ableism and provide respectful, accessible care. Each recommendation is listed alongside quotes from the studies' participants, and the researchers hope this is the first of many resources they'll create.

The studies are part of a larger investigation into the health care experiences of people in Ontario with disabilities during the perinatal period—the time from [pregnancy](#) to one year after giving birth. Brown says the investigation's findings are reinforcing that the [health](#) care system needs transformative change.

"It's important to acknowledge that a lot of these disparities are driven by social and structural factors," Brown says. "These are inequities that need to be corrected."

More information: Lesley A. Tarasoff et al, Prenatal Care Experiences of Childbearing People With Disabilities in Ontario, Canada, *Journal of Obstetric, Gynecologic & Neonatal Nursing* (2023). [DOI: 10.1016/j.jogn.2023.02.001](https://doi.org/10.1016/j.jogn.2023.02.001)

Lesley A. Tarasoff et al, Unmet needs, limited access: A qualitative

study of postpartum health care experiences of people with disabilities, *Journal of Advanced Nursing* (2023). [DOI: 10.1111/jan.15642](https://doi.org/10.1111/jan.15642)

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