



Reporting from out East: The perinatal health care experiences of people with physical, sensory, and intellectual/developmental disabilities in Ontario

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Healthy Mothers And Healthy Babies Conference - February 22, 2020

ACKNOWLEDGEMENTS

- This study was funded by the Eunice Kennedy Shriver National Institute of Child Health & Human Development of the **National Institutes of Health** (Award No. 5R01HD092326-02), awarded to Hilary Brown (University of Toronto Scarborough) and Yona Lunsky (Centre for Addition and Mental Health).
- This study was supported by **ICES**, which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The opinions, results, and conclusions reported are those of the authors and are independent from the funding sources. No endorsement by ICES or the MOHLTC is intended or should be inferred. Parts of this material are based on data and information compiled and provided by the Canadian Institute for Health Information (CIHI). However, the analyses, conclusions, opinions, and statements expressed herein are those of the author, and not necessarily those of CIHI.
- This work is conducted by an international team of researchers in partnership with a dedicated **Advisory Committee** comprised of individuals with lived experience, health and social service providers, and policymakers.



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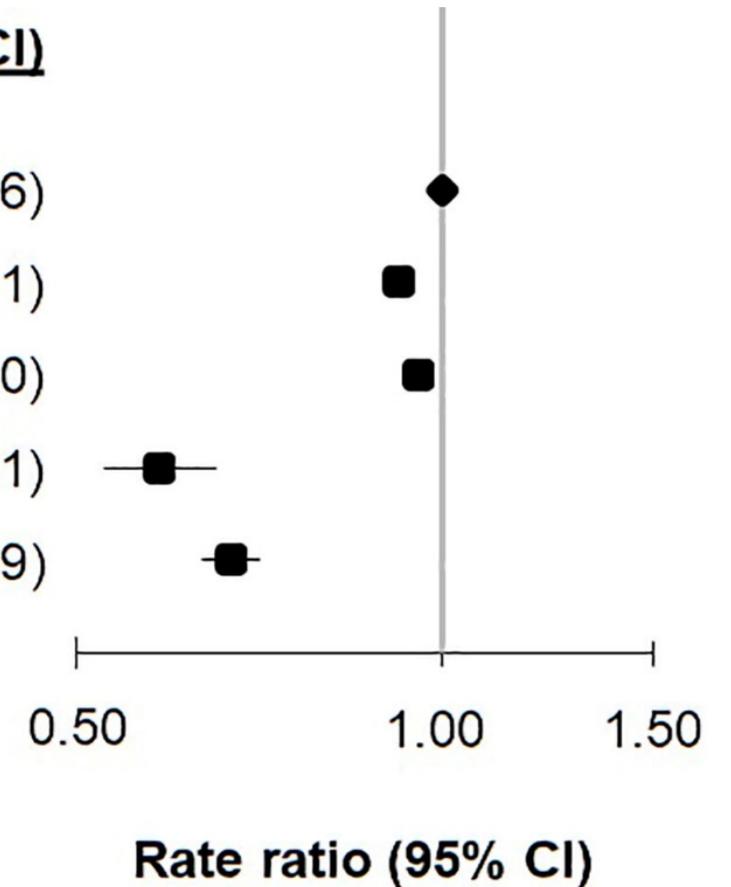
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BACKGROUND

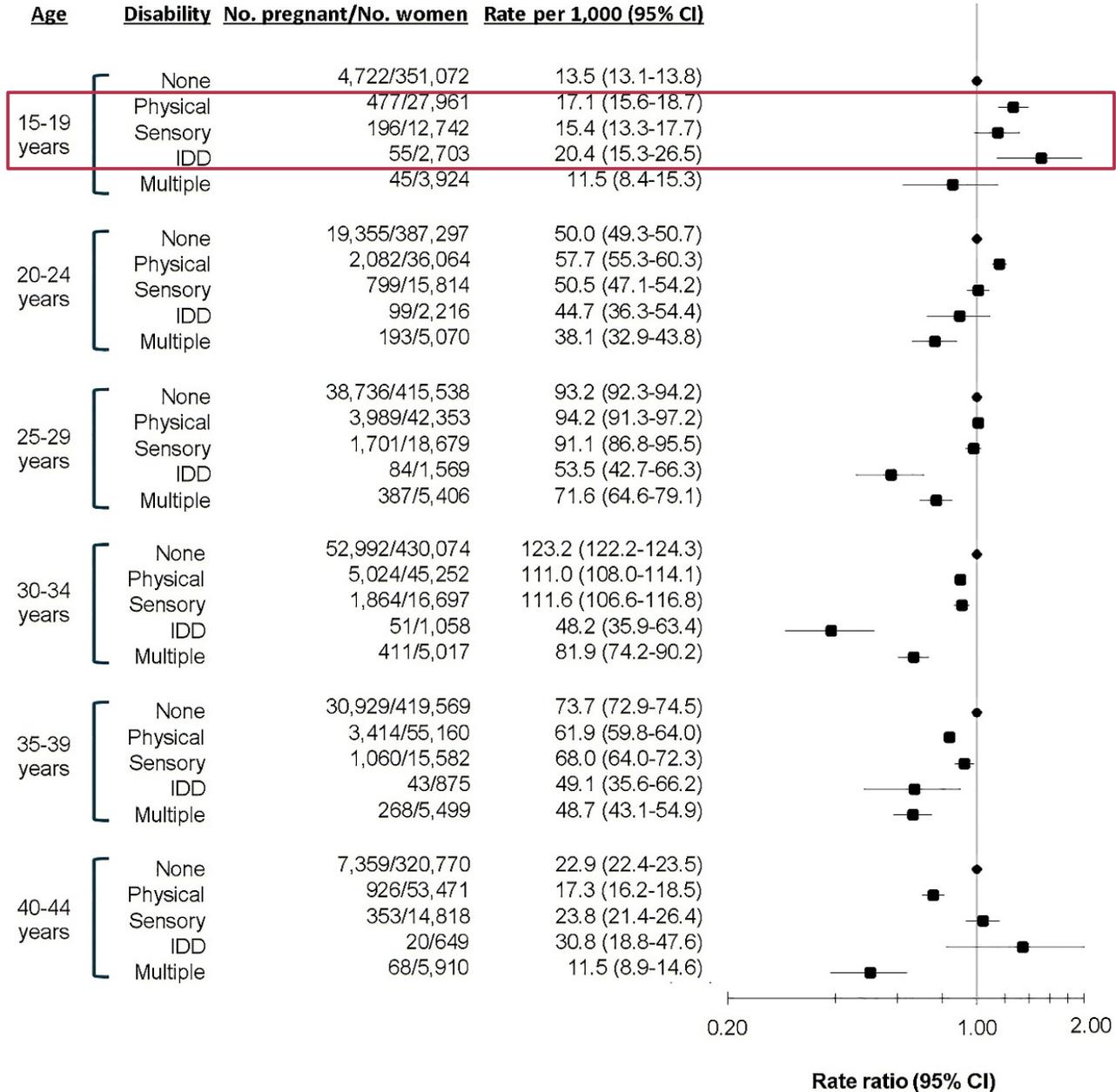
- About 12% of reproductive-aged women have a disability (Statistics Canada, 2016)
- In 2005, the World Health Organization called for **better reproductive health care** for women with disabilities
- Yet, women with disabilities **continue to be underserved** in reproductive health care settings

RATES OF RECOGNIZED PREGNANCY AMONG WOMEN WITH AND WITHOUT DISABILITIES AGED 15 TO 44 IN ONTARIO, 2017/18

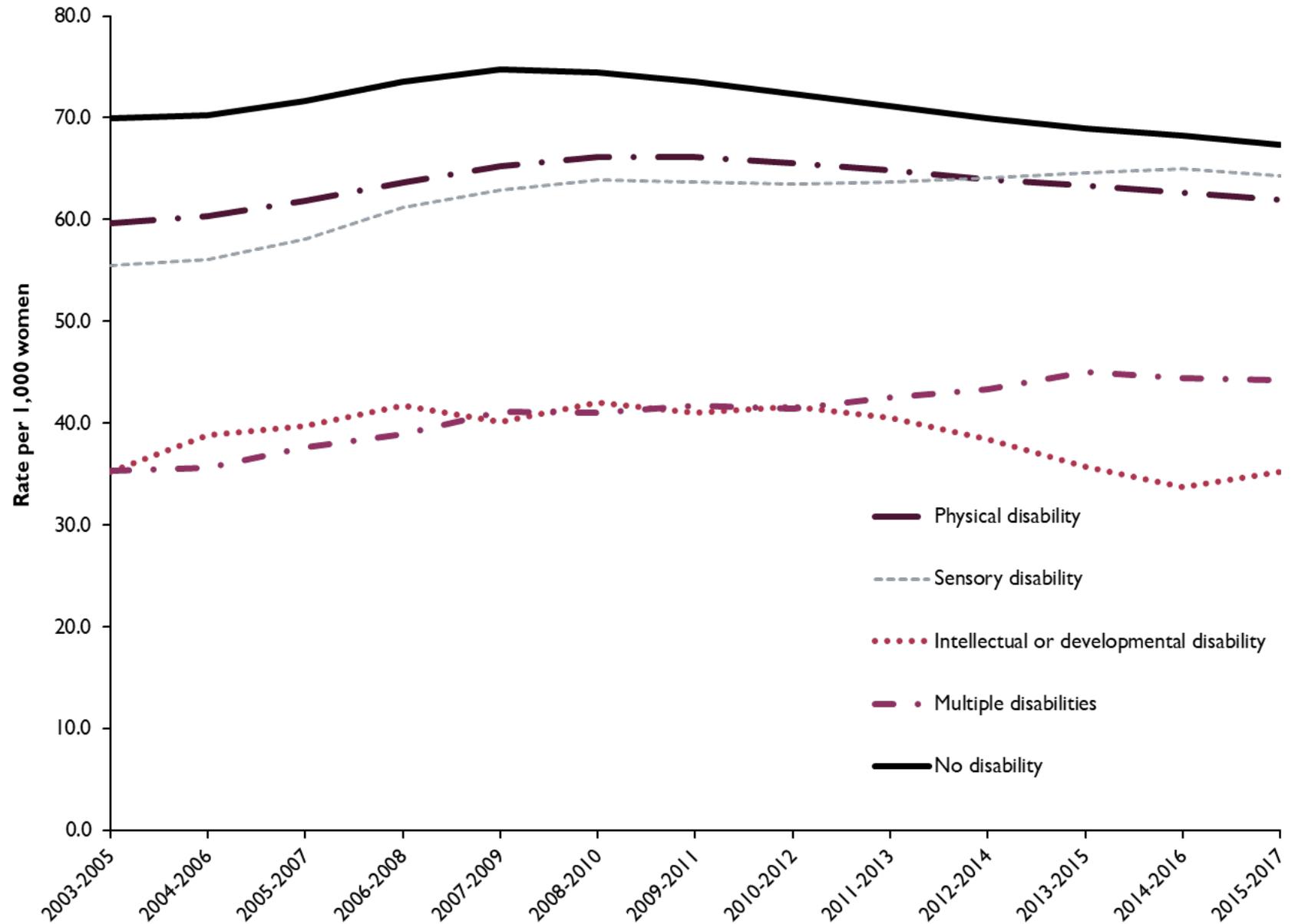
<u>Disability</u>	<u>No. pregnant/No. women</u>	<u>Rate per 1,000 (95% CI)</u>
None	154,093/2,324,320	66.3 (66.0-66.6)
Physical	15,912/260,261	61.1 (60.2-62.1)
Sensory	5,973/94,332	63.3 (61.7-65.0)
IDD	352/9,070	38.8 (34.9-43.1)
Multiple	1,372/30,826	44.5 (42.2-46.9)



AGE-SPECIFIC PREGNANCY RATES (ONTARIO)



TIME TRENDS, 2003/04 TO 2017/18 (ONTARIO)



PERINATAL OUTCOMES

- Analyses of Ontario health administrative data underway to determine pregnancy, delivery, and postpartum outcomes of women with disabilities in Ontario, compared to those without disabilities (as well as outcomes of their newborns and infants up to age 2)
- From research done elsewhere, mostly the US, we know that many women with disabilities are at increased risk of pregnancy, delivery, and postpartum complications (Tarasoff et al., 2020; Mitra et al., 2015)

OBJECTIVES

- To understand the perinatal health care experiences of women with physical, sensory, and intellectual/developmental disabilities in Ontario
- To identify similarities and differences in perinatal care experiences and needs based on disability type
- To identify ways to improve the perinatal health care experiences of women with disabilities

METHODS

- Recruitment
 - With the assistance of our advisory committee and peer researchers, we shared recruitment materials on social media and with over 100 organizations and groups that serve pregnant women, new parents, and/or people with disabilities across Ontario and Canada
- Inclusion criteria and purposive sampling
 - People* with physical, sensory, and/or intellectual/developmental disabilities
 - Have given birth in the last five years
 - Living in Ontario and age 18 or older

METHODS

- Data collection
 - 1-2 hour long, semi-structured interviews
 - Interviews focused on participants' care experiences during pregnancy, delivery, and the early postpartum period, including what services and supports they accessed, and what they liked or did not like about these services.
- Analysis
 - Thematic content analysis (just beginning)

PARTICIPANTS: PEOPLE WITH DISABILITIES

Disability	N=30
Physical	13
Sensory	
Deaf/hearing loss	5
Blind/vision loss	2
Intellectual/developmental (IDD)	6
Multiple	
Physical and IDD	2
Sensory and IDD	2

PARTICIPANT DEMOGRAPHICS

- **Age:** 3 participants were under the age of 25; 13 were aged 26-34; 14 were aged 35+
- **Gender Identity:** Most (n=28) identified as cisgender; 2 identified as trans/non-binary
- **Sexual Orientation:** Most (n=24) identified as heterosexual; 1 identified as lesbian, 2 as bisexual, 2 as queer, 1 as asexual
- **Relationship Status:** The majority (n=21) were married or in a common-law relationship
- **Racial/Ethnic Background:** Many (n=19) identified as White or Caucasian
- **Highest Level of Education Completed:** 14 had completed high school or less than high school
- **Child Welfare Involvement:** Several, notably those with IDD, reported current or previous involvement with child welfare/protection services
- **Other Disabilities and Health Concerns Reported:** Learning disability, ADHD, ODD, central auditory processing disorder, depression, anxiety, bipolar disorder, dissociative identity disorder, problematic substance use, diabetes, anorexia

EMERGING THEMES: ACROSS DISABILITY GROUPS

- (Fear of) disability stigma and being treated differently
- Lack of supports in the postpartum period

EMERGING THEMES: INTELLECTUAL/DEVELOPMENTAL DISABILITIES

- Not disclosing disability

*“I never told the doctors that I had a disability. [And do you remember why? Or it just didn’t come up?] [I] felt ashamed. Felt embarrassed. Didn’t want to admit to myself—well, I knew but I was still trying to hide it from myself too, at the same time, and **I didn’t want people looking at me different because I had a disability.** Because a lot of people, when you have a disability, they look at you a lot different”*

- Woman with IDD

EMERGING THEMES: SENSORY DISABILITIES

- The importance of taking time to explain things in detail (for those who are blind/have vision loss)
- Failure to provide an interpreter or providing inadequate “interpreters” (for those who are Deaf or have hearing loss)

“I was getting prepped for surgery [emergency c-section] and I had no interpreter. My husband was there and I kept looking, you know, is the interpreter going to be here? I didn't want to miss the baby being born, of course, that's the important thing right? When you're in labour, you want to see the baby. And I knew that my husband was going to be able to help in terms of the communication. So he's not an interpreter but I at least felt a little bit better by having him there. ... I wasn't feeling very good but my hands were tied on each side of my body. And actually, they should actually leave one, especially for deaf patients. They should leave one hand that's free because if not, I have no way of expressing myself. Like if your patient can't communicate.”

“Usually, it's cost-benefit to the hospitals but not necessarily a benefit to me because they are not exactly as well-versed or as well-trained as the CHS qualified interpreters. Sometimes, the hospitals want to save a little bit of money so they hire other types of interpreters but then when they get there, I'm like, ‘You're a signer, you're not an interpreter.’”



*“I could see my husband was crying and there was no interpreter around. And the nurse came back and she said something to my husband and he was listening and my husband was just in total shock. And he signed **‘dead’** [to me].”*

- Woman who is Deaf and has Usher syndrome. One of her twins was stillborn.

EMERGING THEMES: PHYSICAL DISABILITIES

- Being my own care coordinator

“I recall being the person having to do a lot of the calling, and appointment-making, and seeking out the supports... [I was] communicating back and forth to each specialist what I’m doing.” –Woman with rheumatoid arthritis

- Disability-related medical trauma

“She [obstetrician] didn’t even take—I don’t think she even took the paper [with my birth plan]. I said, ‘I have it here and these are the things that are important to me.’ And she just brushed it off” –Woman with multiple sclerosis

RECOMMENDATIONS TO IMPROVE CARE

- More frequent appointments, longer appointments
- Adapt resources and ways of delivering health information to meet the diverse learning and communication needs of people with disabilities; utilize technology
 - Clear, detailed descriptions
 - Images and videos instead of just text/written
 - Interpreters *must* be available
- Work proactively, together with people with disabilities (and their social supports/caregivers, as appropriate), to ensure that resources and supports – related to disability *and* other life circumstances – are in place before, during, and after pregnancy
- **Ask** people with disabilities what already works for them and what they need

RECOMMENDATIONS TO IMPROVE CARE

“Be more open. Listen to the client. It's not easy to have a disability nor is it easy to go in it and facing it alone. Also, give more resources. Help the client find places that can help them instead of saying, ‘Well, you have a disability, let's write down your faults.’ ...more support, someone to talk to and not so rushy-rushy.”

- Woman with IDD

THANK YOU!

- For more information about this study, contact lesley.tarasoff@utoronto.ca
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