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# PRECONCEPTION HEALTH, PREGNANCY OUTCOMES, AND CARE EXPERIENCES AMONG WOMEN WITH DISABILITIES IN ONTARIO

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BOUNDLESS

# DISCLOSURES

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- None of the presenters have potential conflicts of interest to declare.

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- 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.



# LEARNING OBJECTIVES

1. Summarize evidence on the preconception and pregnancy outcomes and care experiences of women with disabilities in Ontario
2. Discuss the importance of developing and implementing tailored resources for women with disabilities around the time of pregnancy
3. Identify the roles that public health professionals may play in promoting the health of women with disabilities in the preconception and perinatal periods

# CONTEXT



# DISABILITY IN REPRODUCTIVE-AGED WOMEN

- 12% of reproductive-aged women have a disability (Statistics Canada, 2018)
- In 2005, the World Health Organization called for better reproductive health care for women with disabilities (WHO, 2005)
- The 2006 United Nations Convention on the Rights of Persons with Disabilities protects reproductive rights (United Nations, 2006)
- Women with disabilities **continue to be underserved** in reproductive health care settings

# POPULATION- BASED DATA

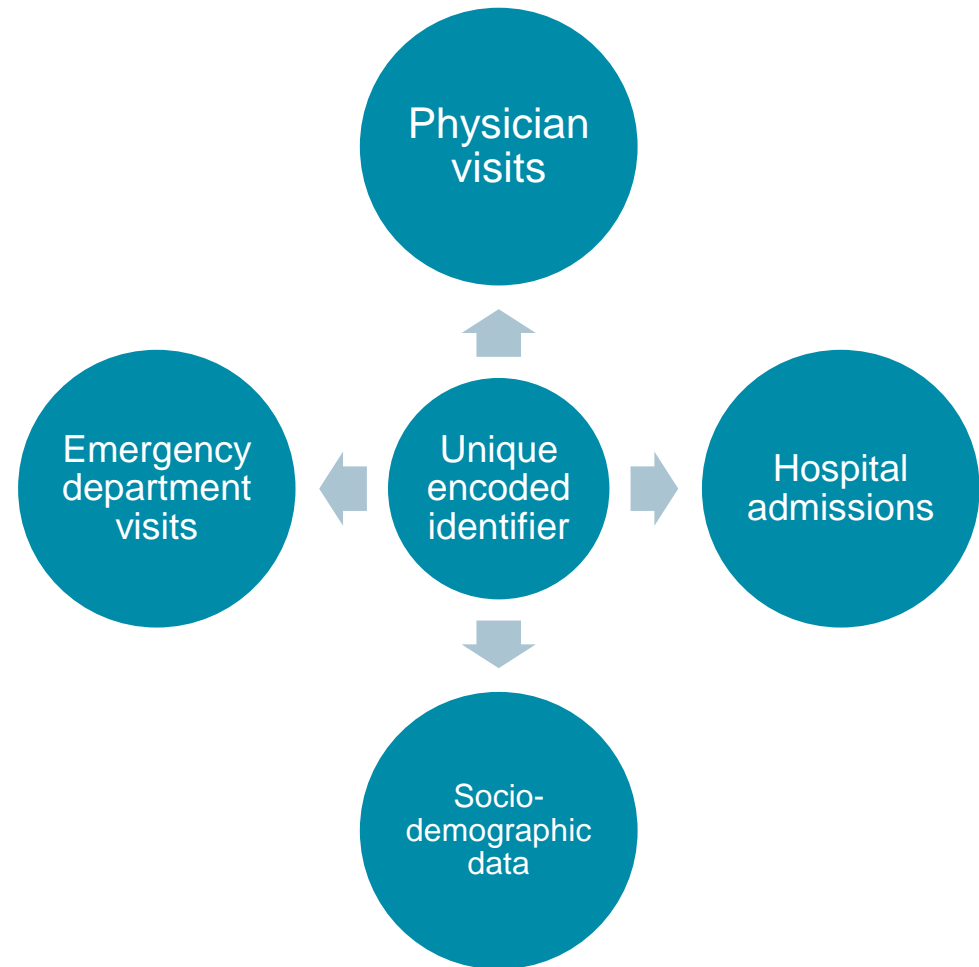




# OBJECTIVES AND APPROACH

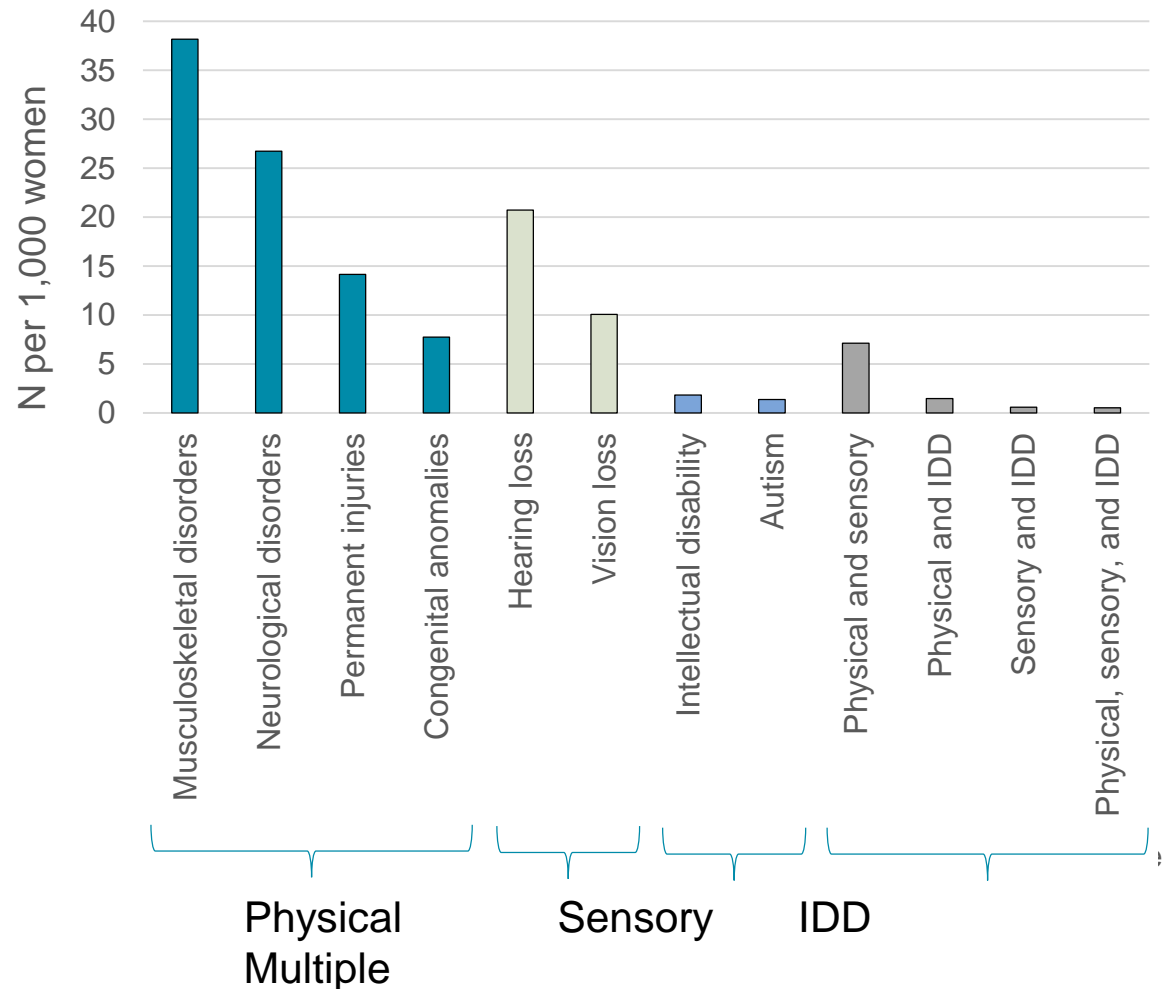
Using data for the entire province of Ontario, we aimed to examine:

1. Preconception health
2. Pregnancy rates
3. Prenatal care access
4. Perinatal outcomes

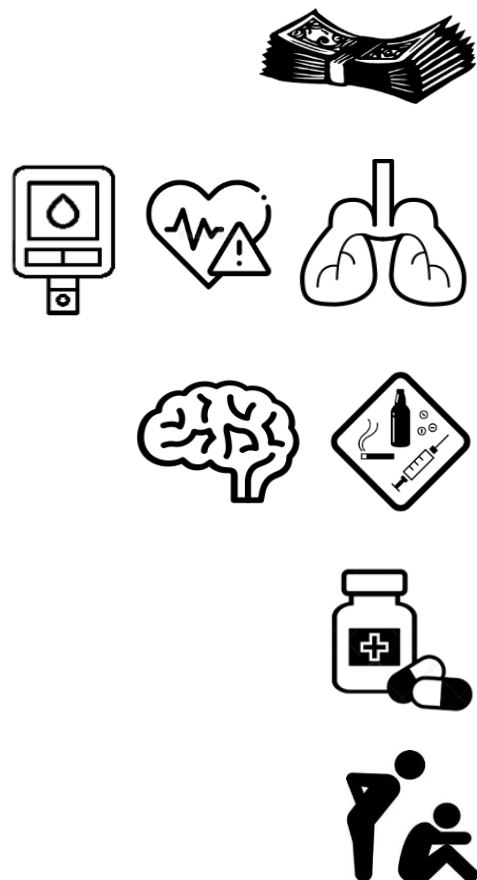


# COHORT CHARACTERISTICS

- 200,205 women with disabilities
- 1.6 million women without disabilities
- One or more births between 2003 and 2018

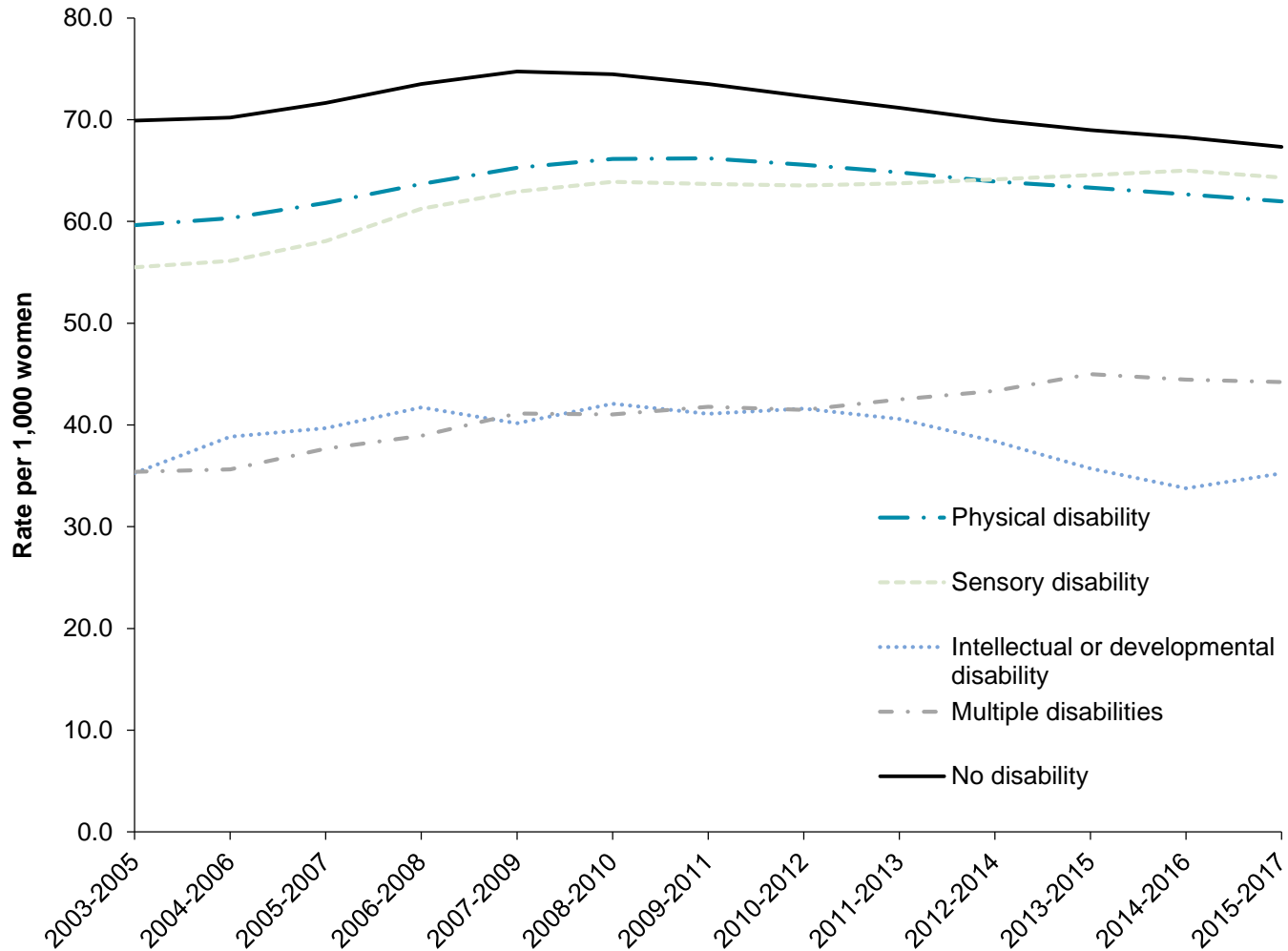


# PRECONCEPTION HEALTH

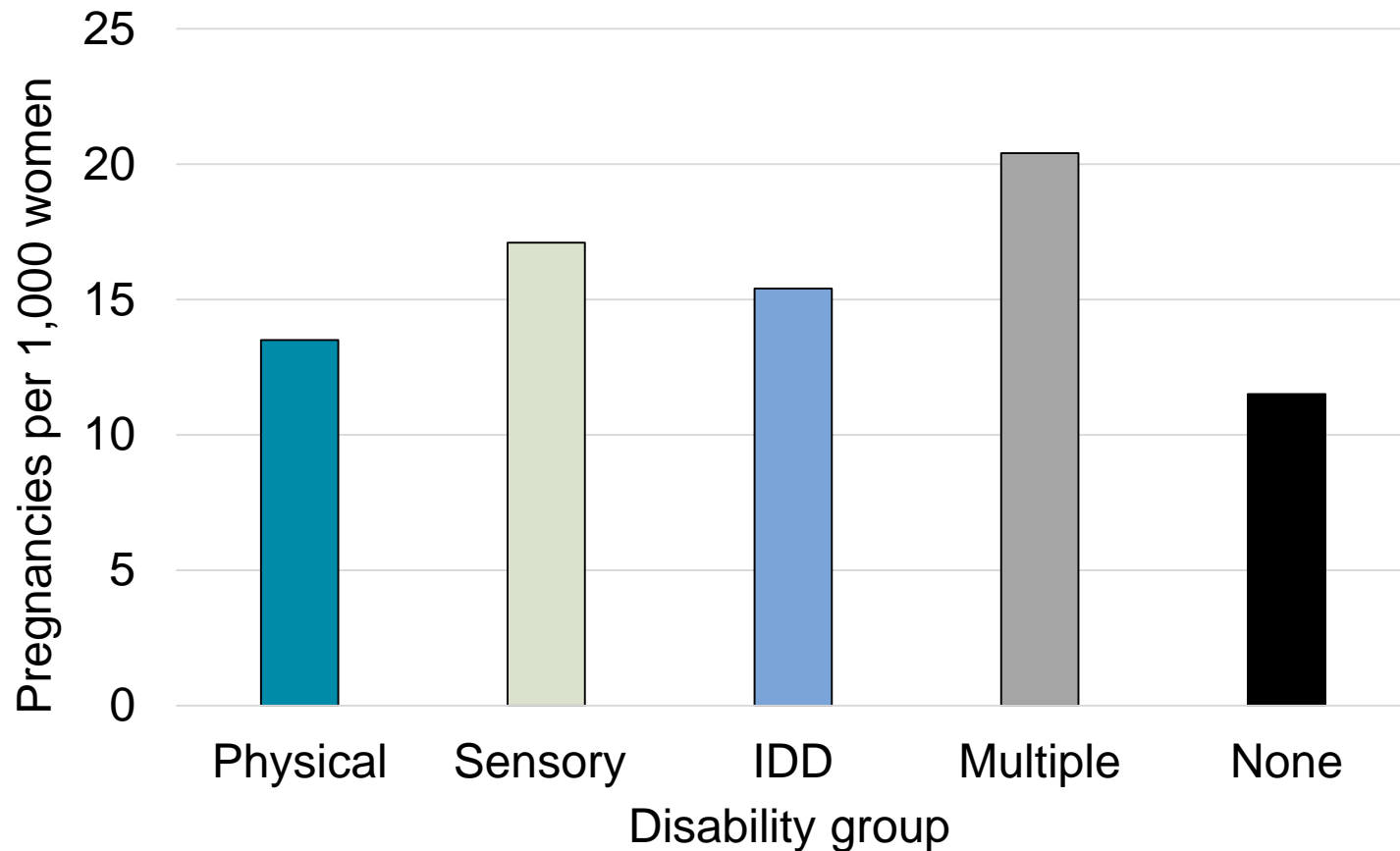


- Disparities on many markers of preconception health
- Notable disparities: chronic disease, mental illness, teratogenic medication use, history of experiencing assault
- Consistent across groups, but women with intellectual/developmental disabilities shown to experience largest disparities

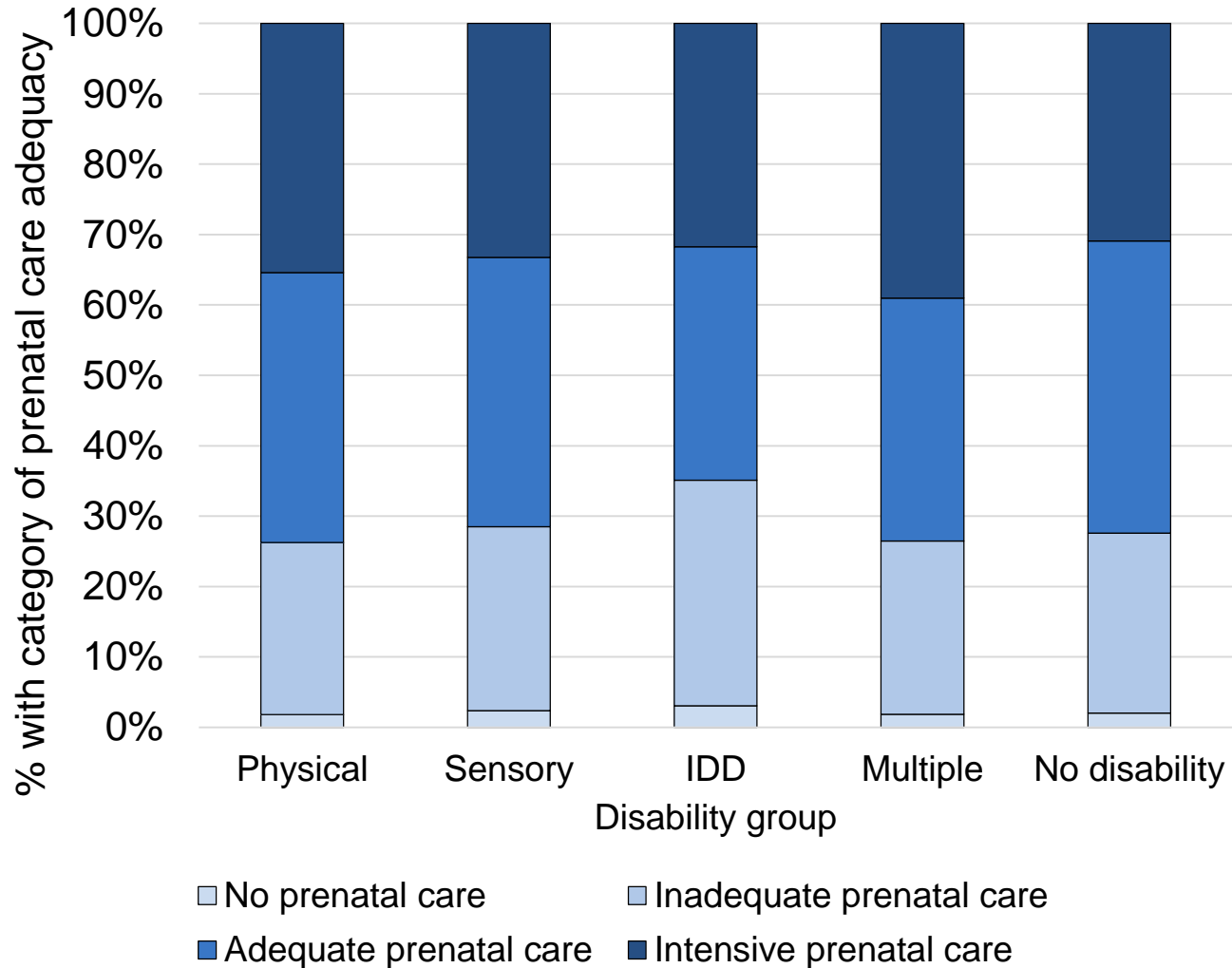
# PREGNANCY RATES: OVERALL



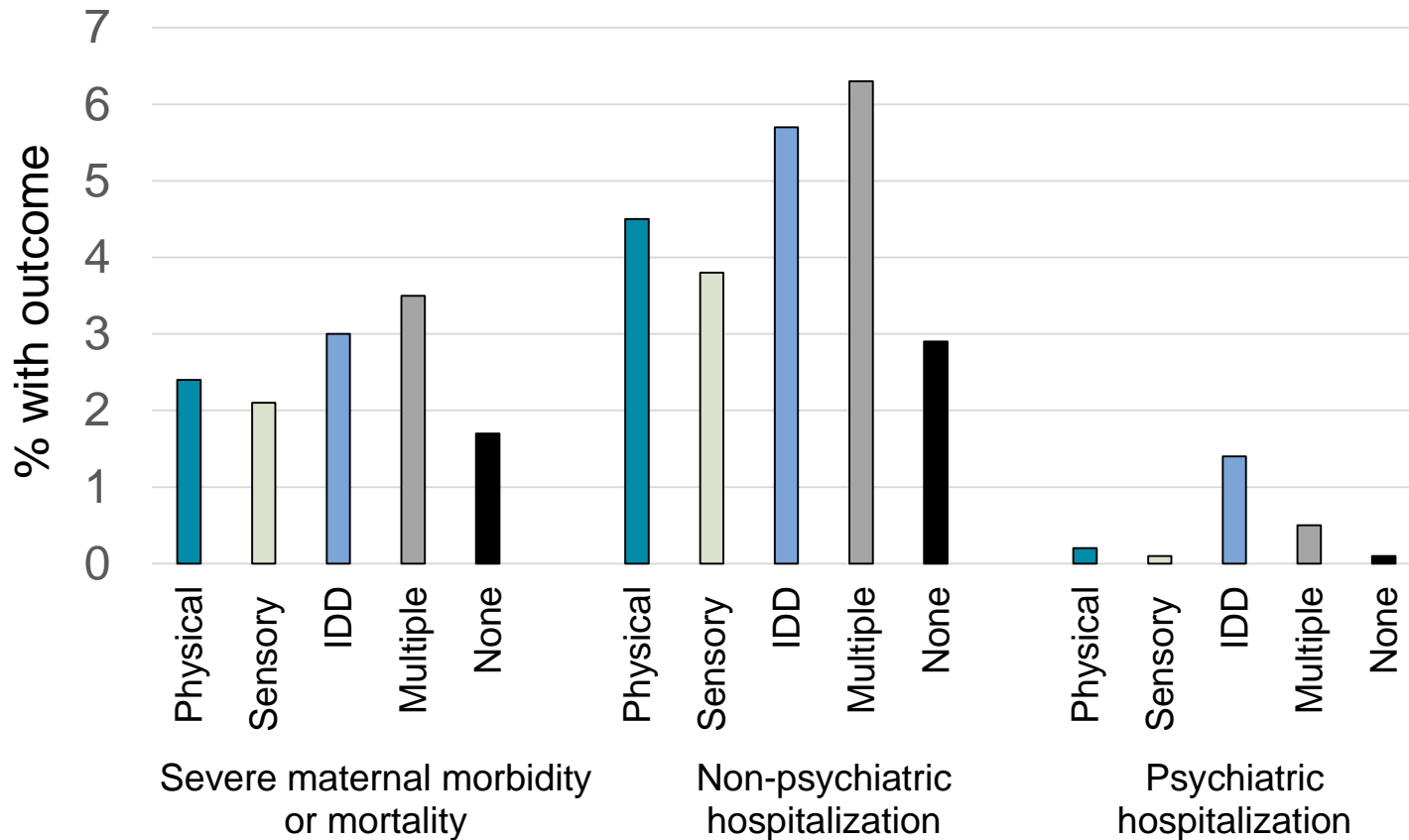
# PREGNANCY RATES: 15-19 YEAR OLDS



# PRENATAL CARE ACCESS

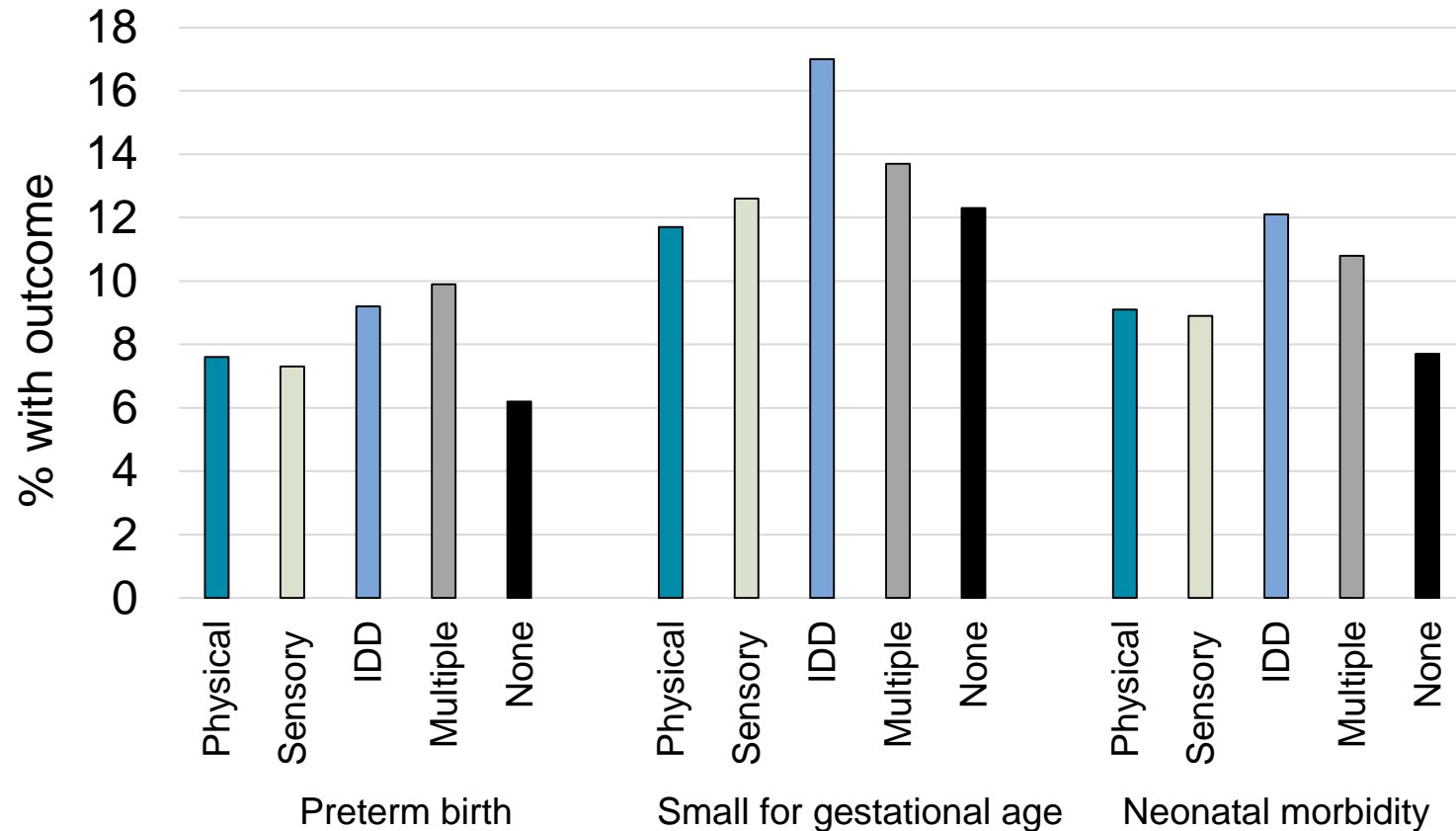


# PERINATAL OUTCOMES: MOTHERS



***Similar results for gestational diabetes, gestational hypertension, cesarean delivery (though differences not as notable)***

# PERINATAL OUTCOMES: NEWBORNS



***Similar results for NICU admission, neonatal abstinence syndrome, congenital anomalies, neonatal mortality***



# CONSIDERATIONS

- Cohort limited to women with a disability diagnosis (uses medical model of disability, not social model)
- Somewhat limited ability to account for other factors (e.g., individual-level socioeconomic status, race/ethnicity, health behaviours) that could explain disparities

# SUMMARY OF FINDINGS

- Pregnancy not uncommon in women with disabilities
- Clear evidence of significant disparities in preconception health among women with disabilities
- Some evidence of barriers to accessing prenatal care, especially for women with intellectual/developmental disabilities
- Higher rates of maternal and neonatal complications among women with disabilities, not completely explained by preconception health disparities

# QUALITATIVE INTERVIEWS



# OBJECTIVE AND APPROACH

- Community-informed (advisory committee)
- Using qualitative interview data, we aimed to understand the perinatal health care experiences of people with disabilities, from the perspective of:
  1. People with physical, sensory, and intellectual/developmental disabilities who have recently given birth
  2. Health and social service providers and decision-makers who work with people with disabilities and/or in perinatal health and/or disability policy

# APPROACH: PEOPLE WITH DISABILITIES

- Semi-structured interviews with 31 people with physical, sensory, and intellectual/developmental disabilities who had recently given birth (last 5 years) in Ontario
- **Interviews focused on:**
  1. Services and supports accessed during pregnancy, labour / delivery, and the early postpartum period
  2. What participants liked and did not like about services and supports and what they found helpful / not helpful
  3. Recommendations to improve care

# PARTICIPANT CHARACTERISTICS

Disability Type	N=31
Physical disability only	14
Sensory disability only	7
Intellectual/developmental disability (IDD) only	6
Multiple	
IDD + Physical	2
IDD + Sensory	2

- 18 used an assistive device or communication aid
- 25 identified as heterosexual; 22 were married/common-law
- 20 identified as white
- 13 had an education level of high school or less
- 20 had an obstetrician as their primary perinatal care provider

# PRENATAL EDUCATION

- 21/31 participants accessed some sort of prenatal education for at least one of their pregnancies
- Not accessible (not physically accessible, no ASL interpreters)
- Not tailored to disability or “high risk” pregnancies and deliveries

# PRENATAL EDUCATION

*“I probably would have went to Lamaze [childbirth education class], I would have went to some other stuff but then again, I probably wouldn’t have because I didn’t even have interpreters. So I did find that it was difficult not having the same amount of access that other people have because if I had those access, then I probably would be a bit more prepared. It might help with the whole pregnancy.”*

- Deaf participant



# PRENATAL EDUCATION

*“I didn’t go to anything like that [prenatal classes] just because I felt like I wouldn’t be able to relate to it because it’s all talking about natural, like vaginal birth and like healthy people and healthy babies, and it just seemed like it was kind of not the right place for me to go.”*

– Participant with a physical disability

# POSTPARTUM/PARENTING SUPPORT

- Several did get support from Healthy Babies, Healthy Children or an equivalent program in their community – sometimes just one call or visit
- Many services and supports in the postpartum period were not accessible
- Providers limited disability-related training and experiencing working with moms/parents with disabilities

# POSTPARTUM/PARENTING SUPPORT

*“Whenever I’m in any discussion with any moms-to-be with disabilities, many moms are afraid of it and they have experiences that are the opposite, where that system is going to find the risk and the concerns and you know, call CAS.”*

- Participant with a physical disability who had a positive experience with Well Baby program/home visitors for 6 months postpartum

# POSTPARTUM/PARENTING SUPPORT

*“I just sent them [public health] away because it was stressful because I was like, ‘Oh, they’re coming! We have to clean up the house!’ And it always felt like I needed to present this picture, pretty picture that everything was going fine. So I think that would have been helpful but I don’t know how to do that and still feel safe enough to talk about what you need to talk about. Maybe someone who actually sat you down and said, ‘I know this is an issue with disability, I’m aware of it. These are the only instances that I would call CAS.’ You know? ‘I’m here to support you. It’s normal to struggle,’ like I don’t know what that would look like but I think I would have more trust if I knew the person was aware of that or were disabled themselves.”*



# POSTPARTUM/PARENTING SUPPORT

*“Yeah they [public health nurses/home visitors] were helpful and even though when they came they don’t know how to help me any way. ... they used to learn from me because it was their first time to take care of [someone who was] visually impaired...”*

– Participant who is blind

*“I declined a public health nurse visit because of my disability and fear of lack of understanding from their part. ... my fear of disclosure and judgement.”*

– Participant with a physical disability

# POSTPARTUM/PARENTING SUPPORT

*“Even the resources that they did send me, there was no awareness of disability, all the mothers’ groups, [were] like not really accessible. It was awkward that I had to bring my attendant with me and I couldn’t sit on the ground and do the thing, it was awkward. ... And then sometimes, the coordinators are awkward and they’re just like, ‘Can you park here?’ Trying to manage you.”*

- Participant with a physical disability

# CONSIDERATIONS

- Few participants with sensory disabilities, notably those with vision loss, and few participants from western Ontario (e.g., London, Windsor)
- Some participants did share positive experiences, including public health nurses and other providers who went out of their way to support them

# OVERALL KEY FINDINGS

- (Fear of) stigma, discrimination, and negative attitudes from providers
- Lack of disability training among providers (identified by both participants with disabilities and providers)
- Inaccessible care settings and services; unmet communication access needs (e.g., lack of ASL interpreters)
- Lack of coordinated care
- Postpartum care gaps (e.g., mental health, breastfeeding)



# RECOMMENDATIONS TO IMPROVE CLINICAL CARE



# 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.”*

- Participant with IDD

# RECOMMENDATIONS TO IMPROVE CARE

*“Get an interpreter from the get go, because it’s for them; the interpreter’s for them [the health care provider], not for me. ... during pregnancy if a baby has a heart problem they bring in a cardiologist to focus on that problem, so the interpreter’s the same thing. ... getting the interpreter in the first place so you’re preventing any of the miscommunications and misunderstandings that could happen in the future.”*

- Deaf participant

# RECOMMENDATIONS TO IMPROVE CARE

*“I think it would have been helpful to have some sort of—whether it be mental health support or just support from other disabled people. Because I remember feeling very isolated .... And I also was wary of appearing to struggle too much. So if there was a way to have a safe person to share what you’re struggling with. I don’t know if that means having another disabled person as your support or like a group or something.”*

- Participant with a physical disability

# RECOMMENDATIONS TO IMPROVE CARE

- Life Course Approach to Reproductive Care
  - Starting with sexual health education and preconception care (including discussions about reproductive life plans) at an earlier stage
  - Continue across first year postpartum and focus on interconception health as well



# RECOMMENDATIONS TO IMPROVE CARE

- Disability-related training for public health nurses and home visitors

*“Service providers like public health nurse and home visitor they should be even training on the inclusion. It’s like they don’t know how to deal with people with disabilities. ... And we get other maybe different people with disabilities who have such an experience to teach them...”*

– Participant who is blind

# RECOMMENDATIONS TO IMPROVE CARE

- Adaptable resources to meet diverse learning, communication, and sensory concerns and needs
  - Utilize technology
  - Interpreters must be available
  - Detailed explanations and tactile / hands-on demonstrations

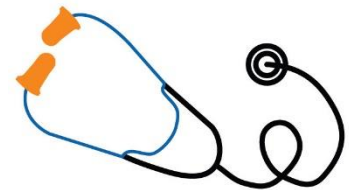


*“My first pregnancy, I did take a child birth class and that was fantastic... the teacher of that child birth class was really accommodating and I really appreciated that. Like she let me feel all these models of pelvises and things like that and she asked if I needed to be oriented to the space...”*

- Participant who is blind

# RECOMMENDATIONS TO IMPROVE CARE

- Longer and more frequent appointments and visits; home visits if possible
- Work proactively, together with people with disabilities (and their social supports/caregivers, etc.), to ensure that resources and supports are in place before, during, and after pregnancy
- Ask THEM what works for THEM





# RESOURCES

- Links to published papers and research snapshots (summaries of published papers): <https://latarasoff.com/publications/>;  
<https://www.utsc.utoronto.ca/people/hbrown/publications/>
- [Parenting With a Disability Network](#), Centre for Independent Living in Toronto, Toronto: Cross-disability network for parents and prospective parents with disabilities
- [The Parenting Enhancement Program](#), Surrey Place, Toronto: Parent skill training and support to parents with developmental disabilities
- [Accessible Care Pregnancy Clinic](#), Sunnybrook Health Sciences Centre, Toronto: A specialized clinic that provides care for women, trans and non-binary people with physical disabilities who are pregnant or are contemplating a pregnancy
- [The National Research Center for Parents with Disabilities](#), The Heller School for Social Policy and Management, Brandeis University, USA: Research and training and technical assistance to improve the lives of parents with disabilities and their families
- [A Perinatal Health Framework for Women with Physical Disabilities](#): Academic paper by Mitra et al., 2015

# THANK YOU

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