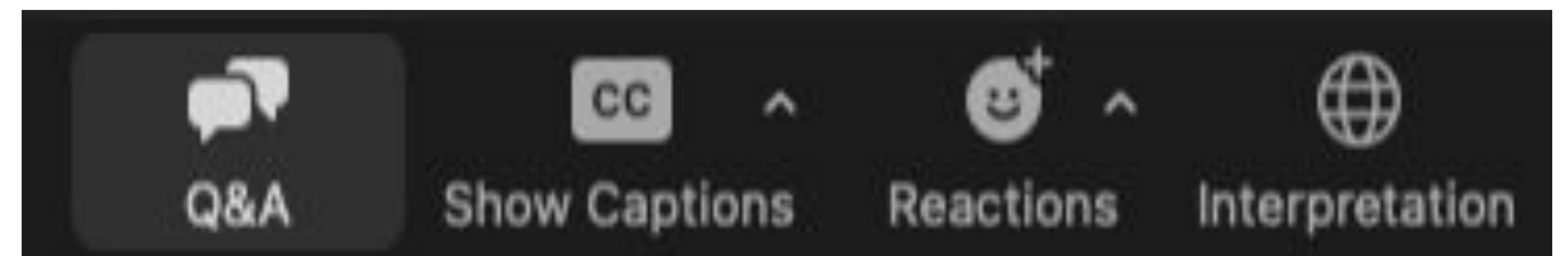
Delving Into Maternal Mental Health Webinar Series

Disability, Pregnancy and Maternal Mental Health Webinar

Questions, Captions, & ASL Interpretation

At the bottom of your screen use the:

- Q&A button to ask a question.
    - ASL: If you would like to express your question in ASL, let us know in the Q&A box.
- Show Captions button to see live captions.
- Reactions button to share an emoji.
- Interpretation button to see our ASL interpreters.



Maternal Mental Health Leadership Alliance (MMHLA)

We are a nonpartisan 501(c)3 nonprofit organization dedicated to improving the mental health of mothers and childbearing people in the United States with a focus on policy and health equity.

Learn more at mmhla.org.

What we'll cover...

- **Overview** of perinatal mental health among women with disabilities.
- **Ableism** and its impact on people with disabilities.
- **Pilot program** that is designed to improve the perinatal health of pregnant people with disabilities.
- **Lived experience** from Dr. Kara Ayers about her perinatal health as a disabled mom.

After this webinar, we will email you:

- Brief survey
- Powerpoint presentation
- Webinar recording

Webinar Self-Care

Some information may be challenging. Please take breaks as needed.

Our Presenters

Overview & Research

Hilary K. Brown, PhD

- Associate Professor, University of Toronto
- Adjunct Scientist, Women's College Hospital and the Institute for Clinical Evaluative Sciences
- Holds a Tier 2 Canada Research Chair in Disability & Reproductive Health

Lived Experience & Potential Strategies

Kara Ayers, PhD

- Associate Director, University of Cincinnati Center for Excellence in Developmental Disabilities
- Associate Professor of Pediatrics, Cincinnati Children's Hospital Medical Center
- Co-founder, Disabled Parenting Project
- Co-investigator, National Center for Disability and Pregnancy Research

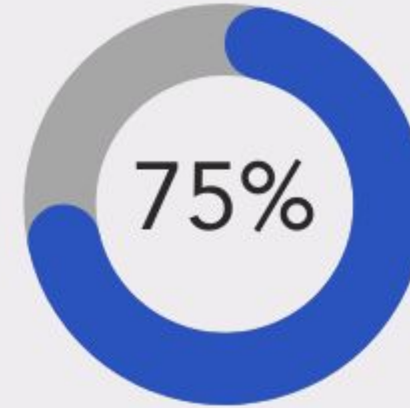
Key Facts about Maternal Mental Health

1 in 5 Mothers Are Impacted by Mental Health Conditions

Maternal mental health (MMH) conditions are the MOST COMMON complication of pregnancy and birth, affecting 800,000 families each year in the United States.[1,2]

Mental Health Conditions Are the Leading Cause of Maternal Deaths

Suicide and overdose are the LEADING CAUSE of death for women in the first year following pregnancy.[3]

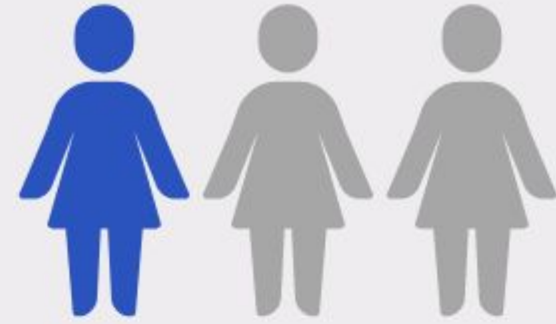


$14 Billion: The Cost of Untreated MMH Conditions

The cost of not treating MMH conditions is $32,000 per mother-infant pair, or $14 BILLION each year in the United States.[5]

Most Individuals Are Untreated, Increasing Risk of Negative Impacts

75% of individuals impacted by MMH conditions REMAIN UNTREATED, increasing the risk of long-term negative impacts on mothers, babies, and families.[4]



Certain Individuals are at Increased Risk for Experiencing MMH Conditions

High-risk groups include people of color, those impacted by poverty, military service members, and military spouses.[6,7]

It's Not Just Postpartum Depression: There are a Range of MMH Conditions

MMH conditions can occur during pregnancy and up to one year following pregnancy and include depression, anxiety disorders, obsessive-compulsive disorder, post-traumatic stress disorder, bipolar illness, psychosis, and substance use disorders.[8]

More information in our *new* Disability, Pregnancy & Maternal Mental Health Fact Sheet!

We will email you the new Fact Sheet after this webinar.

MMHLA
Maternal Mental Health
LEADERSHIP ALLIANCE

FACT SHEET | APRIL 2023

Disability, Pregnancy, and Maternal Mental Health

info@mmhla.org www.mmhla.org @mmhla2

This Fact Sheet uses the term "women with disabilities" in keeping with current literature and studies; however, we recognize that not all individuals who give birth identify as women.

Key Facts: Maternal Mental Health (MMH) Conditions

- MMH conditions are the **MOST COMMON** complication of pregnancy and birth, impacting 1 in 5 childbearing people (800,000 families) each year in the U.S.[1,2]
- Suicide and overdose are the **LEADING CAUSE** of death for women in the first year following pregnancy.[3]
- 75% of women impacted by MMH conditions **REMAIN UNTREATED**, increasing the risk of long-term negative impacts on mothers, babies, and families.[4]
- The cost of untreated MMH conditions is $32,000 per mother-infant pair or **$14 BILLION** each year in the U.S.[20]
- MMH conditions can occur during pregnancy and up to one year following pregnancy and include depression, anxiety disorders, obsessive-compulsive disorder, post-traumatic stress disorder, bipolar illness, psychosis, and substance use disorders.[21]
- Learn more about MMH conditions with MMHLA's Fact Sheet on Maternal Mental Health.

Key Points: Disability, Pregnancy, and Maternal Mental Health

- Approximately 20% of individuals who give birth in the United States identify as having a disability,[5] and approximately 1 in 8 births are to women with disabilities.[6]

One of the most frequent concerns raised by women with disabilities is a lack of health care professional knowledge and awareness about how their disability could affect their pregnancy and how pregnancy might affect disability-related symptoms, progression, and other concerns. Likewise, health care professionals report a lack of training and insufficient resources related to disability.[6]

- Women with disabilities are twice as likely to experience MMH conditions as compared to women without a disability.[7]
- Women with disabilities face challenges accessing health care before, during, and following pregnancy, potentially exacerbating risk of pregnancy complications and maternal morbidity, including MMH conditions.[8]
- Women with disabilities are more likely to be individuals of color and more likely to live in poverty, increasing their risk for experiencing MMH conditions and increasing challenges in accessing appropriate mental health care.[9]

1

21. Postpartum Support International. 2023. https://www.postpartum.net/learn-more/

Research: Perinatal Mental Health Among Women with Disabilities

Hilary K. Brown, PhD
University of Toronto

Overview & Research

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- Associate Professor, University of Toronto
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Disability in Reproductive-Aged Women

- 20% 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
- Yet, women with disabilities continue to be underserved in reproductive health care settings, including perinatal mental health care

Historical Context

Source: Ministry of Community and Social Services, 2009. Ontario closes institutions for people with a developmental disability. Available from: https://news.ontario.ca/en/release/5214/ontario-closes-institutions-for-people-with-a-developmental-disability

Social and Health Disparities

Childhood experiences

Education

Employment

Housing

Family income

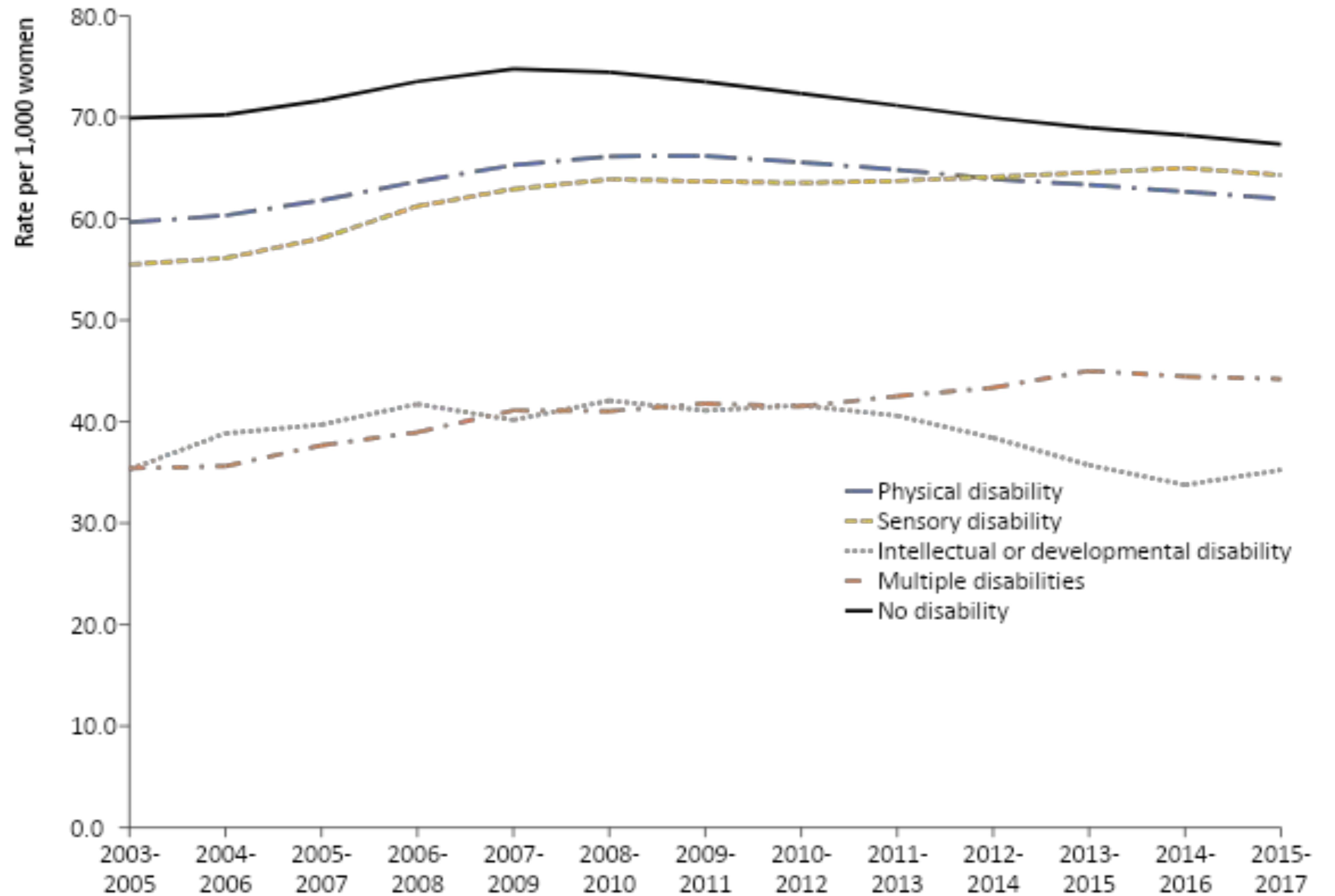
Social support

Access to health services

Our communities

Source: NHS Scotland, 2017. The right to health. Available from: http://www.healthscotland.scot/health-inequalities/the-right-to-health

Pregnancy Rates



Source: Brown HK et al., Am J Obstet Gynecol 2020;222(2):189-192

Perinatal Health Outcomes

- Maternal complications:
  - Elevated risk of gestational diabetes, gestational hypertension, severe maternal morbidity and maternal mortality, caesarean delivery
    - (e.g., meta-analysis by Tarasoff et al., 2020; Brown et al., 2017; Brown et al., 2021; Mitra et al., 2021)
- Newborn complications:
  - Elevated risk of preterm birth and low birth weight
    - (e.g., meta-analysis by Tarasoff et al., 2020; Brown et al., 2017)

Prior Research on Perinatal Mental Health

Quantitative Research

- Descriptive study of Australian women with IDD attending antenatal clinics: one-third had moderate/severe depression, anxiety, stress. (McConnell et al. 2009)

- Population-based study using Rhode Island Pregnancy Risk Assessment Monitoring System (PRAMS): women with disabilities had elevated risk of postpartum depression (aRR 1.6, 95% CI 1.1-2.2). (Mitra et al. 2015)

Qualitative Research

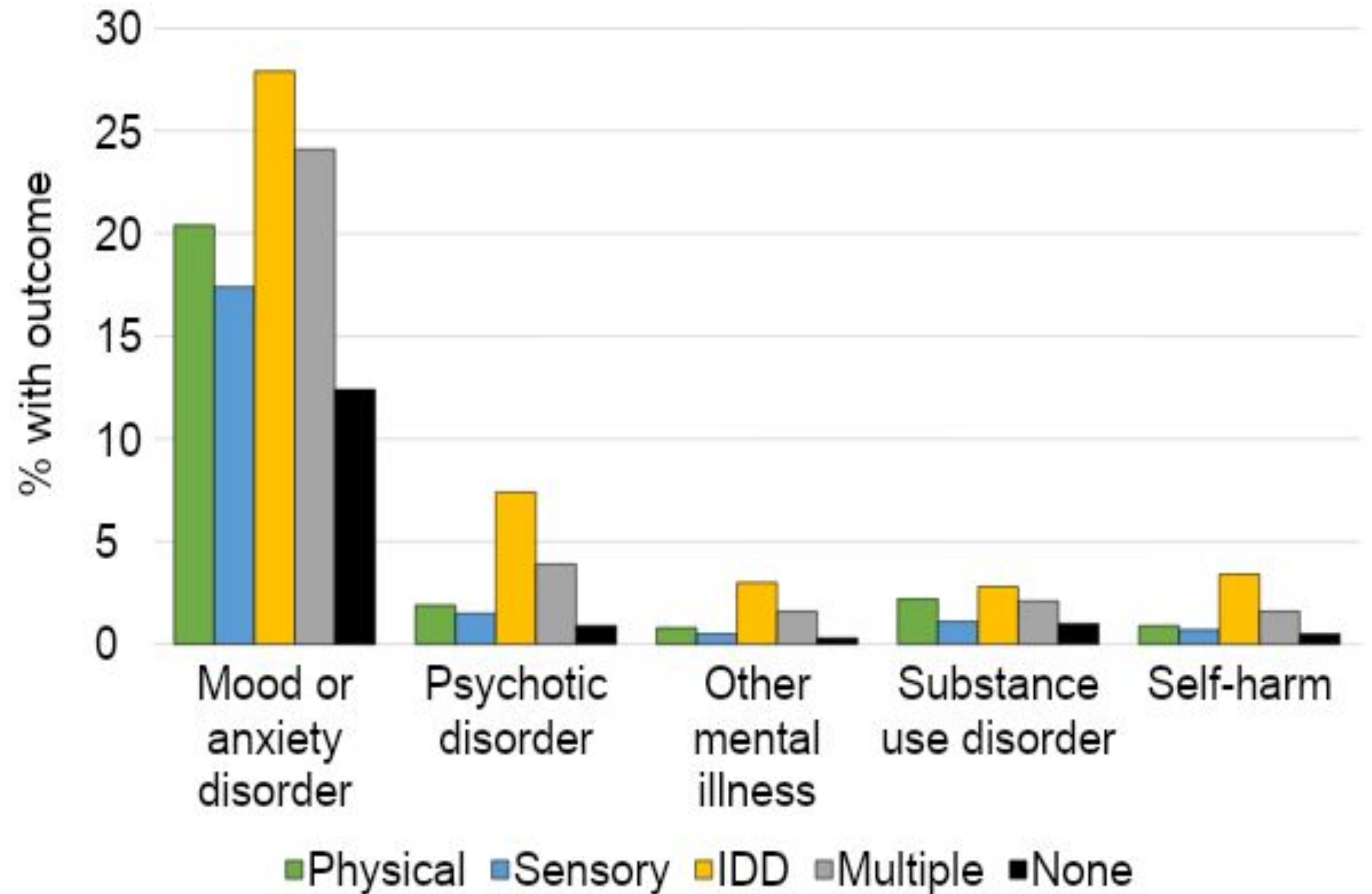
- Handful of studies showing elevated distress in the perinatal period, numerous stressors. (e.g., Potvin et al. 2016)

Research Spotlight

Population-based study on perinatal mental health in women with disabilities, including:

1. Comparison of perinatal mental health outcomes of women with and without disabilities
2. Description of stressors experienced by women with disabilities in the perinatal period

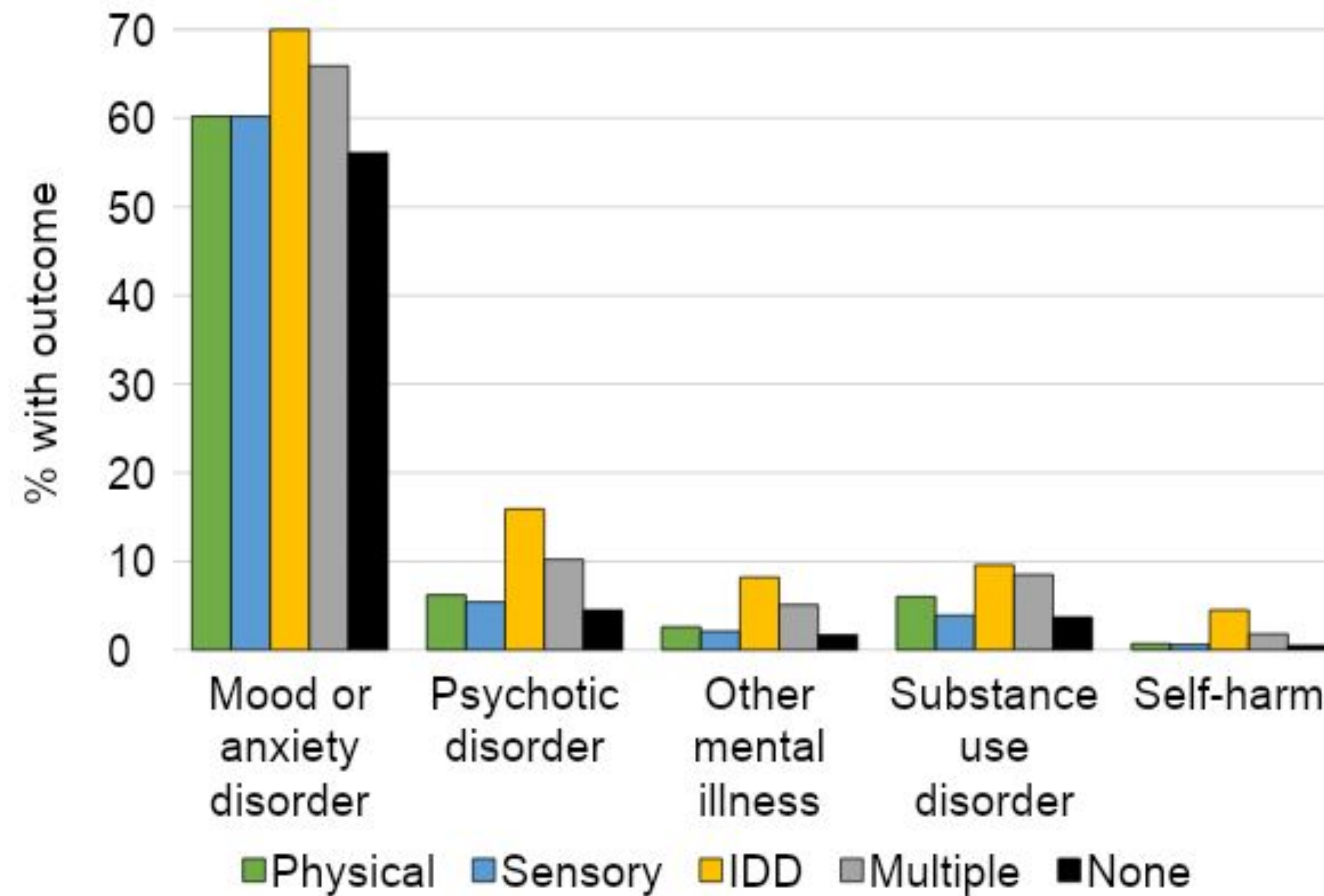
Preconception Mental Health



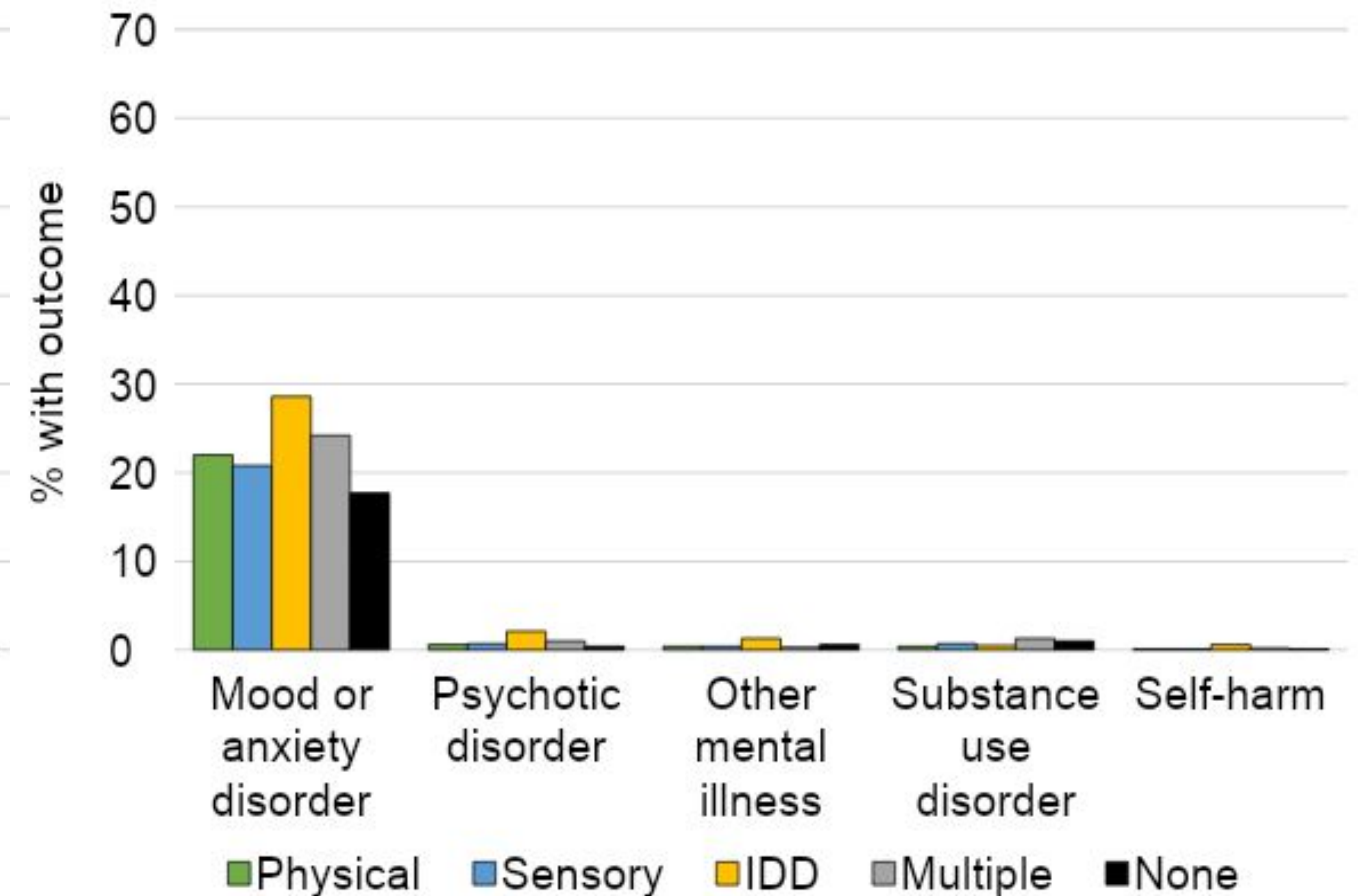
Source: Tarasoff LA et al. J Women's Health 2020;29(12):1564-1576.

Perinatal Mental Health Outcomes

With a history of mental illness



Without a history of mental illness



Negative Provider Assumptions

"I met him [doctor] for the first time when I went in to confirm the pregnancy. And I went in and I said to him like – 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. My mouth fell open – I didn't know what to say… I guess he looked at my wheelchair and thought like 'You don't want it', I guess. It was like no we've been trying for a year and we're really excited, and that was a really weird and terrible kind of experience."

Tarasoff L, et al. Unmet needs, limited access: A qualitative study of postpartum experiences of people with disabilities in Ontario, Canada. *Manuscript submitted*.

Little Professional Support

"I was just a number. The [doctor] gives some instructions to how to follow-up and when to do it during my pregnancy…. But then after that, there was no follow-up and so what happened? …There was no [resources] for postpartum depression. Uh, here's a pamphlet and I said, "Ugh, whatever." They think you're going to go and call everybody. If [I was] screened at the hospital that you're at risk for postpartum which I think I was… [I needed] more mental health support. I think that would have been very helpful."

Tarasoff L, et al. Unmet needs, limited access: A qualitative study of postpartum experiences of people with disabilities in Ontario, Canada. *Manuscript submitted*.

Gaps in Postpartum Care

"There were no resources. I just had the baby and 'we're done with you'. You know, when you're high risk, it's a double-edged sword. One, okay great, you have the obstetrician looking after you… But after you deliver the baby, you're done, nothing happens. If I'm high risk, wouldn't it still be high risk 6 weeks after the postpartum?"

Tarasoff L, et al. Unmet needs, limited access: A qualitative study of postpartum experiences of people with disabilities in Ontario, Canada. *Manuscript submitted*.

Lack of Disability-Affirming Services

"It would have been helpful to have some sort of mental health support or just support from other disabled people. Because I remember feeling very isolated and all the people I was seeing, they didn't get it. 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. …Maybe someone who actually sat you down and say, "I know this is an issue with disability, I'm aware of it. These are the only instances that I would call CAS." …I would have more trust if I knew the person was aware of that or were disabled themselves."

Tarasoff L, et al. Unmet needs, limited access: A qualitative study of postpartum experiences of people with disabilities in Ontario, Canada. *Manuscript submitted*.

Having to Prove Oneself

"As a disabled mom, I felt I had to make it seem like I was doing better than any 'normal' mom because I was afraid if people thought I couldn't do it, then they would assume that it was a mistake for me to have a kid… I didn't reach out to supports because I was trying to hide. That was really hard. Even if people told me 'Yes, it's really hard', I felt I had to still prove that I was doing okay."

Tarasoff L, et al. Unmet needs, limited access: A qualitative study of postpartum experiences of people with disabilities in Ontario, Canada. *Manuscript submitted*.

Perceived Dangers

"I think that was brushed off and it's so dangerous. If you have a mom with a high risk of postpartum depression, who has heavy, hardcore painkillers at home, I think that's a deadly combination. …I was almost suicidal. …I was disappointed in that way. …I definitely wish that there was some sort of mental health support. …And something that you can probably get started towards the end of the pregnancy and continue on, not just do it until the baby comes and see if you're going to develop postpartum [depression]."

Tarasoff L, et al. Unmet needs, limited access: A qualitative study of postpartum experiences of people with disabilities in Ontario, Canada. *Manuscript submitted*.

Fear of Child Protective Services

“It took me to get the parenting program worker and the Adult Protective Service Worker and every other support involved in order for my child to be home. I had child protective services involvement from my previous kid, I didn’t feel very open about having all these people come and be involved in my life because I thought everybody would be against me instead of trying to help me.”

Tarasoff L, et al. Unmet needs, limited access: A qualitative study of postpartum experiences of people with disabilities in Ontario, Canada. *Manuscript submitted*.

Ableism, Potential Strategies to Improve Perinatal Health & Lived Experience

Kara Ayers, PhD
National Center for Disability and Pregnancy Research

Lived Experience & Potential Strategies

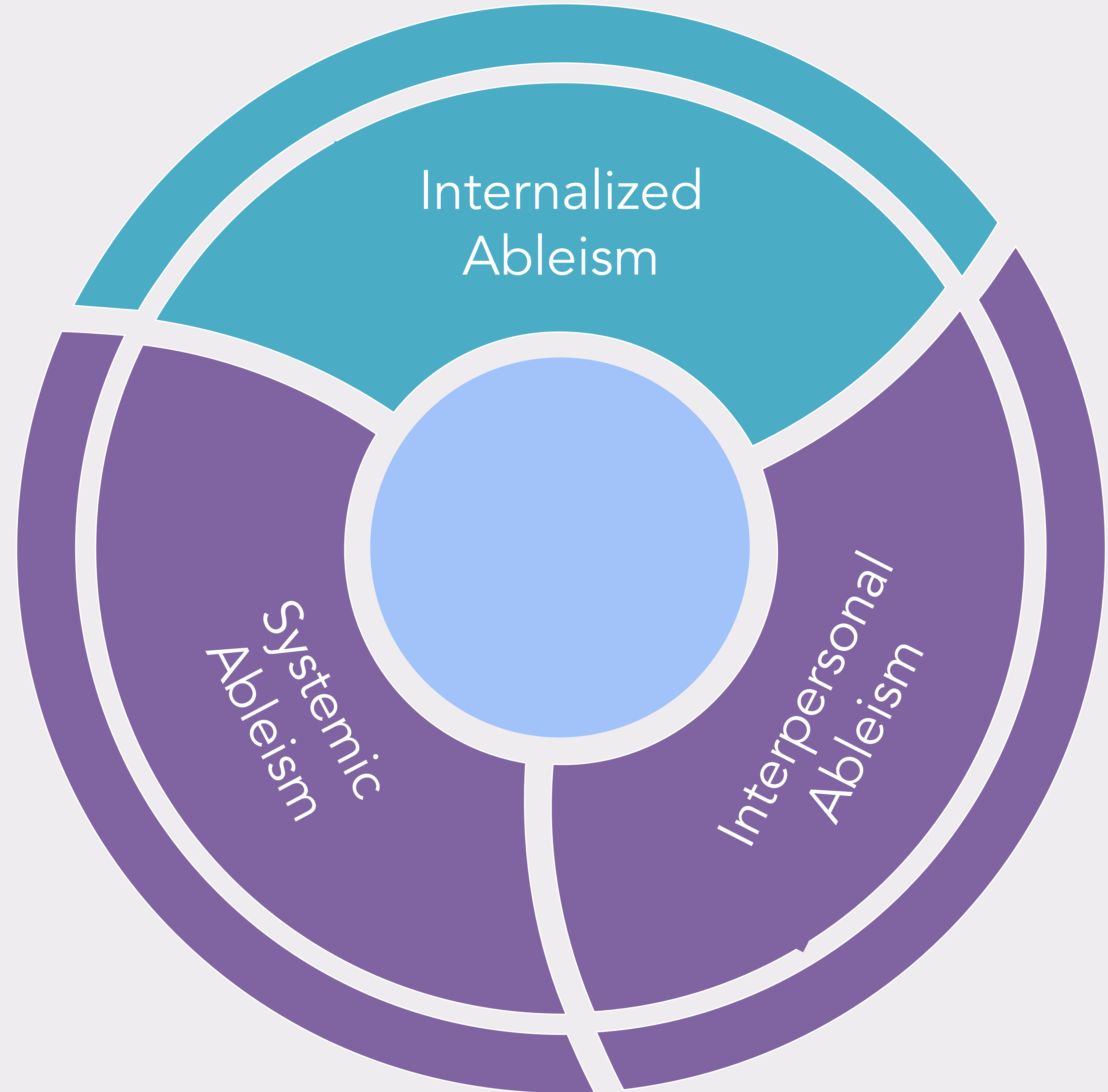
Kara Ayers, PhD

- Associate Director, University of Cincinnati Center for Excellence in Developmental Disabilities
- Associate Professor, Pediatrics at Cincinnati Children's Hospital Medical Center
- Co-founder, Disabled Parenting Project
- Co-investigator, National Center for Disability and Pregnancy Research

Understanding Ableism

- Ableism is discrimination and social prejudice against people with disabilities based on the belief that nondisabled people are superior.
- Ableism harms people with and without disabilities.
- The training that healthcare providers receive often lacks focus on disability and perpetuates ableism.
    - (Kaundinya & Schroth, 2022)

Types of Ableism Impacting Perinatal Mental Health



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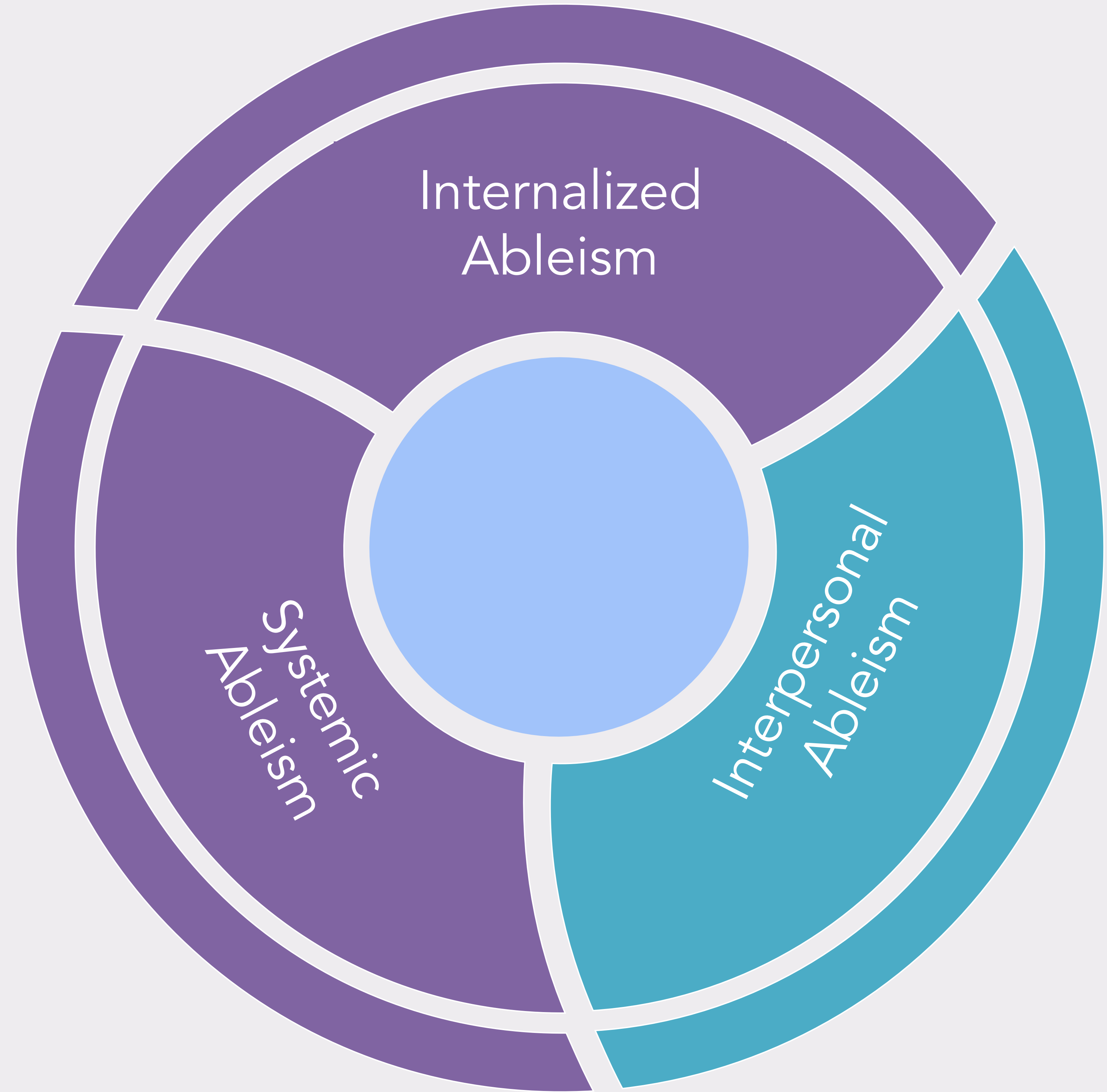

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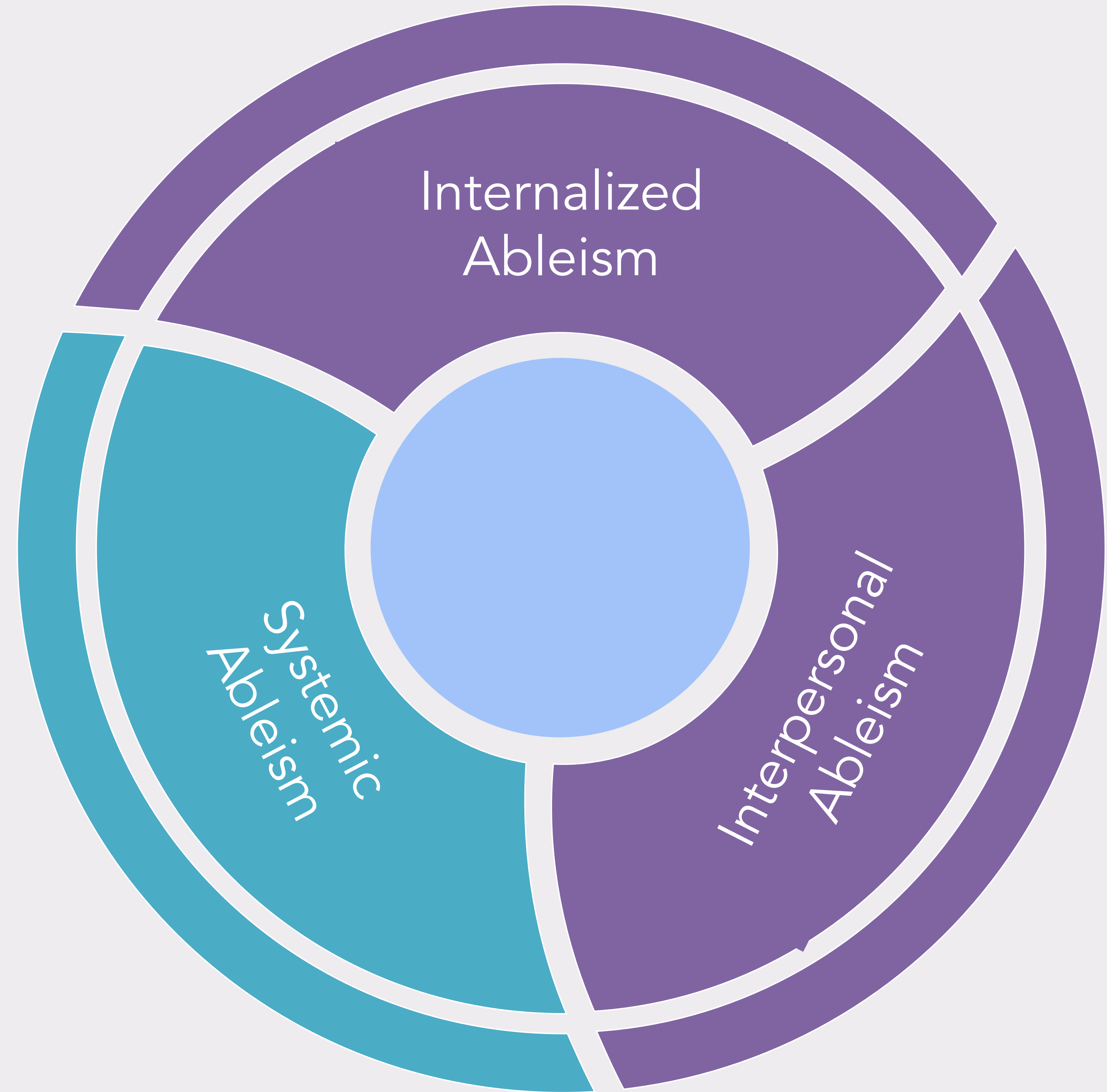


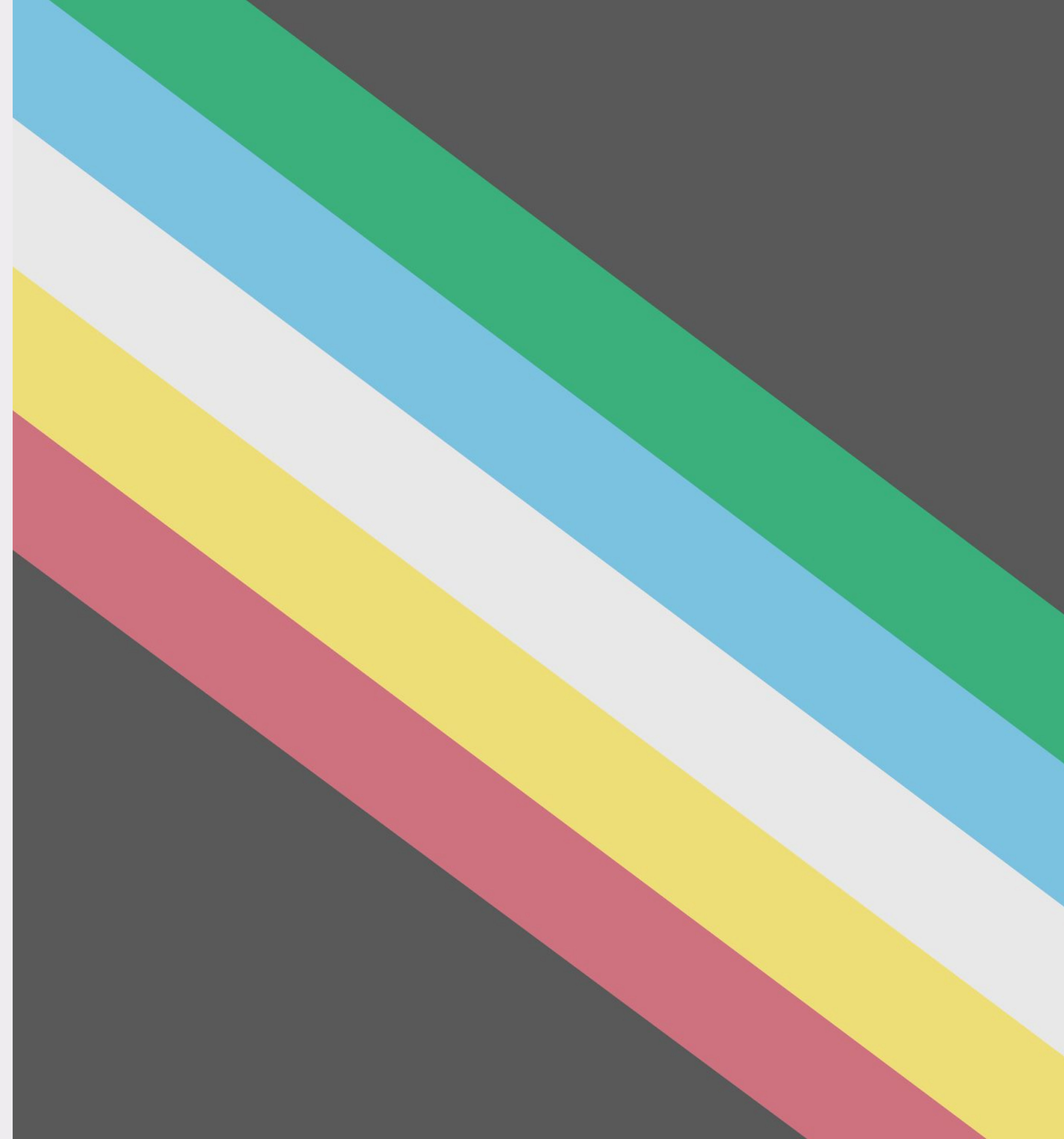
Ableism as a Smog

Ableism is often...

- Cumulative
- Implicit
- Unaddressed even in anti-bias or diversity efforts
- Overlooked as contributing to mental health

Anti-ableism

- Centers disabled people
- Recognizes intersectionality
- Includes active allyship
- Is needed at individual, interpersonal, and systemic levels
- May include disability pride



Previewing the Accessible Pregnancy Action Plan

- The process of planning for birth can reduce anxiety, identify unanswered questions, and help pregnant people and their healthcare teams communicate.
- The Accessible Pregnancy Action Plan pilot:
  - is a peer-to-peer intervention that supports pregnant disabled people to plan for pregnancy, labor, birth, and the few days after birth with another disabled parent
  - is conducted online over Zoom in 3-4 sessions
  - identifies disability-related needs, supports, and strengths
  - directly discusses the impact of stigma and discrimination

Accessible Pregnancy Action

Plans for Pregnancy

The best environment for me:
- Has everyone masked (KN95 or better)
- Has the option of an adjustable exam table
- Is fragrance-free
- Has closed captions and recording option for telehealth appointments
- May include my support person or people

Providers can help by:
- Masking (KN95 or better) whenever in the room with me
- Talking directly to me
- Checking for understanding
- Providing information in advance
- Providing written summaries
- Limiting touch
- Confirm my consent
- Acknowledging my knowledge about my disability
- Believing me about reports of pain, other symptoms, and research in the field.

What matters most to me is:
- My providers are informed about EDS and my other disabilities
- Finding balance between rest and maintenance of health

Plans for Labor and Birth

The best environment for me:
- Has everyone masked (KN95 or better) and includes my own air purifier
- Includes my support team (James and doula)
- Has options for positioning
- Is fragrance-free
- Includes options for massage
- Recognizes my need for pain control, like TENS units, gas/air,and heat/cold therapy
- Includes access to a bath or shower
- Includes access to food I prefer

Providers can help by:
- Masking (KN95 or better) whenever in the room with me
- Limiting the number of people in the room
- Helping me with transitions between levels
- Writing instructions, timelines, or what to expect on a whiteboard
- Ensuring you have consent before touching me

What matters most to me is:
- My providers are informed about EDS and my other disabilities
- My baby and I are protected from Covid

Supports and Plans for after Birth

The best environment for me after birth:
- Has everyone masked (KN95 or better) and includes my own air purifier
- Includes James
- Keeps my baby in the room
- Includes my personal items, like body braces, wraps, and ice caps
- Recognizes my symptoms are changing and dynamic
- Plans for flares (pain, mast cell reactions)

Providers can help by:
- Masking (KN95 or better) whenever in the room with me
- Limit my time in the hospital as much as possible
- Helping me manage my pain
- Respecting my wishes for my child
- Acknowledging my knowledge about my disability and my many strengths as a parent
- Believing me about reports of pain, other symptoms, and research in the field.

What matters most to me is:
- Creating a restful, low-stress environment
- Our family being protected from Covid
- Coming home as soon as possible

Invisible Disabilities

"I don't know a lot of disabled parents so and you don't see or read much about disabled parenting unless it's a negative way. Yeah, I guess like the stigma, and like f**** up ways that mandated reporting can really interfere, interfere with disabled people becoming parents and I feel like I mean, that's even like part of that. But you know, that's those are those are considerations that even go into like not wanting to get like an autism diagnosis, because I know the way that that can be viewed by the wrong person who's who's making passing judgment on my ability to be a parent. Fortunately, I think, fortunately, and unfortunately, there's pros and cons to having a dynamic and sometimes invisible disability."

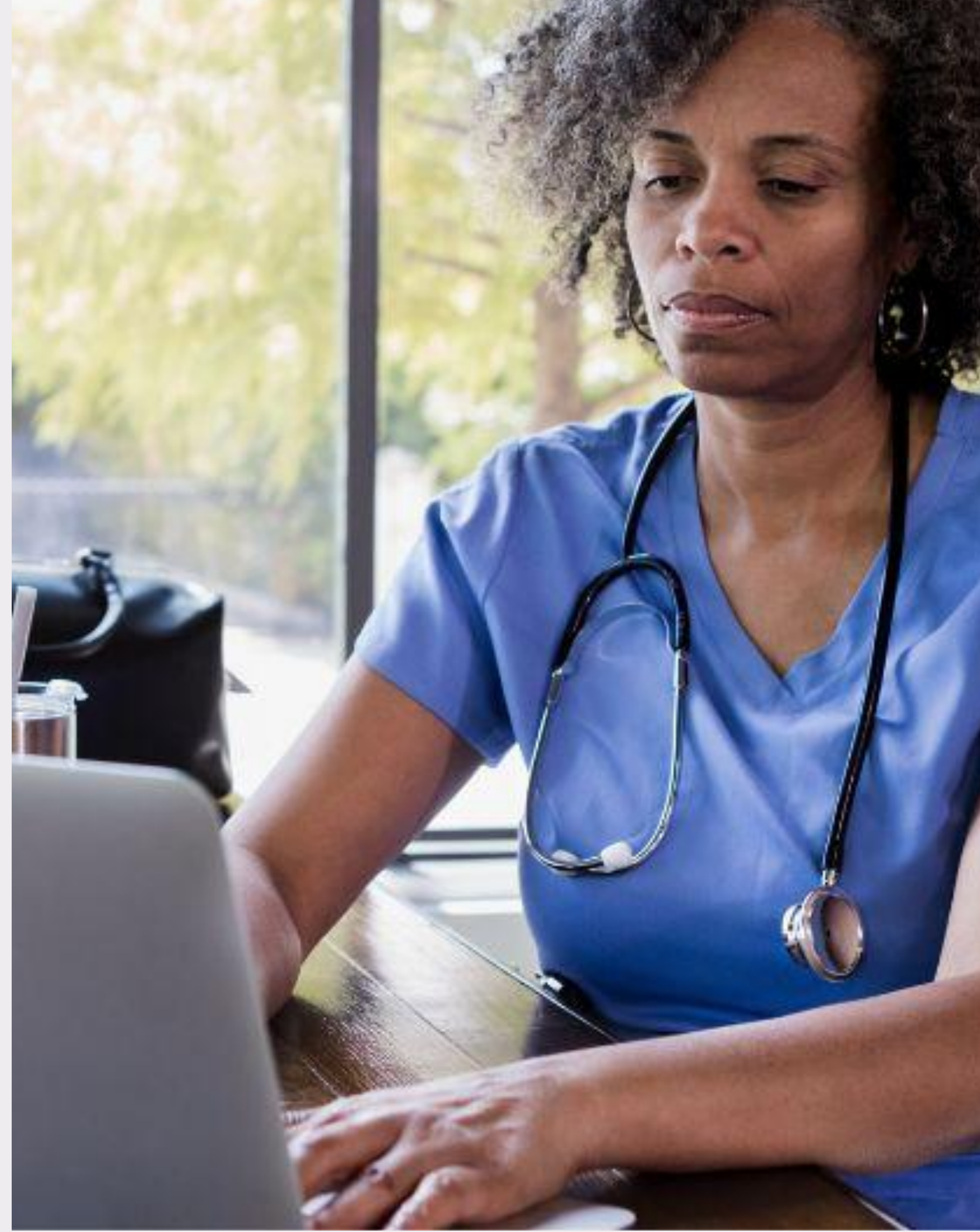
Dr. Kara Ayers' Story

Kara Ayers, PhD
National Center for Disability and Pregnancy Research

Resources: Perinatal Mental Health for Women with Disabilities

Resources

- Childbirth Preparation and Support Tool
- PCMCH Disability and Pregnancy Resources
- Supporting People with Disabilities in Pregnancy, Labour and Delivery, and Postpartum: Resources for Public Health Nurses



REMINDER

After this webinar, we will email...

- Brief survey
- Powerpoint presentation
- Webinar Recording
- Fact Sheet on Disability, Pregnancy and Maternal Mental Health

Quick Poll

Thank you! *Stay in Touch!*

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Maternal Mental Health Key Facts

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References

Perinatal Mental Health Among Women with Disabilities: Ayers

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