



The Need for Inclusive Perinatal Care for People with Disabilities: A Call to Action

Monika Mitra, Ph.D.

Director, Lurie Institute for Disability Policy
Nancy Lurie Marks Associate Professor of Disability Policy
Heller School for Social Policy and Management
Brandeis University

Acknowledgements

Support for the research in this presentation was provided by:

National Institutes of Health and Human Development (NICHD)
R01HD074581, R01HD082105

National Institute for Disability, Independent Living, and
Rehabilitation Research (NIDILRR) 90DPHF0011.

The opinions and conclusions are solely ours and should not be construed as representing the funding agency.

Objectives

- 1: Describe the sexual, reproductive, and perinatal health care among women with different disabilities
- 2: Describe the unmet needs and barriers to care among women with disabilities
- 3: List recommendations to improving perinatal care among women with disabilities

Outline

- Why?
- Contraceptive use
- Preconception health
- Pregnancy experiences & outcomes
- Provider perceptions

A photograph of a family of three—two women and one man—smiling and posing in a pumpkin patch. The woman on the left is wearing a white jacket and a purple and black patterned scarf. The woman in the center is wearing a striped shirt and a purple and white patterned scarf. The man on the right is wearing a blue long-sleeved shirt and blue pants, holding a pumpkin. The background shows a field of pumpkins and trees under a cloudy sky.

Historically, women with disabilities were restricted from making their own choices about starting families.



Why?



Eugenics



**Involuntary
sterilization**



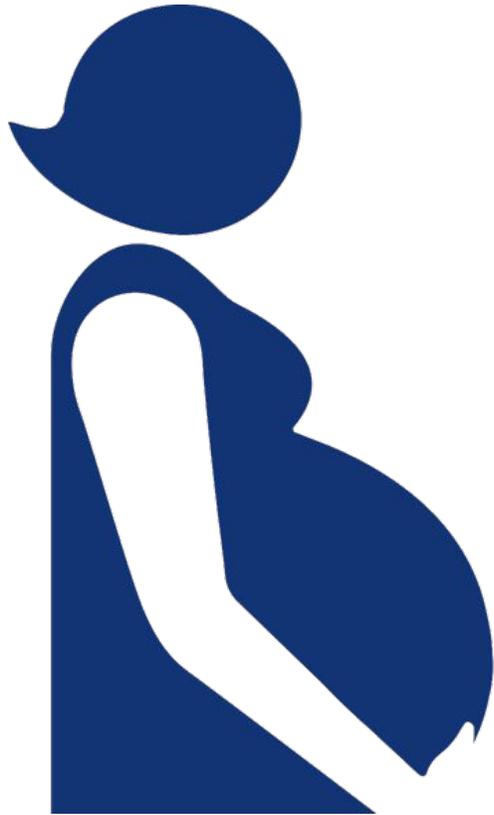
**Forced
institutionalization**



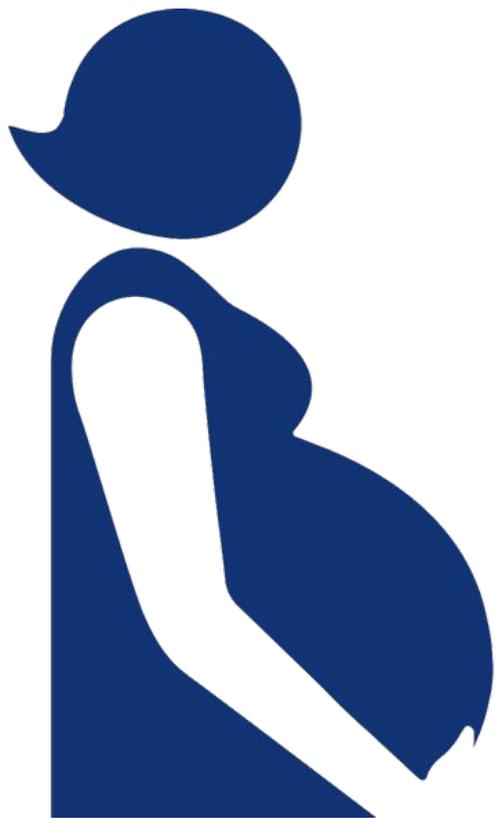
**Stigma and
discrimination**



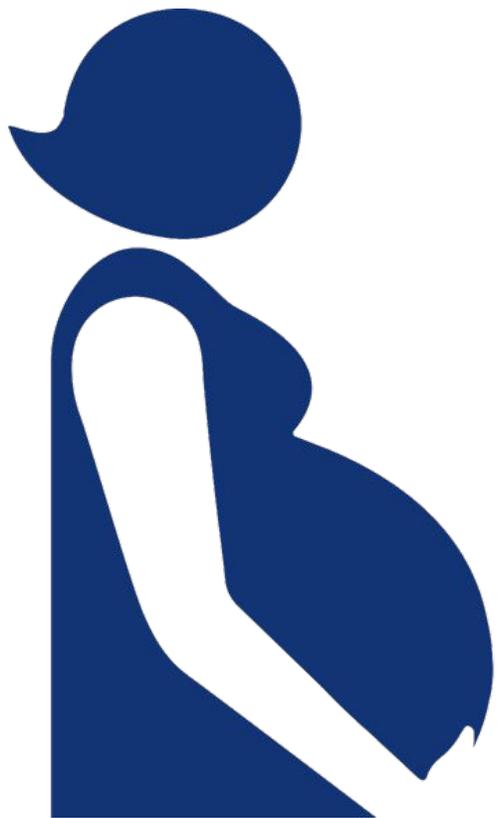
**Are women with
disabilities *still*
restricted from making
their own choices
about starting
families?**



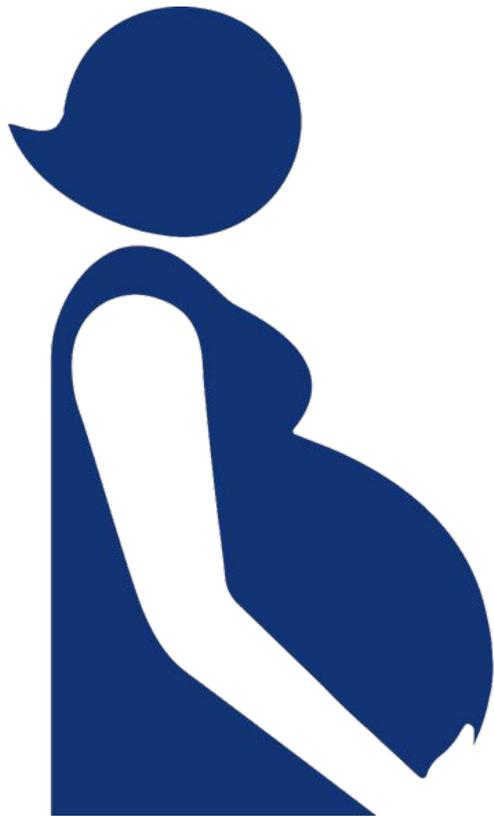
Parents and prospective parents with disabilities still face **stigma** regarding their decision to have children



Many states (in the US) have laws that allow state child welfare agencies to **remove dependent children from disabled parents'** homes solely because of their disability



Across the globe, girls and women with disabilities are still forcibly and involuntarily sterilized



Girls and women with disabilities continue to be denied of their right to experience their sexuality, to have sexual relationships and to found and maintain families

METRO NEWS... BUT NOT AS YOU KNOW IT 135.6M SHARES

NEWS SPORT ENTERTAINMENT SOAPS LIFESTYLE PLATFORM VIDEO MORE TRENDING

SEX HEALTH FASHION FOOD TRAVEL

Credibom credibom.pt 21 413 48 30

Disabled people are being 'excluded' from conversations about sexuality

Retale Morris Wednesday 18 Sep 2019 2:13 pm

134 shares

15 YEARS OF EXPERIENCE? THAT'S A GOOD START

MUST READ

LATEST OBSESSIONS FEATURED **QUARTZ** SHARE 201908 BECOME A MEMBER

As a disabled woman, my abortion wasn't questioned—but my pregnancy was

By Nicole Lee · September 18, 2019



Global NEWS

World Canada Local Politics Money Health Entertainment Lifestyle Watch

//ABANCA
Venha conhecer-nos

LIFESTYLE

Canada's health-care system isn't designed for parents with disabilities: experts

BY [MEGHAN COLLIE](#) · GLOBAL NEWS

Posted September 22, 2019 8:00 am
Updated September 22, 2019 2:17 pm





[Home](#) \ [World](#) \ [Mothers with disabilities: The forgotten margin in the feminist struggle](#)

Mothers with disabilities: The forgotten margin in the feminist struggle

By Admin Added 16th October 2019 11:26 AM

More recently, a few scholars have begun exploring the intersection of sex and disability, highlighting the unique obstacles facing women with disabilities.



CULTURE NEWS

Love and Other Disabilities

A British judge is forcing a disabled woman to have an abortion. As the son of a disabled woman, I can tell you: The decision is evil.

By [Harold Braswell](#)

When I was a kid, a strange woman would visit our house. Short, with stubbily cut hair, she would almost never turn to you, not responding even if you called her name. She dressed flagrantly, in patchwork clothing that she had sewn herself, and spent the entirety of her visits in a maelstrom of cleaning. Whipping the record player with a rag, banging colored pencils into a souvenir plastic cup, she appeared as some hybrid of the Tasmanian devil and a hobo clown. Yet she did appear, every month, and at the end of her appearances, I would hug her, tell her I loved her, and give her two kisses: one on each cheek. A strange woman, a strange ritual—even stranger because, as I knew, this strange woman was my mom.

[/ ABA Groups](#) / [/ Solo, Small Firm and General Practice Division](#) / [/ Publications](#) / [/ GPSolo Magazine](#) / [/ GPSolo March/April 2014: Disability Law](#)

April 02, 2019

Can Parents Lose Custody Simply Because They Are Disabled?

Robyn Powell

Share this:





Listen Live · 88.9 Bowling Green | 89.5 Owensboro | 89.7 Somerset | 90.9 Elizabethtown
A Way with Words



Home

Support Us ▾

WKU NPR ▾

Classical 97.5 ▾

Streaming ▾

About Us ▾

Events ▾

Search

THE SECOND CITY: GREATEST HITS
November 15, 2019 • Henderson, KY

HENDERSON AREA ARTS ALLIANCE

[GET YOUR TICKETS NOW!](#)

Owensboro Health

At Stake In Kentucky Supreme Court Case: Rights Of Parents With Intellectual Disabilities

By LISA GILLESPIE • JUN 6, 2019



Share



Tweet



Email



The Kentucky Supreme Court will soon



EMAIL NEWSLETTER

**SIGN UP FOR
OUR FREE
NEWSLETTER**

Pacific Standard

NEWS IN BRIEF ECONOMICS EDUCATION ENVIRONMENT SOCIAL JUSTICE FEATURES & INVESTIGATIONS IDEAS AUDIO

NEWSLETTER



HOME > SOCIAL JUSTICE

PARENTS WITH DISABILITIES FACE AN UPHILL BATTLE TO KEEP THEIR CHILDREN

Child removals due to disability are increasingly common, but parents have begun to fight back.

ROBYN POWELL · JAN 3, 2018



Up to 10% off for members.

There is a world of reasons
to book on Hyatt.com.

BOOK NOW

Or contact your personal travel advisor.





Contraceptive Use in Women with Disabilities

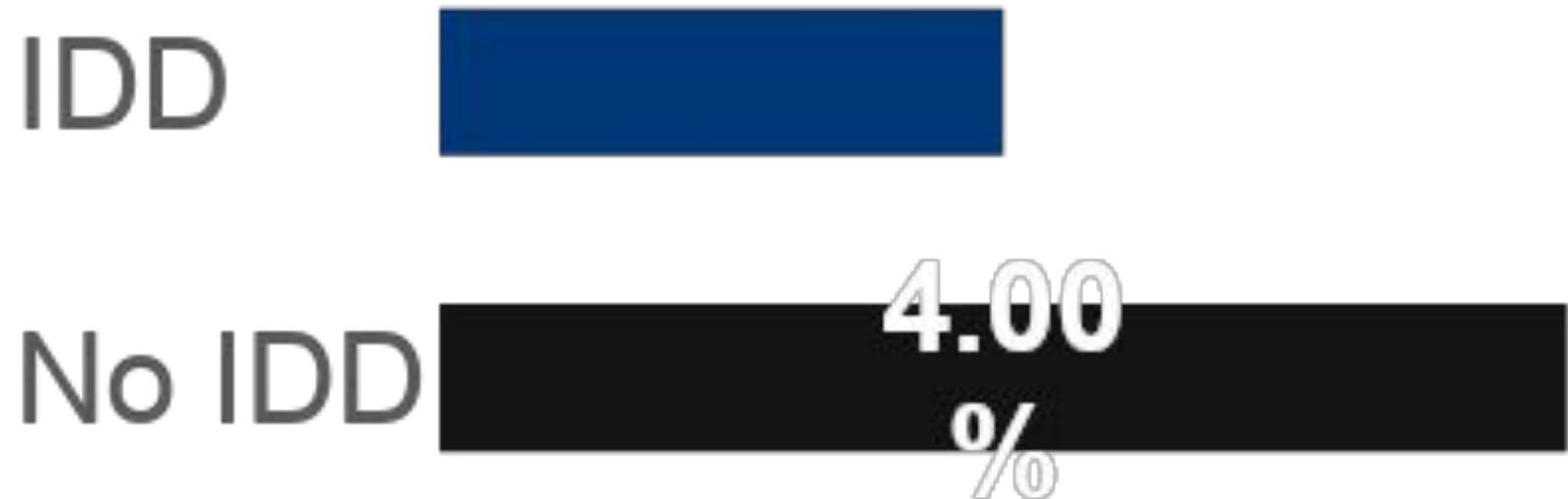


Women with disabilities often experience disparate treatment compared to women without disabilities when seeking contraceptive care.



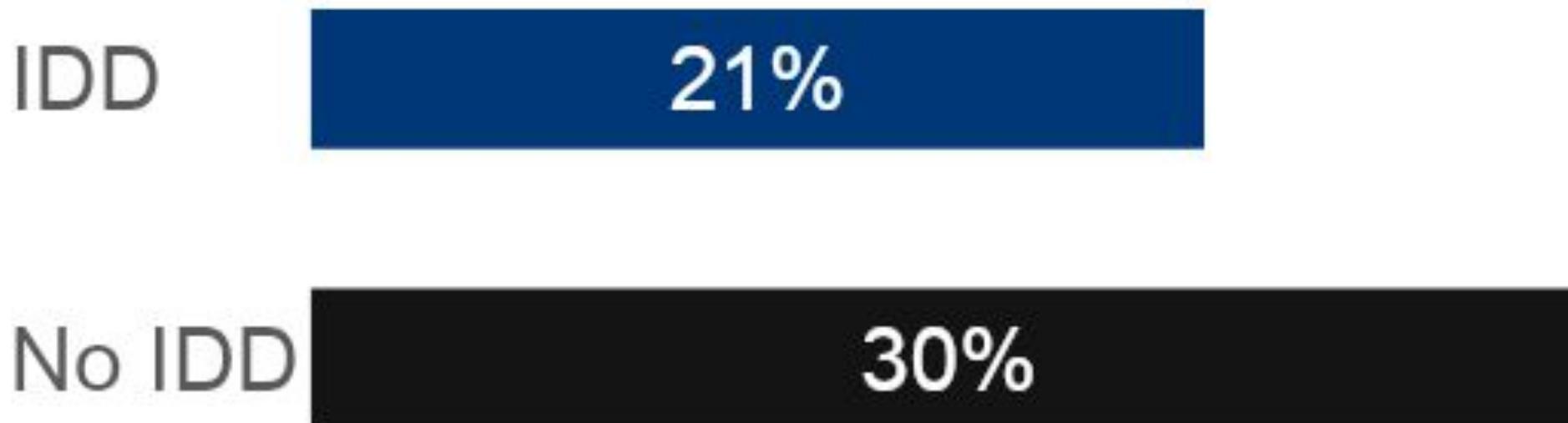
Adolescent and young adult women with disabilities report lower rates of contraceptive use

Long-Acting Reversible Contraception Use (LARC) among Women with Intellectual and Developmental Disabilities (IDD)



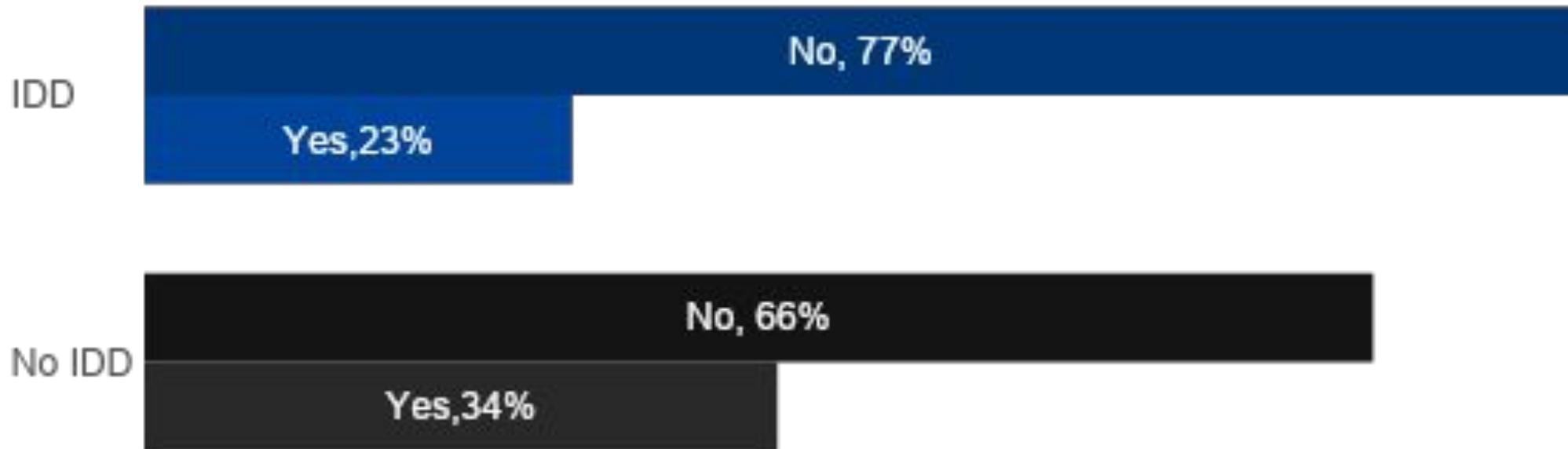
Women with IDD were **half as likely to receive LARC** as women without IDD

Moderately Effective Contraceptive Use among Women with Intellectual and Developmental Disabilities (IDD)



Women with IDD were less likely to receive moderately effective contraception than women without IDD

Did Women with IDD Receive Any Reversible Contraception at All?

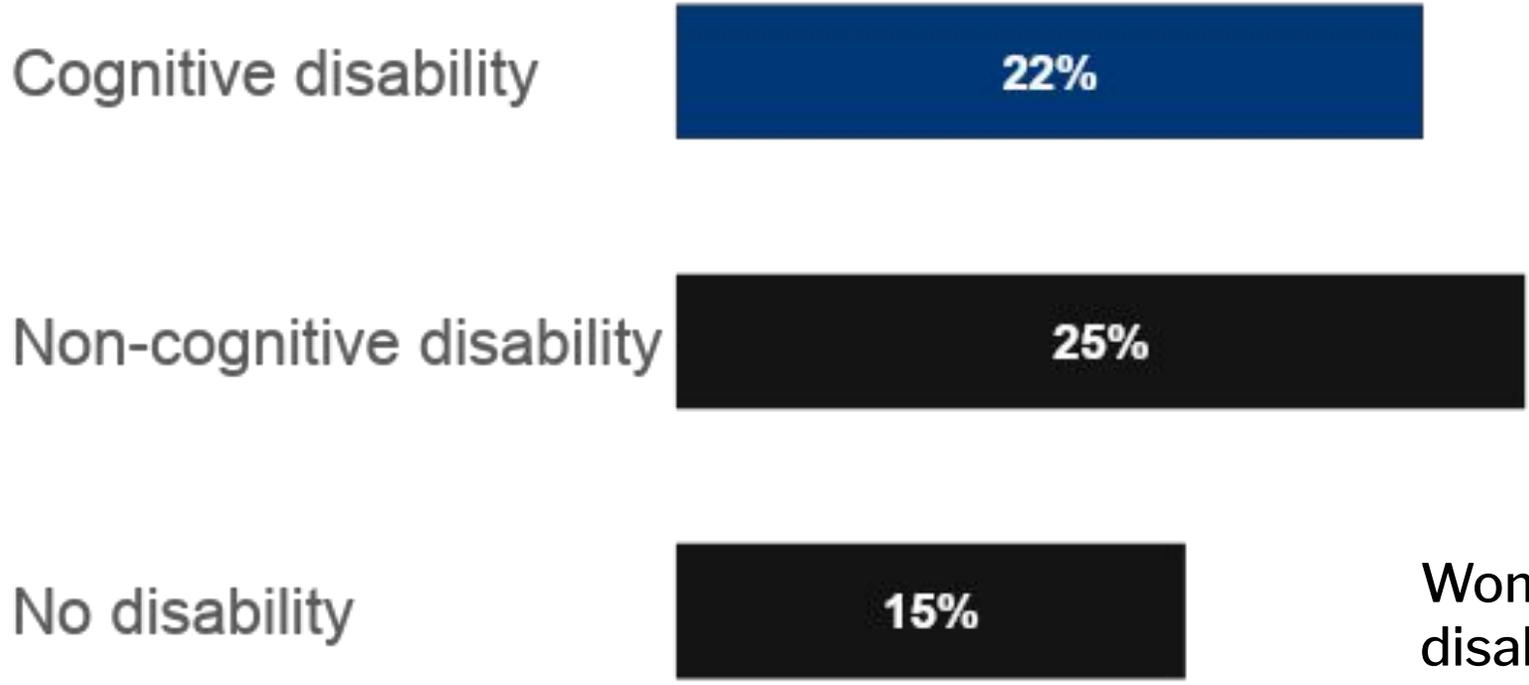


Only about 1 in 4 women with IDD received any form of reversible contraception



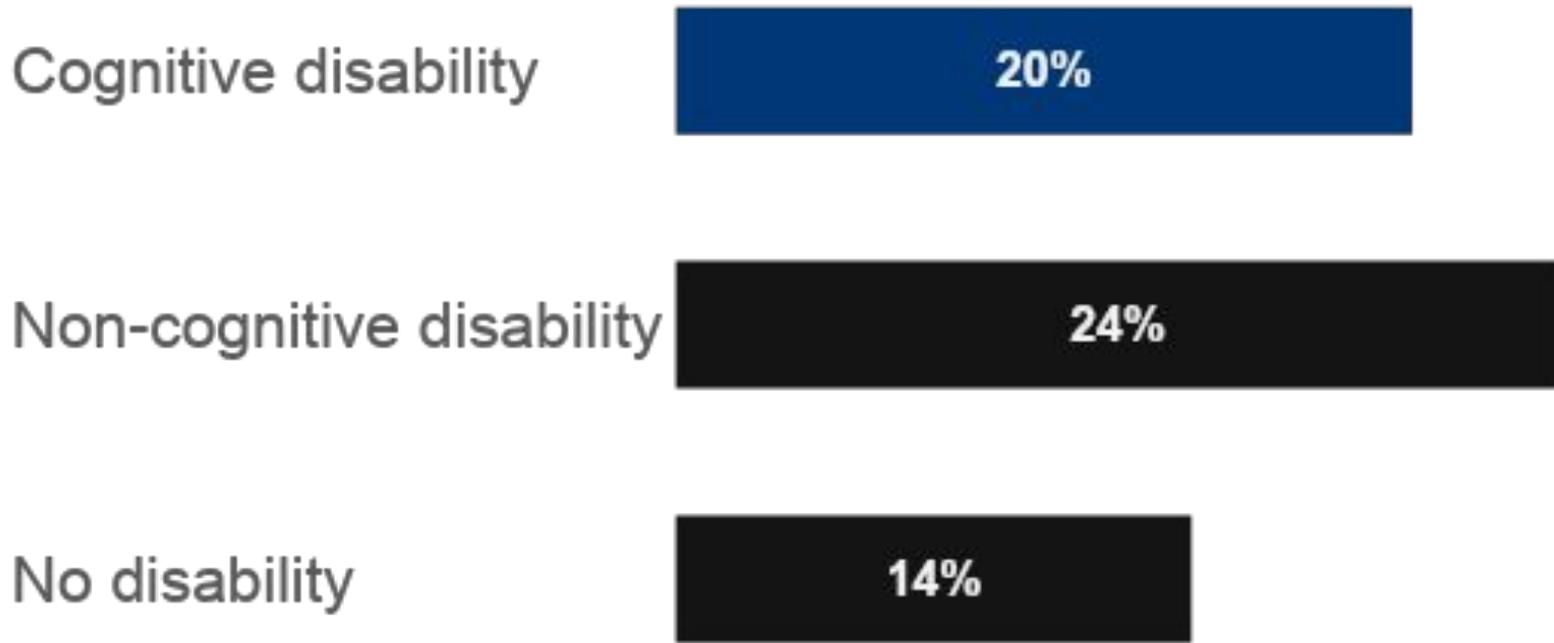
Sterilization of Girls and Women with Disabilities

Sterilization Rates by Disability Status



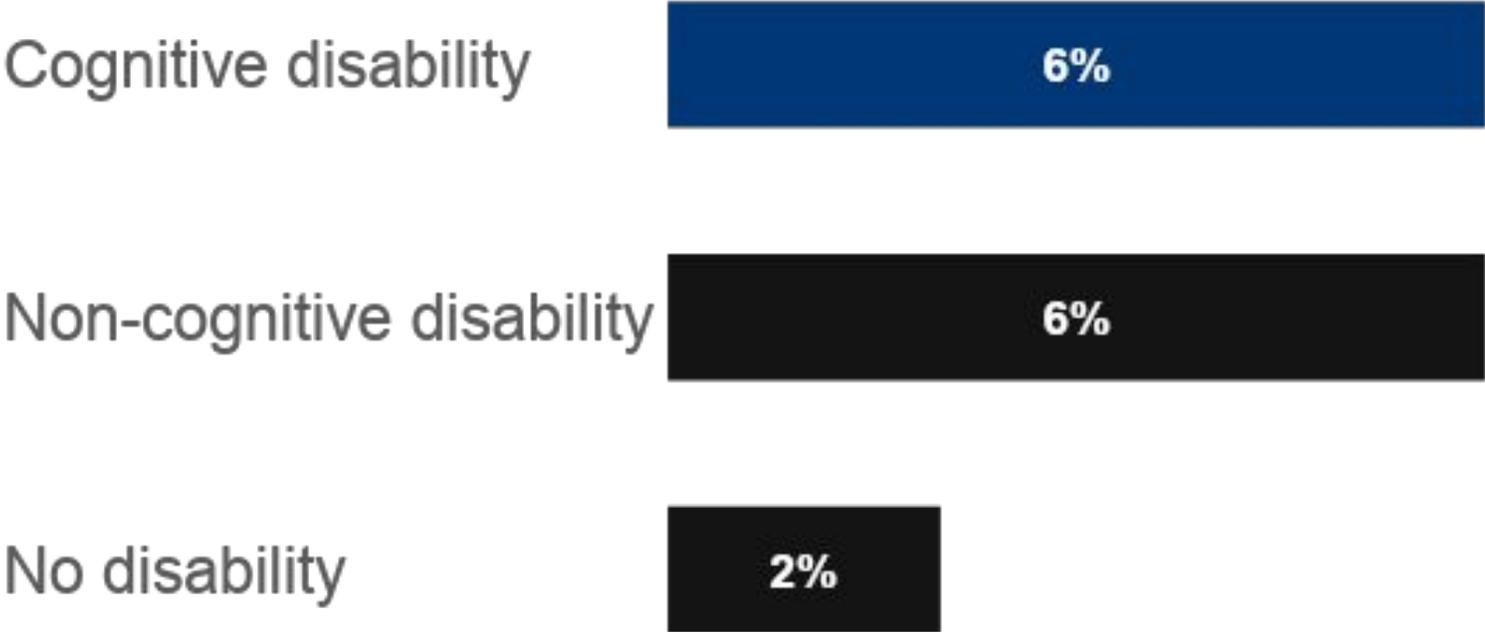
Women with all kinds of disabilities were more likely to be sterilized at all than women without disabilities

Tubal Ligation Rate by Disability Status



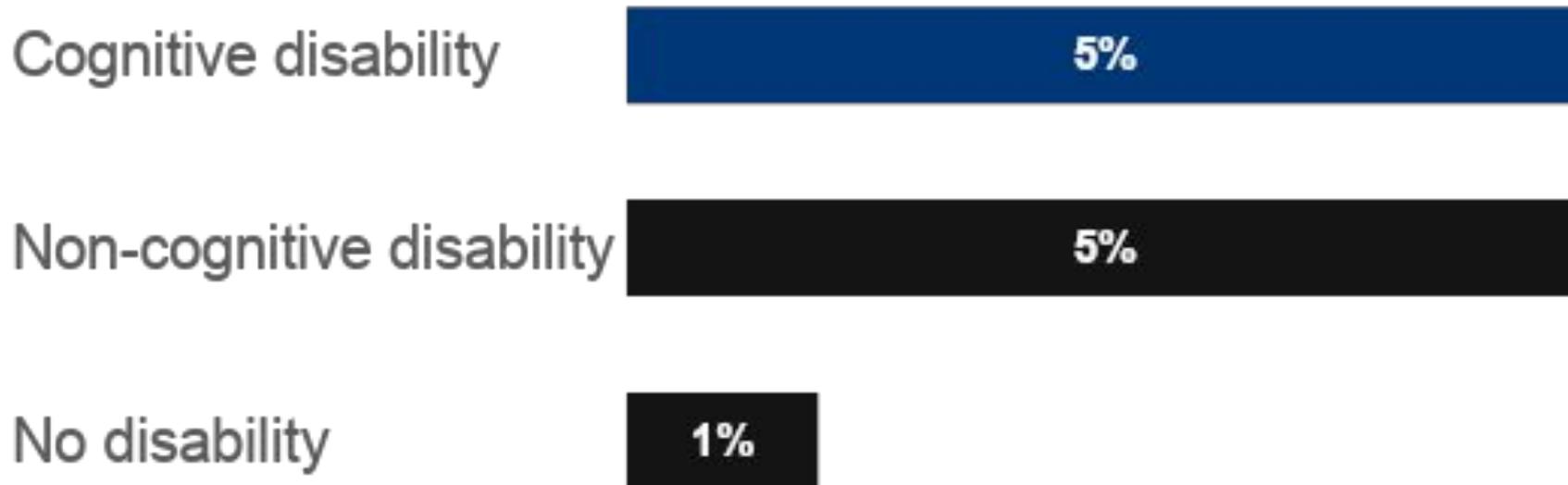
Women with all kinds of disabilities were more likely to receive tubal ligations than women without disabilities

Hysterectomy Rate by Disability Status



Women with all kinds of disabilities were more likely to receive hysterectomies than women without disabilities

Tubal Ligation and Hysterectomy Rate by Disability Status



Women with all kinds of disabilities were more likely to receive hysterectomies and tubal ligations than women without disabilities



- Women with both cognitive and non-cognitive disabilities were **more likely** to be sterilized than women without disabilities
- Women with cognitive disabilities were more likely to be sterilized at a **younger age**
- After taking into account race and other sociodemographic variables, women with **cognitive disabilities** were also more likely to be sterilized than women without disabilities or women with non-cognitive disabilities



Preconception Health of Women with Disabilities



Preconception Health

Similar proportions of women with and without disabilities experienced **sexual intercourse** between ages 12 and 24.



Preconception Health

Among women without children, women with and without disabilities report similar **pregnancy intentions** and desire for children



Preconception Health

Women with disabilities at reproductive age are more vulnerable to **multiple risk factors** associated with adverse pregnancy outcomes compared to their counterparts without disabilities



Preconception Health

In contrast to other women, women of childbearing age with disabilities were more likely to report

- fair or poor health,
- frequent mental distress,
- less emotional support.
- less exercise
- higher weight
- smoking in the past month,
- asthma
- diabetes



Perinatal Health of Women with Disabilities



Continuing healthcare inequities and the increased prevalence of pregnancy and motherhood among women with disabilities are the impetus for research on the **perinatal health** of women with disabilities.

Pregnancy among Women with and Without Disabilities

Similar proportions
of women with
physical disabilities
(10.4%) and
women without
disabilities (12.6%)
are pregnant
(Horner Johnson et
al 2016)



Pregnancy among Women with and Without Disabilities

Adjusting for age,
women with
chronic physical
disabilities and
non-disabled
women are equally
likely to be
pregnant (Iezzoni
et al 2015)

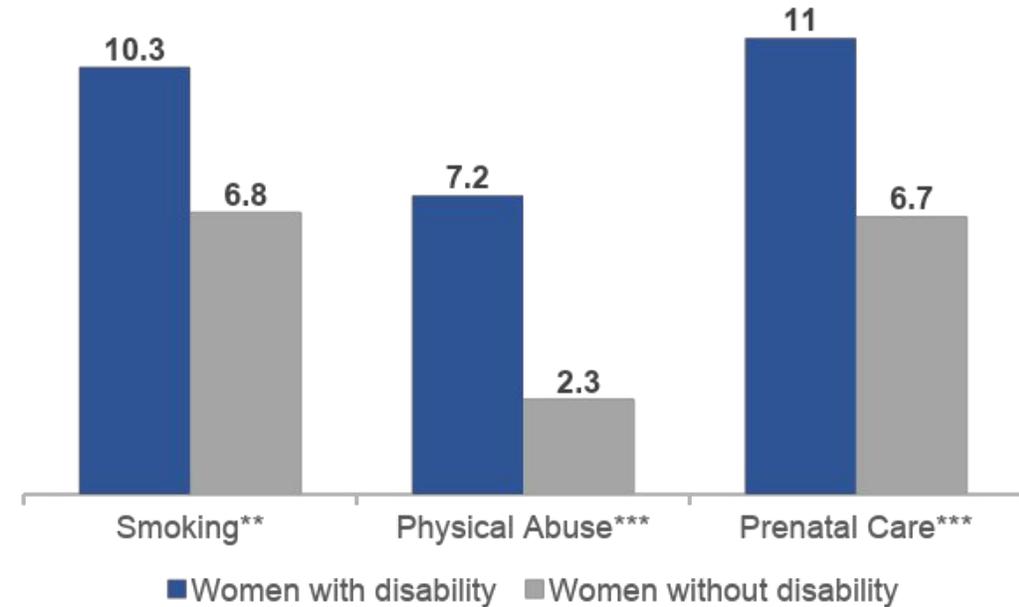


Smoking, Violence, and Access to Prenatal Care

Compared to non-disabled women, women with disabilities who recently gave birth were:

- Smoking
- Physical abuse
- Start prenatal care after the first trimester

Characteristics and Experiences of Women with Live Births During Pregnancy, by Disability Status



** p<0.01, ***p<0.001

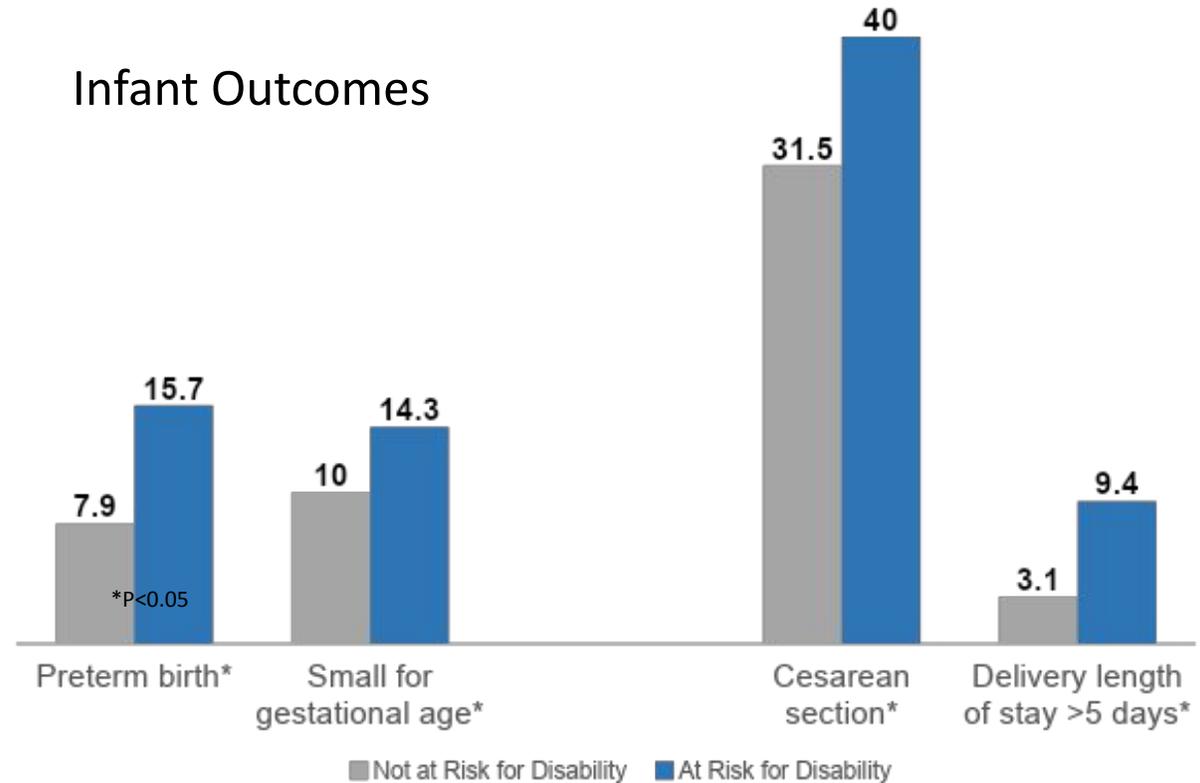
Data Source: 2002-11 RI PRAMS

Maternal and Birth Outcomes

Maternal Outcomes

Compared to non-disabled women, *women at risk for disabilities* who recently gave birth were:

- More likely to have a preterm birth infant
- Cesarean section



Women with Intellectual and Developmental Disabilities (IDD)



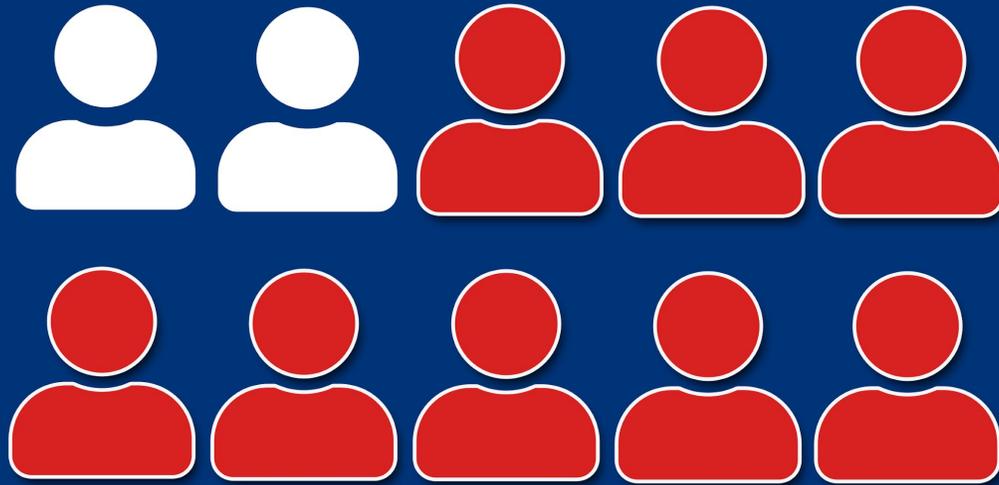
Compared to women without IDD, women with IDD

- Have higher risk of **emergency department visits and hospital stays** both before and after giving birth
- Are more likely to **stay in the hospital** longer

Women with Intellectual and Developmental Disabilities (IDD)

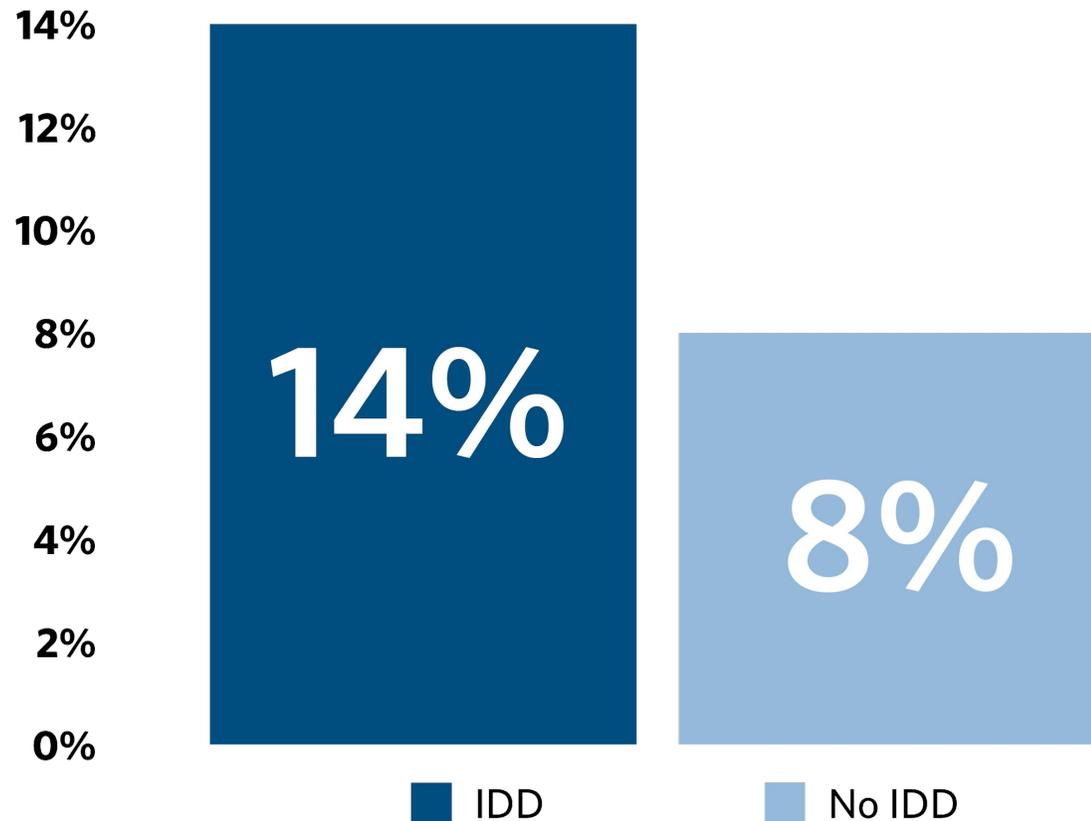


Women with IDD have higher risk for **pregnancy complications** and **poor birth outcomes** than women without disabilities



**Eight in 10 women with intellectual
and developmental disabilities
experience other complications
during pregnancy.**

Early or Threatened Labor (%)



Compared to women without IDD, women with IDD were almost twice as likely to experience early or threatened labor

Severe Maternal Morbidity

- Severe Maternal Morbidity includes multiple, possibly life-threatening outcomes of labor and delivery that can significantly affect women's short- and long term health
- Unintended outcomes of the process of labor and delivery that result in significant short-term or long-term consequences to a woman's health
- Women in the US have higher rates of SMM than women in similar countries

Women with Intellectual and Developmental Disabilities (IDD)



Women with IDD were

- 3.5 times higher risk of SMM compared to non-IDD (unadjusted)
- Adjusting for covariates, 2x risk of SMM (RR=1.98, 95% CI:1.76 - 2.22, $p < 0.001$)

Women with Intellectual and Developmental Disabilities (IDD)



Women with IDD

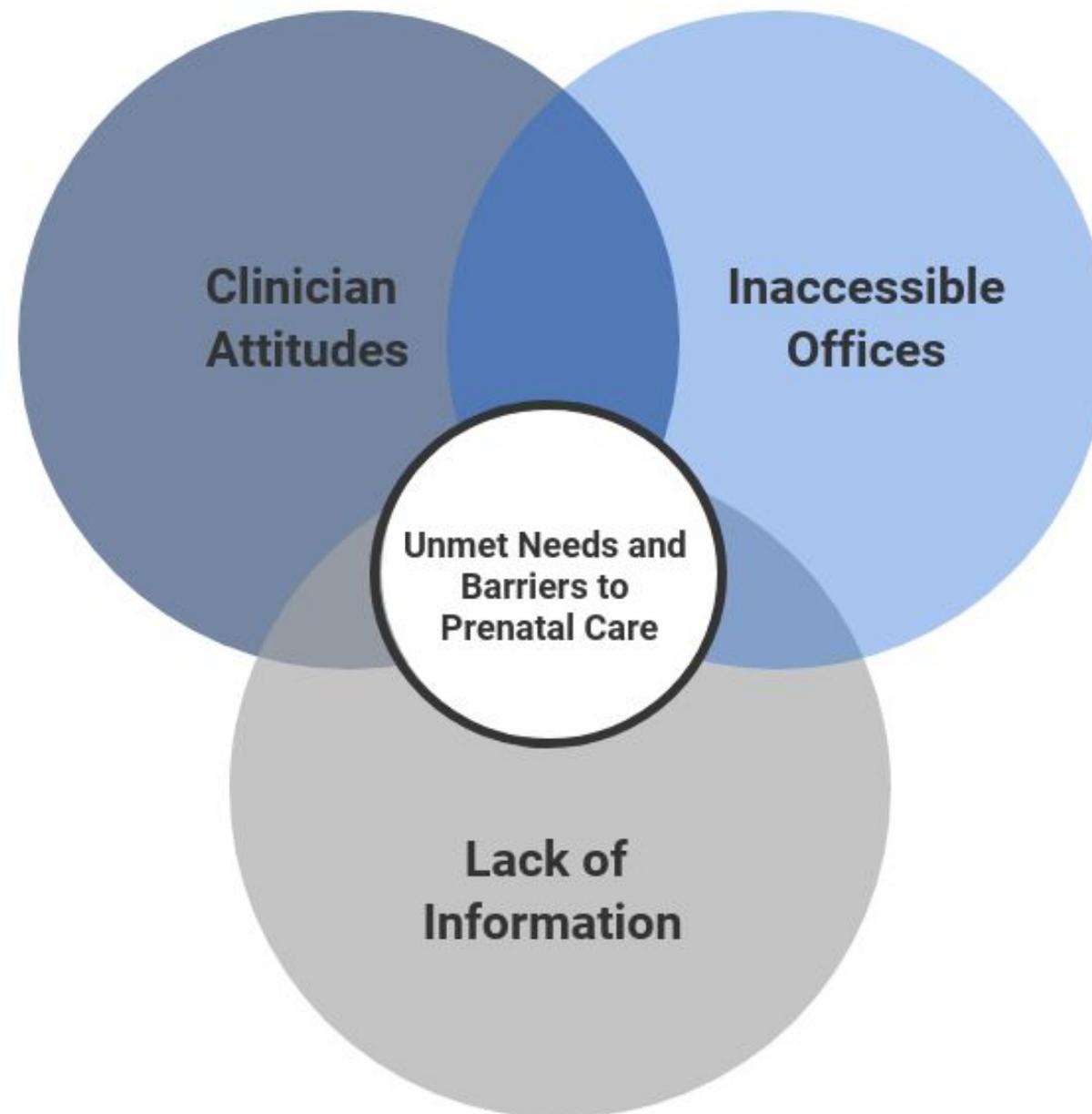
- Adjusting for socioeconomic, hospital-level, and clinical characteristics, 2 times risk of **maternal mortality** (RR=2.01, 95% CI: 1.20 - 3.37, $p < 0.001$)

A young woman with long dark hair, wearing a red hoodie and blue jeans, is lying on her back and smiling at the camera. The image is overlaid with a semi-transparent dark grey box containing white text.

Unmet Needs and Barriers to Care: Perspectives of Women with Physical Disabilities



Interviews with Women with Physical Disabilities in the United States



Clinician Knowledge and Attitudes



Some clinicians were very supportive and respectful

“...she knew how badly we wanted to have a baby and was supportive . . . I feel like she *treats me like a regular patient* and like I don't have a disability.”



Some women described being viewed by their clinicians as non-sexual

“I think probably the weirdest [comment] was ... from my doctor.... He asked us how we got pregnant, *and if we had used a turkey baster.*”



Lack of knowledge about effect of disability on pregnancy

“would automatically deliver at 26 weeks and my child, if it lives, *would be mentally and physically disabled*...Strictly because I was in a wheelchair and I needed care myself.”



Some clinicians had never had patient with a disability before

“(I)t just kind of felt like they didn’t know -- I was teaching them a lot of things, *which is not totally uncommon*.”

Clinician Knowledge and Attitudes

Accessibility of health care facilities and equipment

- “(a)nd after he realized that I only put on like not even six pounds through about half of the pregnancy, [he said], *‘I’m not worried . . . I can tell by looking at you that you’re at a healthy weight, you’re OK.’*”
- *“It’s a pain... pregnant or not. And it was hard and towards the end [of the pregnancy]... I’d get a stool and put a stool next to a chair, put a chair next to the table, and just kind of stair step my way up there.”*



Need for Information



Interaction of disability and pregnancy

“I really didn’t have anybody to turn to, so there -was - not much information that I knew about pregnancy and having a disability . . . *There’s nobody I knew -- who was disabled and having kids.*”



Appropriate prenatal care clinicians

“[Finding a provider] was actually much harder than I thought it was going to be. The first couple preconception appointments I had, the OBs were very negative. They of course did not really understand SMA, so *they were coming in just seeing the disability, with some preconceived notions.*”

A photograph of a man and a woman sitting on a patio. The man, on the left, is wearing a blue shirt and is talking on a mobile phone. The woman, on the right, is wearing a patterned top and is smiling. A black dog is sitting on the patio in front of her. The background shows a blurred outdoor setting with a car and some structures.

Barriers to providing perinatal care to women with physical disabilities: perspective from health care practitioners

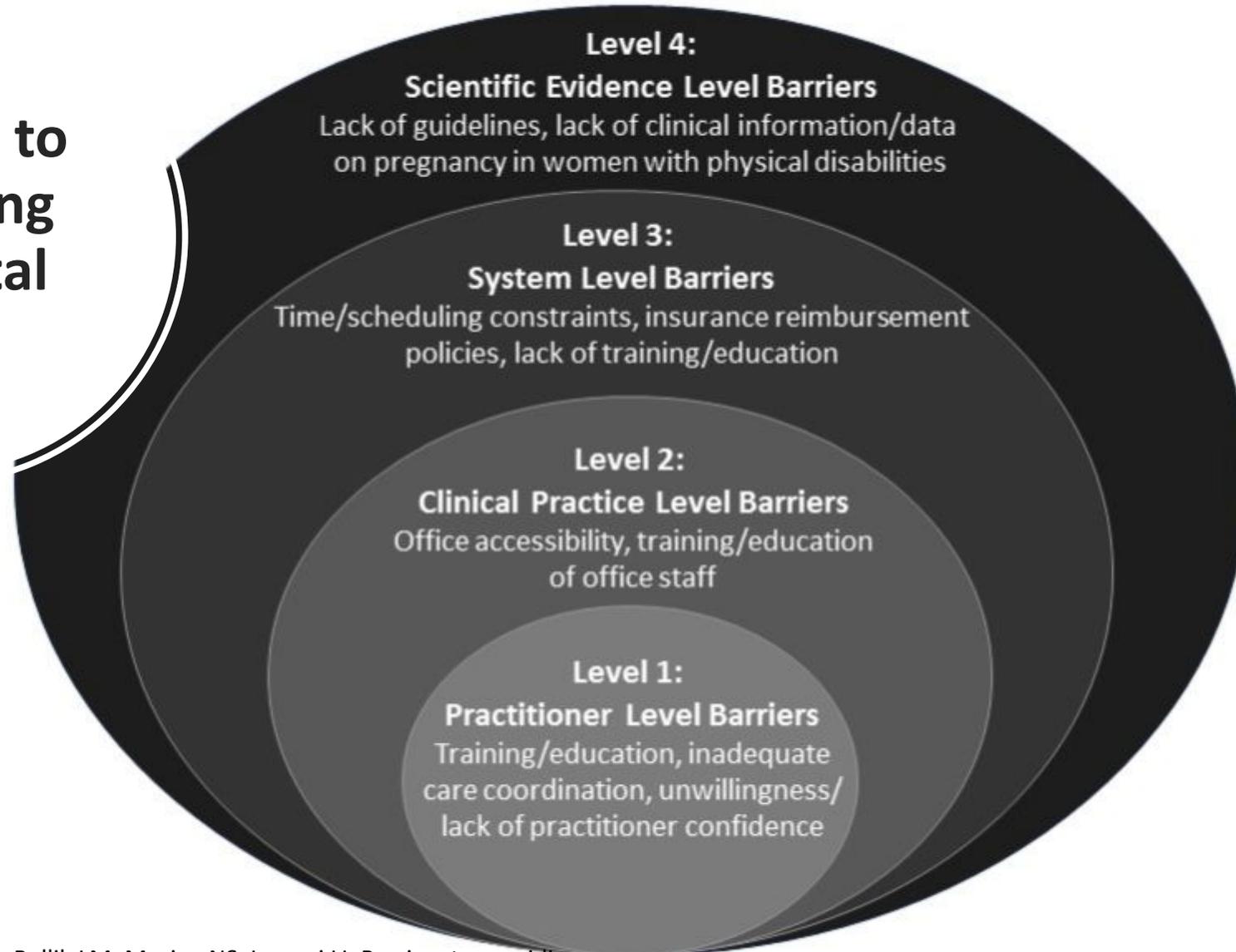
Healthcare providers lack training and experience relating to disability care

- 81% of medical students have no clinical training in disability care
- 75% of residents have no clinical experience in disability care
- 44% of Ob/Gyn clinics in 4 cities reported being unable to provide for people with mobility disabilities

Holder M, Waldman HB, Hood H. Preparing health professionals to provide care to individuals with disabilities. *Int J Oral Sci.* 2009;1(2):66-71.

Lagu T, Hannon NS, Rothberg MB, et al. Access to subspecialty care for patients with mobility impairment: a survey. *Ann Intern Med.* 2013;158(6):441-446

Barriers to Providing Perinatal Care



Practitioner Level Barriers



- Lack of training/education related to maternity care and specific clinical needs
- Unwillingness in providing maternity care to women with physical disabilities
- Inadequate coordination of care between practitioners

Practitioner Level Barriers: Lack of Training

“...physicians feel uncomfortable, untrained, unprepared, and their offices are also equally untrained and unprepared...So unfortunately, they [patients with disabilities] end up in a perinatology office just because they have a physical disability, not because they truly have an unusual obstetrical clinical problem.”

Clinical Practice Level Barriers: Inaccessible Equipment

Accessible exam tables and scales

- “They sometimes get weighed at their other [doctors] that are taking care of them...we kind of rely on them, if they can’t get out of their wheelchair.”
- “I generally just *eyeball*. We spend a lot of time talking about it.”

System-Level Barriers: Scheduling and Reimbursements

Pressure to keep appointment times within prescribed time slots (often 10 or 15 minutes)

“We are so locked into these 15- and 30-minute slots now, in medical practice, that it’s very hard...for any one doc[tor] to *isolate an hour or an hour and a half for a patient visiting*. And many of these patients will take an hour.”

“You don’t get paid any extra. *You do this because it’s the right thing to do and you want to do it and you love to do it and the patients appreciate it*. And that’s why you do it. You don’t do it for money. It’s a money loser. No insurance company, whether it’s commercial, state, or federal is going to pay me more.”

Need for Guidelines and Evidence-Based Clinical Data

Extrapolating data about non-pregnant women and even men with disabilities to pregnant women

On-the-job learning and training

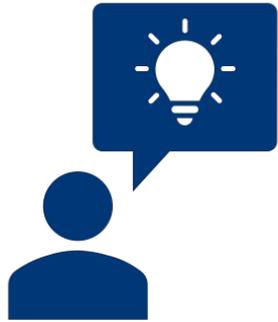
“...in my general practice almost any decision I make...I can [go] to UpToDate or some sort of reference, ACOG recommendation, and they'll tell me exactly what to do, but *in the disability clinic, that's not the case.*”

Preparing for Patients with Disabilities

- Helpful to **know specific, intensive needs** of each patient with disabilities beforehand
- **Flag visits** with helpful information including need for extra staff members, special equipment, etc.
- Increase the **length of the scheduled appointment**
- Learn where **resources** like patient lifts or transfer boards are located

Dr. John Harris, MD, MSc, McGee Women's Research Institute, 2019, Presentation at the National Perinatal Association Annual Conference, Providence, Rhode Island.

Recommendations



Providing
information for
women and
healthcare
professionals



Training for
providers and hiring
more providers with
expertise



Improving
provider
communication
and interaction

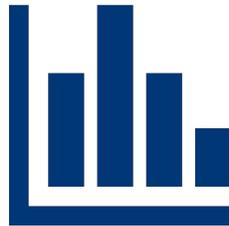
Recommendations



Improving physical
accessibility of
healthcare
facilities



Developing
appropriate
interventions and
guidelines to address
disparities



Improving data and
surveillance

[Español](#)

National Research Center for Parents with Disabilities

Parents Empowering Parents

Padres Empoderando a Padres



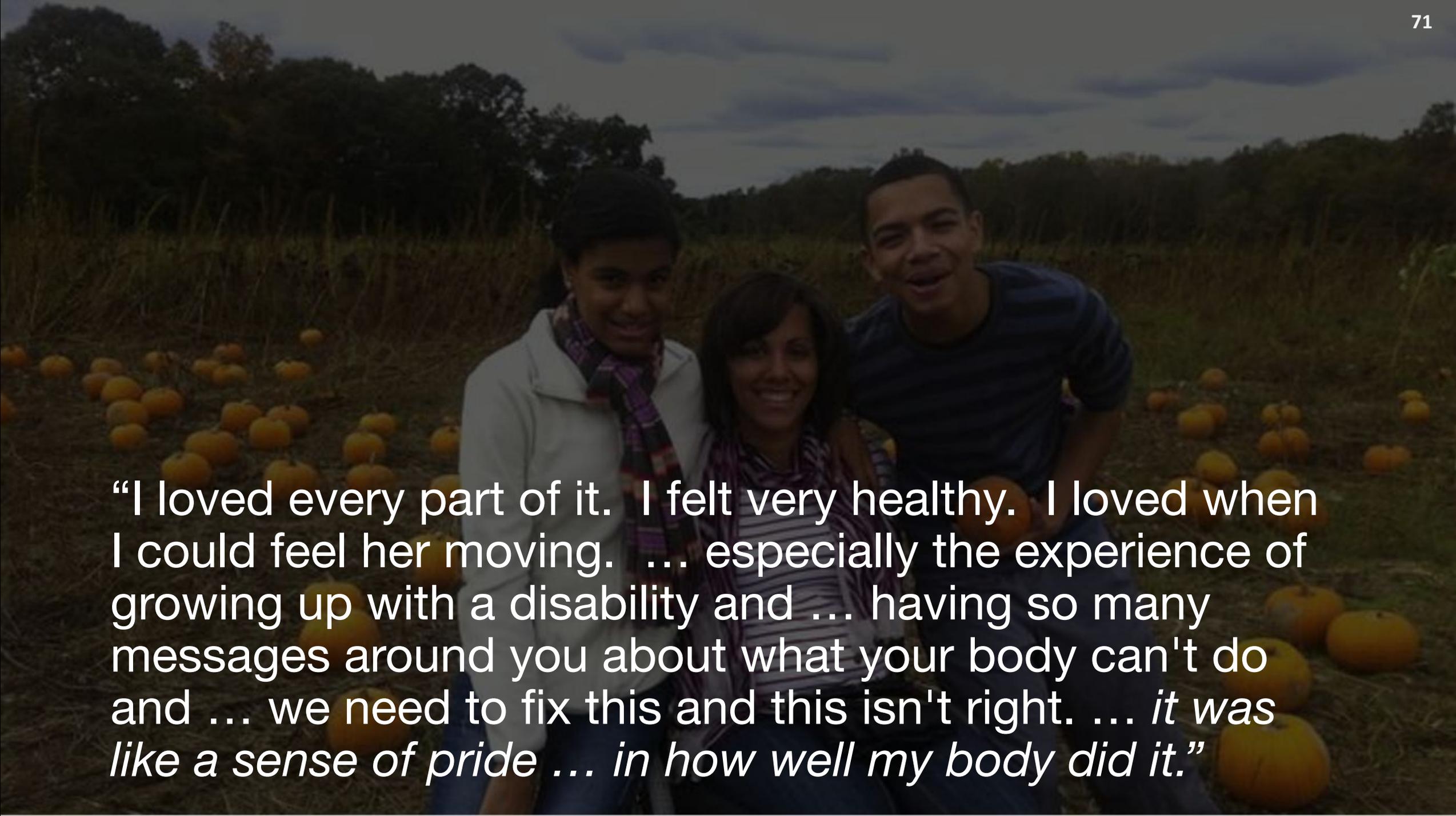
The National Research Center for Parents with Disabilities conducts research and provides training and technical assistance to improve the lives of parents with



We offer resources to support [parents](#) with disabilities, and information about working with parents with disabilities for [social workers](#), [researchers](#) and [legal](#)



The Center for Parents recognizes that parents with disabilities know what they need. We are guided by the principle "nothing about us without us."



“I loved every part of it. I felt very healthy. I loved when I could feel her moving. ... especially the experience of growing up with a disability and ... having so many messages around you about what your body can't do and ... we need to fix this and this isn't right. ... *it was like a sense of pride ... in how well my body did it.*”



Thank You