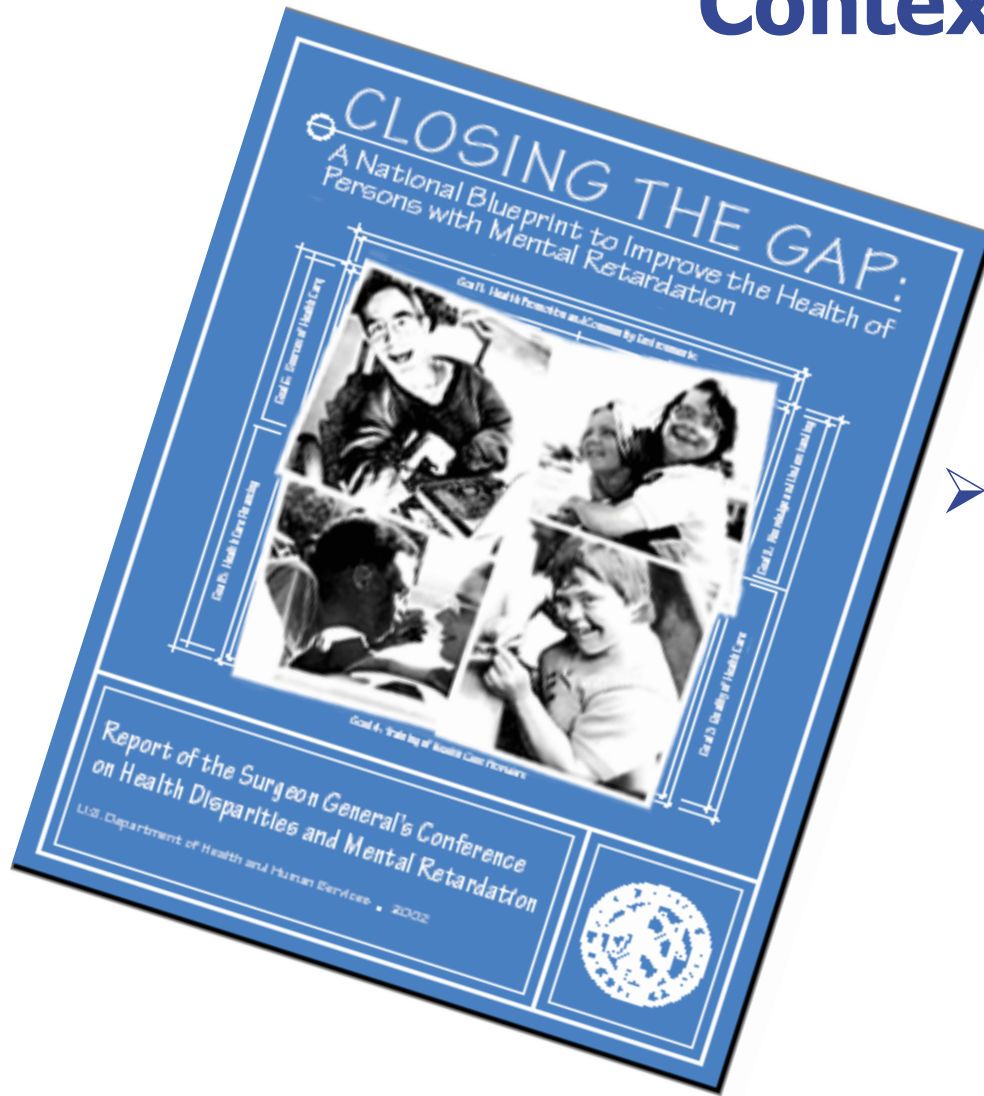


Pregnancy Outcomes of Women with Developmental Disabilities

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*Health Matters***

Context



- “Cascade of disparities” for people with developmental disabilities (Krahn *et al.*)

Eugenic History

- Eugenics movement in the early part of the 20th century
 - 31 American states passed laws prohibiting women with intellectual and developmental disabilities from marrying or procreating
- Institutionalization and involuntary sterilization prevented pregnancy among women with intellectual disabilities
- At least 60,000 women with ID/DD were sterilized by 1950 (Cepko, 1993)
- Recent generations of such women have had the same reproductive rights as their non-disabled peers

Background

- Women with intellectual and developmental disabilities are becoming pregnant and giving birth
 - Coercive sterilization, institutional segregation and marriage restrictions of the past are giving way to community living in the US
- Prevalence of childbirth among US women with intellectual and developmental disabilities is not known
 - Using US Census Bureau data and CDC prevalence estimates that 1.3% of women have IDD, we estimate nearly 820,000 US women of childbearing age have intellectual and developmental disabilities
- Very few population-based studies of pregnancy outcomes (Australia, Sweden)
 - Generally negative outcomes for mothers and infants

Research Questions

- In the US, are pregnancy outcomes for women with intellectual and developmental disabilities worse than for other women?
- What are the characteristics of deliveries to US women with ID?

Research Strategy

- Two levels of analysis:
- **HCUP Data**
- Healthcare Cost and Utilization Project
- National, cross-sectional data to understand of obstetric complications and outcomes
- **PELL Data**
- Pregnancy to Early Life Longitudinal
- Longitudinal linked data from Massachusetts to document complications, outcomes among deliveries to women with ID

Design: HCUP Analysis

- Secondary analysis of data from the Healthcare Cost and Utilization Project for calendar year 2010
- Nationally-representative hospitalizations for pregnancies in US hospitals
 - Fewer than 3% of US births occur outside of hospitals
 - US women with intellectual and developmental disabilities highly unlikely to have non-hospital births
- Independent variable: women with intellectual and developmental disabilities identified by ICD9 codes
- Data derived from hospital discharge records

Outcomes

- Caesarean delivery
- Early labor
- Hypertensive complication
- Preterm birth
- Fetal growth restriction
- Days in hospital for delivery

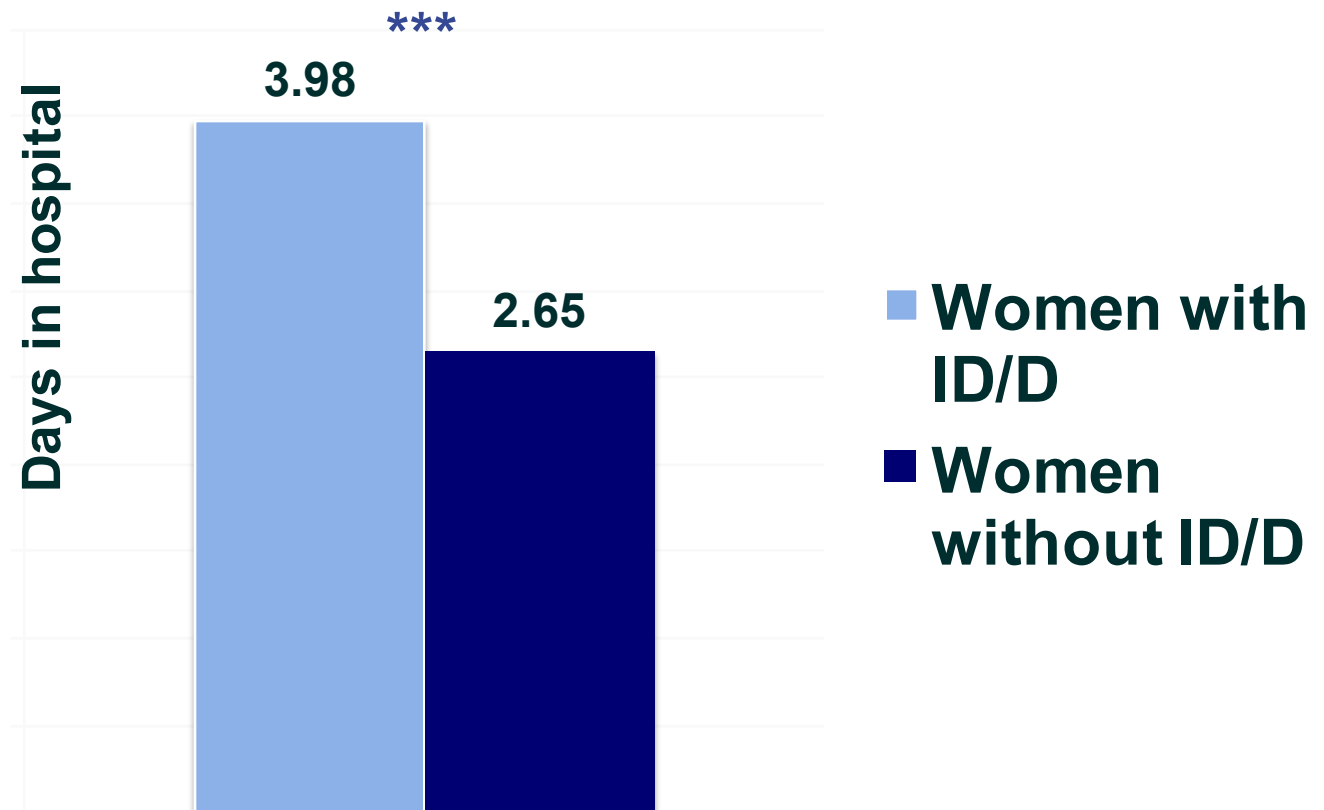
Description of the HCUP Sample

Characteristics	Women with IDD n = 340	Women without IDD n = 768,891
Race is Black***	28%	15%
Ethnicity is Latina or Hispanic***	12%	22%
Aged 18-24 years***	42%	31%
Aged 25-34***	44%	52%
Aged >34 years***	9%	14%
Has public health insurance***	74%	47%

*** $p < .001$

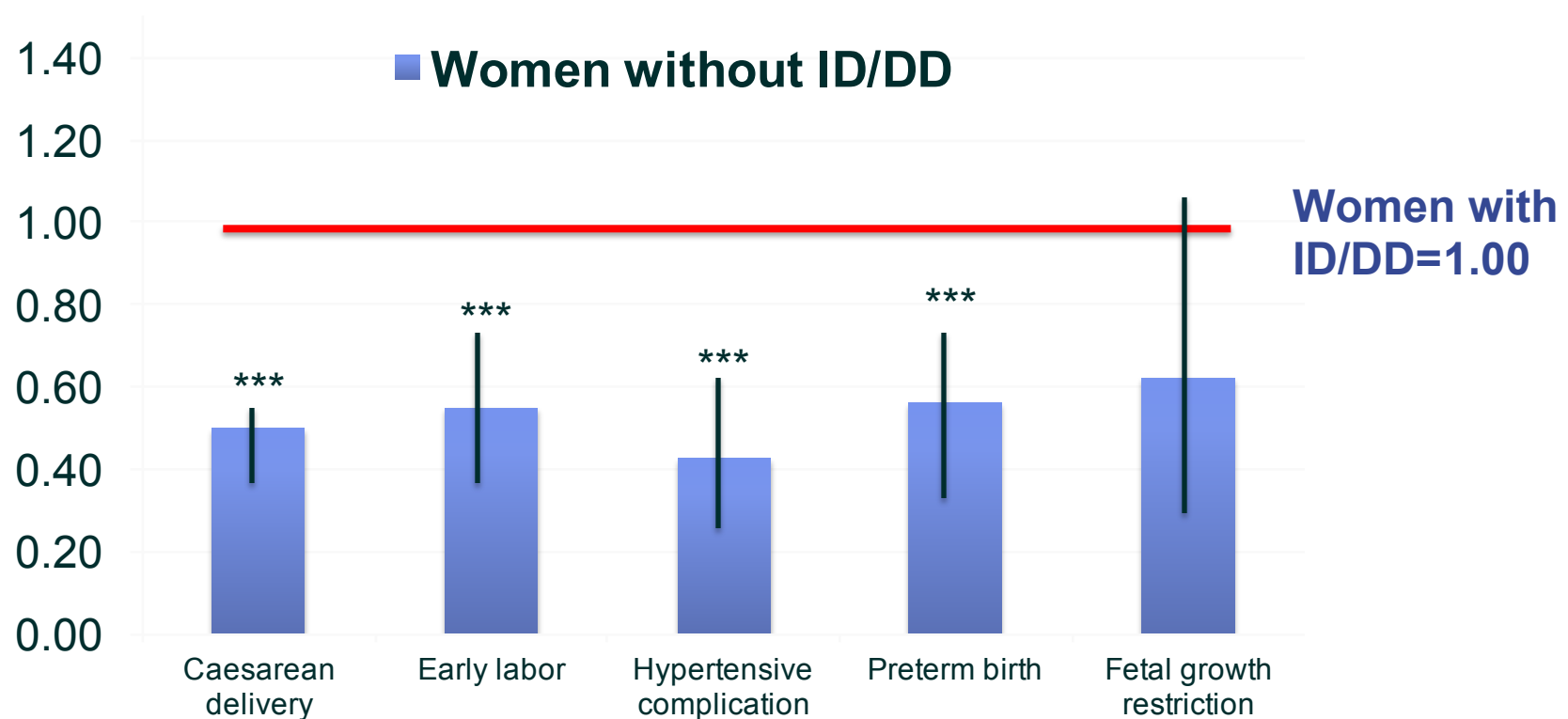


Mean days of delivery-related hospitalizations for women with and without IDD, 2010



*** $p < .001$

Adjusted odds ratios of adverse delivery outcomes for US women with and without ID/DD



Notes. Adjusted for race, Hispanic ethnicity, insurance type, age
*** $p < .001$

Summary: HCUP analyses

- Women with intellectual and developmental disabilities were more likely to have:
 - Caesarean deliveries
 - Early labor
 - Hypertensive (blood pressure) complications
 - Preterm birth
- These outcomes have high public health costs
- These findings also indicate women with intellectual and developmental disabilities and their infants are not having good outcomes

Design: PELL Analysis

- Longitudinally, linked, population-based reproductive health data system
- Includes Massachusetts birth certificates and fetal death records linked to the corresponding delivery hospital discharge records for both the mother and infant
- Linked annually
- Data analyzed from 1998-2010

Outcomes

- Preterm delivery
- Very low birth weight
- Low birth weight
- Apgar score
(5 min after birth)
- Perinatal mortality
- Method of delivery
- Access to prenatal care in first trimester
- Adequacy of prenatal care (Kotelchuck's Adequacy of Prenatal Care Utilization Index)

Description of the PELL (Massachusetts) Sample, 1998-2010

Characteristics	Women with IDD n = 340	Women without IDD n = 768,891
Race is Black*	14%	8%
Ethnicity is Latina or Hispanic*	17%	13%
Aged 18-24 years*	37%	23%
Married*	34%	70%
Nativity: US born*	82%	73%
Has public health insurance***	80%	35%
Father named on birth certificate***	68%	92%

*** $p < .001$



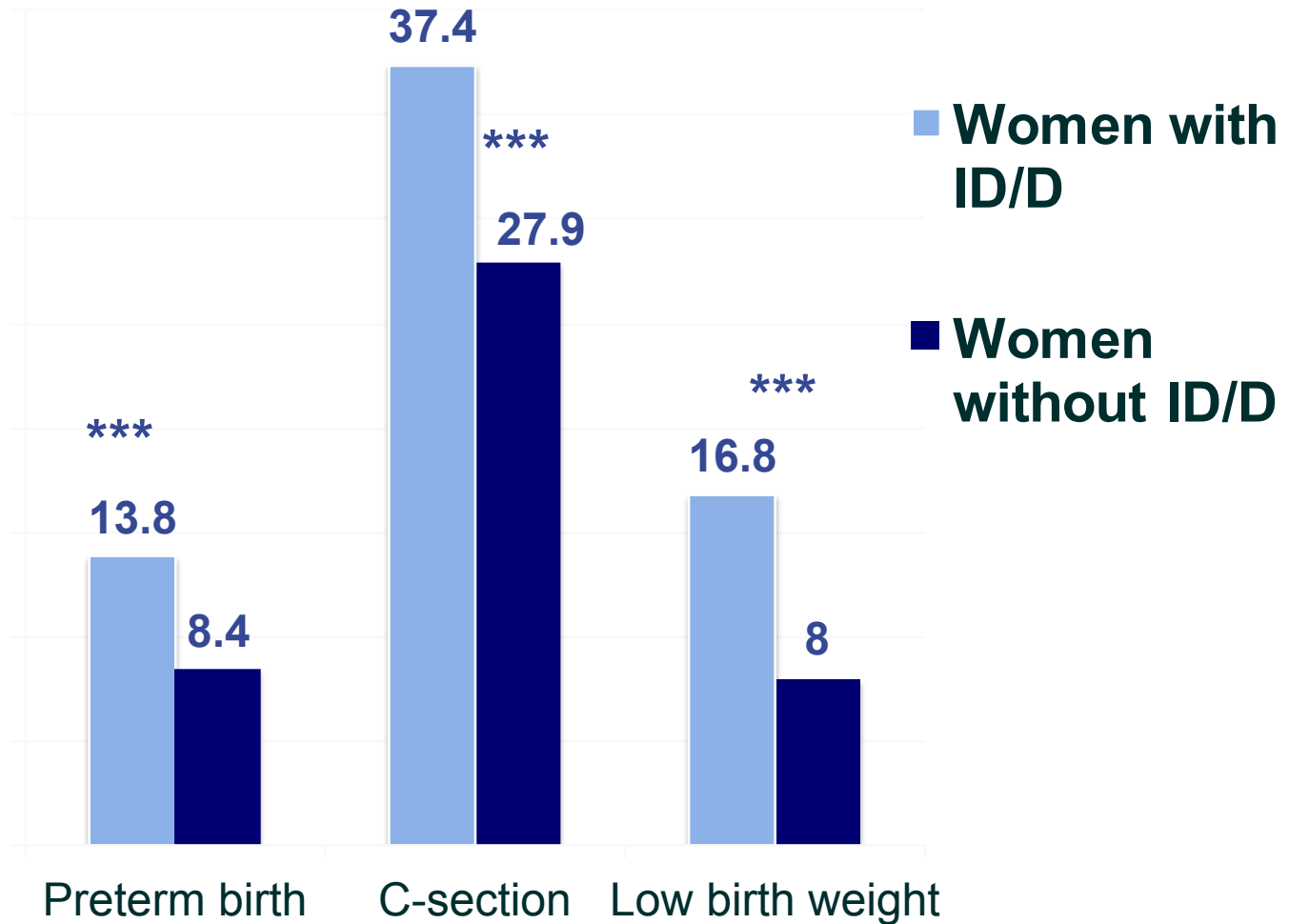
Unadjusted Outcomes, Massachusetts women 1998-2010

Characteristics	Women with IDD n = 703	Women without IDD n = 865,369
Breastfeeding at discharge***	49%	77%
Smoked during pregnancy***	20%	9%
Prenatal care during 1 st trimester***	70%	83%
Inadequate prenatal care quality***	19%	9%

*** $p < .0001$



Percent of Women with Adverse Pregnancy Outcomes (PELL, 1998-2010)

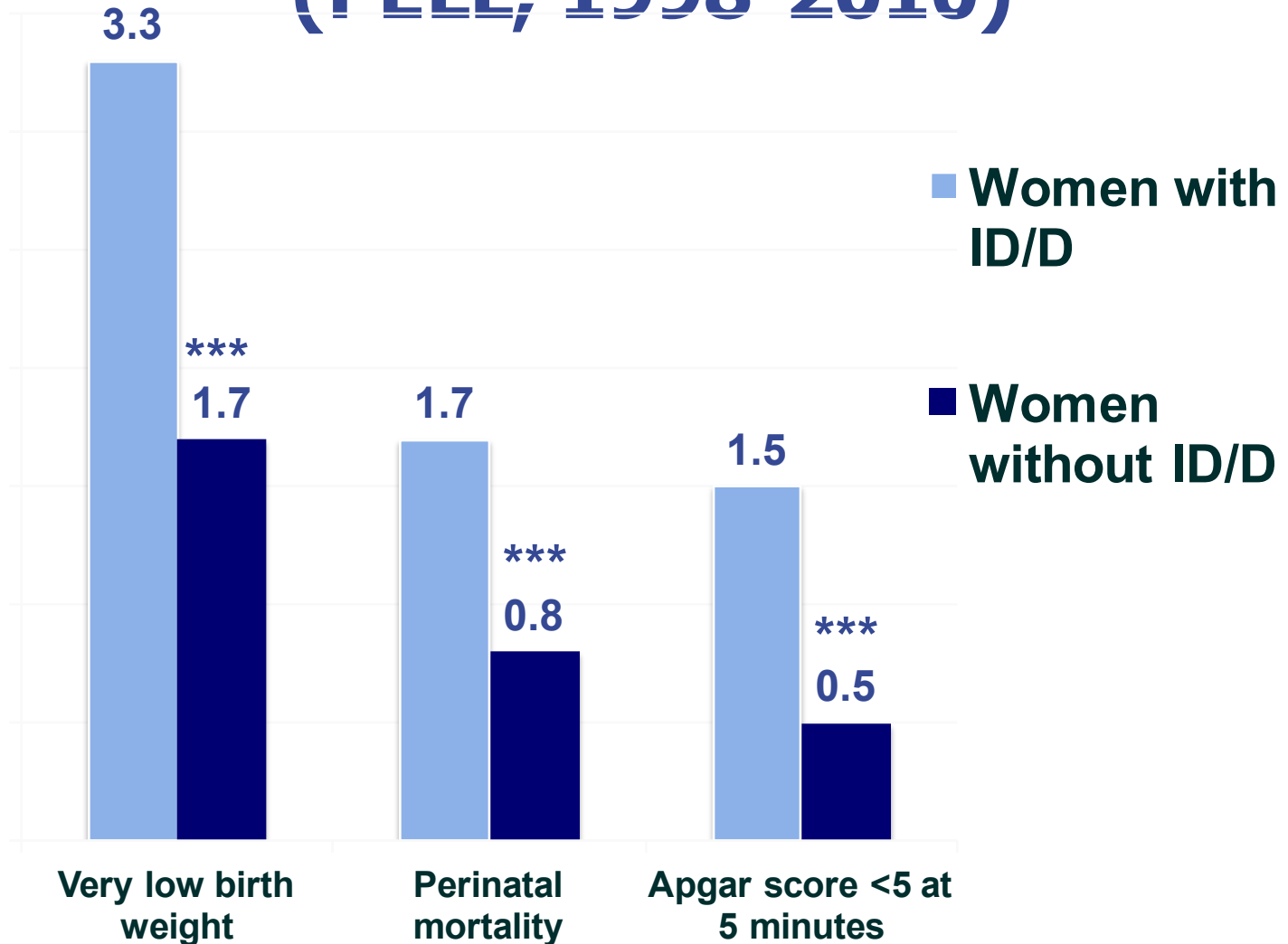


*** $p < .001$

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Percent of Massachusetts women with adverse pregnancy Outcomes (PELL, 1998-2010)



*** $p < .001$

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Conclusions

- US women with intellectual and developmental disabilities have markedly higher rates of adverse pregnancy outcomes in contrast to other women
 - These poor outcomes persist after controlling for age, race, ethnicity, and insurance type
- Findings about poor quality prenatal care, and the reduced likelihood of receiving prenatal care in the first trimester represent potential intervention targets
- Further research is needed to understand why mothers with intellectual and developmental disabilities have worse outcomes than other mothers
- There is a critical need for interventions to improve outcomes for mothers with intellectual and developmental disabilities and their infants

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