Pregnancy Outcomes of Women with Developmental Disabilities

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Health Matters
“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
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 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

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Women with IDD n = 340</th>
<th>Women without IDD n = 768,891</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race is Black</td>
<td>28%</td>
<td>15%</td>
</tr>
<tr>
<td>Ethnicity is Latina or Hispanic</td>
<td>12%</td>
<td>22%</td>
</tr>
<tr>
<td>Aged 18-24 years</td>
<td>42%</td>
<td>31%</td>
</tr>
<tr>
<td>Aged 25-34</td>
<td>44%</td>
<td>52%</td>
</tr>
<tr>
<td>Aged &gt;34 years</td>
<td>9%</td>
<td>14%</td>
</tr>
<tr>
<td>Has public health insurance</td>
<td>74%</td>
<td>47%</td>
</tr>
</tbody>
</table>

*** 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

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

*** p < .001
## Unadjusted Outcomes, Massachusetts women 1998-2010

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Women with IDD n = 703</th>
<th>Women without IDD n = 865,369</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breastfeeding at discharge***</td>
<td>49%</td>
<td>77%</td>
</tr>
<tr>
<td>Smoked during pregnancy***</td>
<td>20%</td>
<td>9%</td>
</tr>
<tr>
<td>Prenatal care during 1st trimester***</td>
<td>70%</td>
<td>83%</td>
</tr>
<tr>
<td>Inadequate prenatal care quality***</td>
<td>19%</td>
<td>9%</td>
</tr>
</tbody>
</table>

*** $p < .0001$
Percent of Women with Adverse Pregnancy Outcomes (PELL, 1998-2010)

- Preterm birth: 13.8% vs. 8.4%
- C-section: 37.4% vs. 27.9%
- Low birth weight: 16.8% vs. 8%

*** p < .001

Noted: LURIE INSTITUTE FOR DISABILITY POLICY
Percent of Massachusetts women with adverse pregnancy outcomes (PELL, 1998-2010)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Women with ID/D</th>
<th>Women without ID/D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low birth weight</td>
<td>3.3</td>
<td>1.7</td>
</tr>
<tr>
<td>Perinatal mortality</td>
<td>1.7</td>
<td>0.8</td>
</tr>
<tr>
<td>Apgar score &lt;5 at 5 minutes</td>
<td>1.5</td>
<td>0.5</td>
</tr>
</tbody>
</table>

*** p < .001
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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