Pregnancy Outcomes of Women with Developmental Disabilities

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

Health and health care access, quality and service utilization are often wholly inadequate for women and men with intellectual and developmental disabilities in the United States.
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
- Very few population-based studies of pregnancy outcomes (Australia, Sweden)
- Generally negative outcomes for mothers and infants
Research Questions

- What is the prevalence of pregnancies among US women with developmental disabilities?
- Are the pregnancy outcomes for women with developmental disabilities worse than for other women?
**Design**

- 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
Outcomes

➢ Caesarean delivery
➢ Early labor
➢ Hypertensive complication
➢ Preterm birth
➢ Fetal growth restriction
➢ Days in hospital for delivery
## Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Women with ID/ DD n = 340</th>
<th>Women without ID/ DD 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 ID/DD, 2010

***

Days in hospital

3.98

2.65

Women with ID/D

Women without ID/D

*** p < .001

LURIE INSTITUTE FOR DISABILITY POLICY
Adjusted odds ratios of adverse delivery outcomes for US women with and without ID/DD

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

- 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.
Thank you!

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