Birth outcomes among US women with intellectual and developmental disabilities

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ABSTRACT

Background: Women with intellectual and developmental disabilities (IDD) are bearing children at increasing rates. However, there is very little research about pregnancy experiences and birth outcomes among women with IDD. No studies to date have examined birth outcomes with a US population-based sample.

Objective: The main objective was to estimate the national occurrence of deliveries in women with IDD and to compare their birth outcomes to women without IDD.

Methods: We examined the 2007–2011 Nationwide Inpatient Sample of the Healthcare Cost and Utilization Project to compare birth outcomes in women with and without IDD. Birth outcomes included preterm birth, low birth weight, and stillbirth. Multivariable regression analyses compared birth outcomes between women with and without IDD controlling for race/ethnicity, maternal age, household income, health insurance status and type, comorbidity, region and hospital location, teaching status, ownership, and year.

Results: Of an estimated 20.6 million deliveries identified through the HCUP 2007–2011 data 10,275 occurred in women with IDD. In adjusted regression analyses, women with IDD compared to those without IDD were significantly more likely to have preterm birth (OR = 1.46; 95% CI: 1.26–1.69, p < 0.001), low birth weight (OR = 1.61, 95% CI: 1.27–2.05, p < 0.001), and stillbirth (OR = 2.40, 95% CI: 1.70–3.40, p < 0.001).

Conclusion: This study provides a first examination of the birth outcomes among women with IDD in the United States using a largest population-based sample. There are significant differences in birth outcomes between women with and without IDD. Understanding the causes of these differences and addressing these causes are critical to improving pregnancy outcomes among women with IDD.

The federal government has encouraged researchers to address the lack of research about healthcare disparities for people with disabilities. The Surgeon General’s Closing the Gap report1 found, “Especially as adolescents and adults, people with [IDD] … face ever-growing challenges in finding and financing primary and specialty health care that responds both to the characteristics of [IDD] and to the distinctive health care needs of each stage of life.” Further, the CDC's Healthy People 2020 initiative outlines various priorities related to improving the well-being of expectant mothers and their children and reducing health disparities of vulnerable populations, including people with disabilities.2

Salient Healthy People 2020 aims include reducing low birth weight and preterm births and increasing receipt of adequate prenatal care.2

Recent studies suggest women with IDD in the United States are at greater risk for pregnancy complications and adverse birth outcomes compared to women without IDD. Negative birth outcomes are likely for women with IDD, because of the “cascade” of health disparities that accrue to people with IDD and which are based on biological, social and environmental factors.3 Parish and colleagues4 analyzed Healthcare Cost and Utilization Project (HCUP) data to understand pregnancy outcomes for mothers with IDD in the United States. They found that women with IDD had longer hospital stays and were more likely to have caesarean deliveries in

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contrast to other women. Mitra and colleagues\(^5\) analyzed Massa- 
chusetts Pregnancy to Early Life Longitudinal data and found that 
women with IDD who delivered were younger, less educated, more 
likely to be black and Hispanic, and less likely to be married than 
other women who delivered.

A handful of research from other countries has found that 
children born to mothers with IDD have increased risk of adverse 
fetal outcomes. Brown and her colleagues examined the pregnancy 
complications and birth outcomes among Canadian women with 
IDD.\(^9\)–\(^12\) Deliveries to Canadian women with IDD in their study were 
more vulnerable to medical complications during pregnancy and 
their babies were more likely to be born preterm and small for their 
gestational age. A Swedish study found that children born to 
mothers with IDD were more often stillborn or died perinatally 
than children born to mothers without IDD.\(^5\) Similarly, an Austra-
lian cohort study found that 28% of children in their sample born to 
mothers with IDD were born prematurely, and 22% had low birth 
weights.\(^5\) However, most of this research has been conducted with 
relatively small samples that are not representative of the general 
population.

Further research is clearly warranted to understand the preg-
nancy experiences and birth outcomes of US women with IDD. To 
address some of these research gaps, this study used a nationally 
representative data set to (1) investigate the number of deliveries 
occurring in women with IDD in the United States, and (2) compare 
the percentage of deliveries complicated by adverse birth outcomes 
in US women with and without IDD. Given the increased risk of 
poor health among people with IDD and their reduced healthcare 
access,\(^11\)\(^–\(^13\) we hypothesized that the birth outcomes of infants 
born to women with IDD would be worse than infants born to the 
general obstetric population.

Methods

Data source

Data for this study were derived from the Nationwide Inpatient 
Sample (NIS) of the Health Care and Cost Utilization Project (HCUP), 
the largest all-payer, publicly available US inpatient healthcare 
database. It contains data on approximately 8 million hospital stays 
each year from about 1000 hospitals. This approach yields 
approximately a 20% stratified sample of US community hospitals. 
The sample of hospitals was drawn from 46 states and was divided 
into 60 strata based on geographic region, ownership, location, 
teaching status, and bed size. Detailed information on the design of 
the survey is available elsewhere.\(^14\)

The HCUP NIS contains more than 100 clinical and nonclinical 
data elements for each hospital stay, including primary and up to 24 
secondary diagnoses and up to 14 procedures coded using ICD-9 
CM. Records also include admission and discharge status, pa-
tients’ demographic characteristics (e.g., sex, age, race), hospital 
characteristics (e.g., size, teaching status), Elixhauser comorbid-
ities,\(^15\) type of health insurance, total charges, and length of stay.\(^16\) 
The HCUP NIS does not include unique patient identifiers, so the 
unit of analysis is the hospitalization and not the woman or the 
infant. However, each delivery is associated with only one preg-
nancy; any woman who delivered more than once in a single cal-
endar year was counted twice. Nevertheless, this situation is 
uncommon because short inter-pregnancy intervals that result in 
US women giving birth twice within a twelve-month period are 
relatively rare.\(^17\)

Sample

All delivery-related hospitalizations were included in the 
analysis. Delivery hospitalizations were identified using the Inter-
national Classification of Disease, Ninth Revision, Clinical Modifica-
tions (ICD-9-CM codes 640.0–676.9), where the fifth digit is 1 
delivered, with or without mention of antepartum condition) or 2 
delivered, with mention of postpartum complication) or ICD-9-CM 
650 (normal delivery).

Women with IDD were identified from ICD-9-CM codes (see 
Table 1 for complete listing). The comparison group was identified 
as any delivery hospitalization among women without IDD. Due to 
the small number of cases of deliveries in women with IDD, we 
combined data from four years (2007–2011) to increase the sample 
size, hence the statistical power of the analyses.

Measures

Dependent variables

The main dependent variables included the following birth 
outcomes: (1) preterm birth\(^1\) identified using ICD-9-CM code 644.2, 
644.20, 644.21, 765.0 and 765.1; (2) low birth weight\(^2\) (656.5, 
656.50, 656.51, and 656.53) and stillbirth identified using ICD-9-CM 
code 656.4, 656.40, 656.41, 656.43, 768.0, 768.1, V271, V273, and 
V274.

Independent variables

The main independent variable was the IDD status of a woman 
with the delivery-related hospitalization.

Covariates

Model covariates included maternal age, racial and ethnic 
identity (non-Hispanic White, non-Hispanic Black, Hispanic, non-
Hispanic other), Elixhauser comorbidities (having 1 or more of 
the comorbidities identified by Agency for Health Care Research 
and
developmental disability.

<table>
<thead>
<tr>
<th>Intellectual and developmental disabilities</th>
<th>ICD-9 codes</th>
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<tbody>
<tr>
<td>Mild mental retardation</td>
<td>317</td>
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<tr>
<td>Moderate mental retardation</td>
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<tr>
<td>Severe mental retardation</td>
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<td>Profound mental retardation</td>
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<td>Unspecified mental Retardation</td>
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<td>Fragile X syndrome</td>
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<td>Prader-Willi syndrome</td>
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<td>Lesch Nyhan</td>
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<td>Cri du chat</td>
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<td>Fetal alcohol syndrome</td>
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<td>Cerebral palsy Spastic</td>
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<td>Cerebral palsy spastic non-congenital infantile</td>
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</tbody>
</table>


\(^1\) Birth of an infant before 37 weeks of pregnancy (Source: World Health Organization).
\(^2\) Birth of an infant weighting less than 2500 g (Source: World Health Organization).
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