



SPECIAL ISSUE: Sexual and Reproductive Health of Women with Disability
Research paper

Birth outcomes among US women with intellectual and developmental disabilities



Ilhom Akobirshoev, PhD, MA, MSW^{*}, Susan L. Parish, PhD, MSW, Monika Mitra, PhD,
Eliana Rosenthal

Lurie Institute for Disability Policy, Brandeis University, Waltham, MA, USA

ARTICLE INFO

Article history:

Received 7 December 2016
Received in revised form
2 February 2017
Accepted 19 February 2017

Keywords:

Women intellectual and developmental
disabilities
Pregnancy
Birth outcomes
Low birth weight
Preterm birth
Stillbirth

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.

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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

^{*} Corresponding author. Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University, 415 South Street, Waltham, MA 02453, USA.

E-mail address: ilhom@brandeis.edu (I. Akobirshoev).

contrast to other women. Mitra and colleagues⁵ analyzed Massachusetts 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.^{6–8} 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.⁹ Similarly, an Australian cohort study found that 28% of children in their sample born to mothers with IDD were born prematurely, and 22% had low birth weights.¹⁰ 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 pregnancy 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, patients' demographic characteristics (e.g., sex, age, race), hospital characteristics (e.g., size, teaching status), Elixhauser comorbidities,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 pregnancy; any woman who delivered more than once in a single calendar 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

Table 1
Classification of intellectual and developmental disability.

Intellectual and developmental disabilities	ICD-9 codes
Mild mental retardation	317
Moderate mental retardation	318.0
Severe mental retardation	318.1
Profound mental retardation	318.2
Unspecified mental Retardation	319
Fragile X syndrome	759.83
Prader-Willi syndrome	759.81
Down syndrome	758.0
Rett syndrome	330.8
Lesch Nyhan	277.2
Cri du chat	758.31
Autistic disorder	299.0, 299.00, 299.01
Childhood disintegrative disorder	299.1, 299.10, 299.11
Other Specified pervasive developmental disorder	299.8, 299.80, 299.81
Unspecified pervasive developmental disorder	299.9, 299.90, 299.91
Tuberous sclerosis	759.5
Fetal alcohol syndrome	760.71
Cerebral palsy athetoid	333.71
Cerebral palsy diplegic	343.0
Cerebral palsy hemiplegic	343.1
Cerebral palsy quadriplegic	343.2
Cerebral palsy monoplegic	343.3
Other cerebral palsy	343.4
Infantile cerebral palsy	343.8
Cerebral palsy Spastic	343.9
Cerebral palsy spastic non-congenital non-infantile	344.89

Acronyms: ICD-9- International Classification of Diseases.

analysis. Delivery hospitalizations were identified using the *International Classification of Disease, Ninth Revision, Clinical Modifications* (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, V27.1, V27.3, and V27.4.

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

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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