

Pregnancy Outcomes Among Women with Intellectual and Developmental Disabilities



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Background: There is currently no population-based research on the maternal characteristics or birth outcomes of U.S. women with intellectual and developmental disabilities (IDDs). Findings from small-sample studies among non-U.S. women indicate that women with IDDs and their infants are at higher risk of adverse health outcomes.

Purpose: To describe the maternal characteristics and outcomes among deliveries to women with IDDs and compare them to women with diabetes and the general obstetric population.

Methods: Data from the 1998–2010 Massachusetts Pregnancy to Early Life Longitudinal database were analyzed between November 2013 and May 2014 to identify in-state deliveries to Massachusetts women with IDDs.

Results: Of the 916,032 deliveries in Massachusetts between 1998 and 2009, 703 (<0.1%) were to women with IDDs. Deliveries to women with IDDs were to those who were younger, less educated, more likely to be black and Hispanic, and less likely to be married. They were less likely to identify the father on the infant's birth certificate, more likely to smoke during pregnancy, and less likely to receive prenatal care during the first trimester compared to deliveries to women in the control groups ($p < 0.01$). Deliveries to women with IDDs were associated with an increased risk of adverse outcomes, including preterm delivery, very low and low birth weight babies, and low Apgar scores.

Conclusions: Women with IDDs are at a heightened risk for adverse pregnancy outcomes. These findings highlight the need for a systematic investigation of the pregnancy-related risks, complications, costs, and outcomes of women with IDDs.

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Introduction

In the first half of the 20th century, involuntary sterilization and institutionalization practices were commonly used in the U.S. to prevent women with intellectual and developmental disabilities (IDDs) from becoming pregnant.^{1,2} Deinstitutionalization and repeal of these laws led to unprecedented numbers of women with IDDs living in community settings.^{1,2} Using U.S.

Census Bureau data and CDC prevalence estimates of IDDs of 1.3% among women, an estimated 820,000 U.S. women of childbearing age have an IDD.^{3,4} Many women with IDDs are bearing children,^{5–10} although birth rates have not been established.

IDDs are conditions with childhood onset that are characterized by significant limitations in intellectual functioning and adaptive areas of daily living. The federal definition of IDDs includes individuals with a range of conditions, including intellectual disabilities, cerebral palsy, spina bifida, and autism spectrum disorder (ASD). To date, there is no research on the maternal characteristics or pregnancy outcomes of women with IDDs using a U.S. population-based sample. Research in non-U.S. populations has been limited to four clinical reports of pregnancy outcomes, and three subjective, typically phenomenological studies of women's perceptions of their pregnancy experiences. An Australian study found that women with IDDs ($N=57$) were more likely

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than other women to develop pre-eclampsia and have low birth weight babies.¹¹ Two Swedish national registry studies found significantly elevated rates of cesarean delivery and preterm birth and a higher prevalence of maternal risk factors associated with adverse pregnancy outcomes, including young maternal age, obesity, and current smoking.¹² The second Swedish study found infants of women with IDD (N=326) were more likely to be stillborn or die within the first week of life, preterm, and small for gestational age.¹³ In a U.K. mail survey, women with IDD (N=120) were reported to be less likely than other women to receive prenatal care during the first trimester.¹⁴ These studies suggest women with IDD and their infants are at higher risk of adverse health outcomes, and the public health costs associated with these complications are likely to be high.

Three small-sample studies have investigated women's perceptions of pregnancy and childbirth. Irish women with IDD (N=6) reported that they welcomed pregnancy, but their healthcare providers viewed them as high-risk "liabilities."¹⁵ Australian women with IDD (N=3) reported not receiving support from their family or healthcare providers.¹⁶ Swedish women with IDD (N=10) reported not understanding the labor and delivery process and being unable to cope with hospital events.¹⁷ Together, these small studies suggest that women with IDD need but do not receive support through pregnancy and childbirth.

Further research is clearly warranted to document the maternal characteristics and pregnancy outcomes among U.S. women with IDD. To address some of these research gaps, this study uses a longitudinally linked population-based administrative database to present the descriptive epidemiology of pregnancy characteristics and outcomes among deliveries to women with IDD.

Methods

Data Source and Sample

The data were derived from the Massachusetts Pregnancy to Early Life Longitudinal (PELL) database, a longitudinal, population-based, reproductive health data system that includes Massachusetts birth certificates and fetal death records linked to the corresponding delivery hospital discharge records for the mother and infant. PELL annually links all Massachusetts deliveries with delivery-related hospital discharge records, death certificates of all children and their mothers, and nonbirth hospital discharge records for the mother and child. Details about the PELL data can be found elsewhere.^{18,19}

This study used PELL data from January 1, 1998 to December 31, 2010 to examine the maternal delivery characteristics and outcomes of the 1998–2009 Massachusetts birth cohort. Birth certificate data from 1998–2009 were linked to corresponding maternal or infant hospital discharge records from 1998–2010.

More than 99% of births are linked to their hospital discharge delivery records. This study was approved by the IRB of the Massachusetts Department of Public Health.

Study Population

The study population included all in-state deliveries among Massachusetts resident mothers. The study sample comprised deliveries meeting these criteria during 1998–2009. Using data from delivery and nondelivery hospitalizations available in PELL, women with IDD were identified using specific ICD-9-CM codes for Down syndrome, mental retardation, cerebral palsy, ASD, and other related conditions (Table 1). In order to understand the magnitude of perinatal risks among women with IDD relative to other established high-risk groups, the authors also identified a sample of women with diabetes, as this group is at known risk for adverse pregnancy outcomes and complications. Deliveries among women with ICD-9 codes for established diabetes mellitus or gestational diabetes (and no IDD) were identified; diabetes prior to pregnancy was categorized along with gestational diabetes to avoid potential misclassification between the two.^{20,21} The comparison group consisted of deliveries to women with neither diabetes nor IDD. Because a percentage of women with IDD also had diabetes, sensitivity analyses were performed excluding women with diabetes from the IDD group.

Measures

Maternal characteristics at the time of delivery derived from the birth certificate included age (age groups: <20, 20–24, 25–29, 30–34, 35–39, or ≥40 years); education (some high school, high school graduate, some college, or ≥4 years of college); race/ethnicity (Hispanic, non-Hispanic white, non-Hispanic black, or other); marital status (married or unmarried); nativity (U.S. or foreign born); primary language (English or not English); father named on the birth certificate (yes or no); health insurance at delivery (public or private); smoking during pregnancy (yes or no); parity (first, second, third pregnancy or higher); plurality (singleton or multiple births); and breastfeeding at discharge. Prenatal care as measured by the Adequacy of Prenatal Care Utilization Index (adequate plus, adequate, intermediate, or inadequate)²² was derived from the infant's birth certificate.

Delivery outcomes included preterm delivery (<37 weeks gestation); very low birth weight (<1,500 g); low birth weight (<2,500 g); low Apgar score of infant at 5 minutes after birth (<5); perinatal mortality (fetal and early neonatal deaths at <7 days after delivery); and cesarean method of delivery, which were derived from the infants' birth certificate. For multiple births, the worst outcome of births at the same delivery was selected (e.g., weight of infant with the lower birth weight).

Statistical Analysis

Bivariate analyses were conducted to compare selected maternal characteristics and pregnancy outcomes between deliveries to women with IDD and women with diabetes to women in the general obstetric population. Chi-square statistics were used to compare the distribution of characteristics of the deliveries to the three groups. Unadjusted risk ratios and 95% CIs were calculated

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