



## Birth Outcomes among US Women with Intellectual and Developmental Disabilities

### Introduction

According to a 2002 report from the US Surgeon General, people with intellectual and developmental disabilities (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.” According to a study conducted at the Lurie Institute for Disability Policy, women with intellectual and developmental disabilities (IDD) in the United States are vulnerable to negative health outcomes owing to a combination of systemic and individual factors, including social, biological, and environmental factors. These adverse health outcomes include stillbirths, low birthweight, and preterm births. The study used data from the Health Care and Cost Utilization Project National Inpatient Sample (HCUP-NIS), a national database that contains information on roughly 8 million hospital stays a year from about 1,000 community hospitals in 46 states.

### Findings: facts and figures

- Women with IDD who delivered were more likely to be Black and less likely to be Latina, or from other racial or ethnic groups, than other women.
- The women with IDD had a number of disabilities, including intellectual disability, autism spectrum disorder (ASD), Fragile X syndrome, cerebral palsy, Down syndrome, Rett syndrome, and fetal alcohol syndrome.
- Women with IDD who delivered tended to be younger, on average, than other women.
- Medicaid and Medicare were more likely to cover services provided by hospitals during delivery for women with IDD; conversely, women without IDD were more likely to have the same services covered by private insurance.
- Women with IDD were almost three times as likely to have a co-occurring disability or health condition compared to other women.
- Women with IDD were also more likely to live in low-income areas.

- Women with IDD were more likely to deliver in rural or teaching hospitals. Women with IDD were more likely to experience adverse birth outcomes, including preterm births, low birthweight, and stillbirths. The same applied to Black women with and without an IDD. Latina women, however, had lower odds of having a preterm birth, a child with a low birthweight, or a stillbirth, compared to White women. Women of other races and ethnicities had higher odds of stillbirth and low birthweight than White women, but lower odds of having a preterm birth.

**Discussion: Analysis and next steps**

These results indicate that women with intellectual and developmental disabilities are more likely to experience adverse birth outcomes compared for women without IDD, even when controlling for other factors like race and ethnicity, socioeconomic status, co-occurring disabilities or health conditions, and hospital characteristics. When working with women with IDD, health professionals like obstetricians and midwives should be aware that women with IDD are at a higher risk for adverse pregnancy and birth outcomes.

Most importantly, it is vital to develop and implement integrated standards of health-care provision for women with IDD to lessen the disparities they encounter during pregnancy, childbirth, and beyond. To accomplish this goal, further research into risk factors specifically affecting women with IDD, and ways in which clinicians can improve birth outcomes for this population, is necessary.

*(Adapted from Akobirshoev, I, et al (2017). Birth outcomes among US women with intellectual and developmental disabilities. Disability and Health Journal.*