



SPECIAL ISSUE: Sexual and Reproductive Health of Women with Disability

Research paper

## Time trends in births and cesarean deliveries among women with disabilities



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### ABSTRACT

**Background:** Although it is likely that childbearing among women with disabilities is increasing, no empirical data have been published on changes over time in the numbers of women with disabilities giving birth. Further, while it is known that women with disabilities are at increased risk of cesarean delivery, temporal trends in cesarean deliveries among women with disabilities have not been examined. **Objective:** To assess time trends in births by any mode and in primary cesarean deliveries among women with physical, sensory, or intellectual/developmental disabilities.

**Methods:** We conducted a retrospective cohort study using linked vital records and hospital discharge data from all deliveries in California, 2000–2010 ( $n = 4,605,061$ ). We identified women with potential disabilities using ICD-9 codes. We used descriptive statistics and visualizations to examine time patterns. Logistic regression analyses assessed the association between disability and primary cesarean delivery, stratified by year.

**Results:** Among all women giving birth, the proportion with a disability increased from 0.27% in 2000 to 0.80% in 2010. Women with disabilities had significantly elevated odds of primary cesarean delivery in each year, but the magnitude of the odds ratio decreased over time from 2.60 (95% CI = 2.25–2.99) in 2000 to 1.66 (95% CI = 1.51–1.81) in 2010.

**Conclusion:** Adequate clinician training is needed to address the perinatal care needs of the increasing numbers of women with disabilities giving birth. Continued efforts to understand cesarean delivery patterns and reasons for cesarean deliveries may help guide further reductions in proportions of cesarean deliveries among women with disabilities relative to women without disabilities.

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As medical advances have facilitated longer lifespans and more active lives for women with disabilities, interest in childbearing in this population has increased.<sup>1,2</sup> While women with disabilities still constitute a small proportion of women giving birth,<sup>3,4</sup> that proportion may be growing. However, no empirical data have been published on changes over time in the numbers of women with disabilities giving birth.

Time trends in mode of delivery are also of interest. Incidence of cesarean delivery in the general population increased dramatically from the mid-1990s through 2009 before leveling off and then beginning to decline in 2013.<sup>5,6</sup> In 2010, nearly one third of births in

the U.S. were cesarean deliveries.<sup>7</sup> The overall increase in cesarean deliveries was driven by a sharp reduction in the proportion of women delivering vaginally after a prior cesarean delivery, combined with an increase in primary cesareans (those occurring in women with no prior history of cesarean delivery).<sup>7</sup> There are certain situations (e.g. placenta previa; cord prolapse) when a cesarean delivery is clearly indicated as a life-saving procedure.<sup>8,9</sup> However, there are also more subjective indications (e.g. non-reassuring fetal status, failed progress in labor), in which clinician judgment plays a substantial role in determining whether to proceed with labor or conduct a cesarean.<sup>8,10,11</sup>

Subjective indications appear to have contributed substantially to the increase in primary cesarean deliveries, perhaps in response to fears of litigation if adverse outcomes occurred in the absence of intervention.<sup>8,12</sup> One might expect such concerns to be associated

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with a particularly strong increase in cesarean deliveries among women with disabilities, whose pregnancies may be viewed by clinicians as especially high risk.<sup>13</sup> As yet though, temporal trends in cesarean deliveries among women with disabilities have not been examined.

The purpose of the present study was to assess time trends in births by any mode and in primary cesarean deliveries among women with physical, sensory, or intellectual/developmental disabilities during the 2000–2010 decade. We hypothesized that: 1) the proportion of women with disabilities among all women giving birth would increase over time; and 2) between 2000 and 2009, the proportion of deliveries by cesarean (among women with no previous cesareans) would increase more sharply among women with disabilities than among those without.

## Methods

Our study utilized a retrospective cohort design. The data source consisted of linked hospital discharge and vital records (birth certificates and death files) for all births in the state of California between 2000 and 2010. The dataset contains de-identified data for mother and neonate pairs drawn from the maternal and neonatal hospital discharge record and the birth certificate. The study was approved by the California Office of Statewide Health Planning and Development, and the Institutional Review Board of Oregon Health & Science University.

The dataset included a total of 5,772,198 delivery records. We excluded multiple gestations and breech presentations ( $n = 332,719$ ), identified using either the birth certificate checkboxes or International Classification of Diseases, 9th revision, clinical modification (ICD-9) codes in the discharge file. Records with previable gestational ages (<23 weeks gestation<sup>14,15</sup>) were also excluded ( $n = 6946$ ). Our resulting analytic sample size was 5,432,533 for examination of time trends in births (by any mode) to women with disabilities. Because a previous cesarean delivery is strongly associated with subsequent cesarean, our analysis of time trends in primary cesarean deliveries excluded 827,472 women with prior cesarean deliveries, yielding a sample size of 4,605,061.

Our dependent variable for cesarean delivery analyses was primary cesarean delivery, documented either on the birth certificate or by an ICD-9 diagnosis or procedure code in the discharge file. In accordance with literature on the validity of birth certificate versus hospital discharge data,<sup>16–19</sup> we privileged the discharge record whenever possible.

We identified disability status and type using ICD-9 diagnosis and procedure codes from the patient discharge data file. Our dataset was limited to diagnoses coded at or near the time of delivery; we did not have access to women's full medical records. Therefore, we erred on the side of inclusivity in deciding what codes to categorize as "disability", incorporating some milder conditions that we assumed must have been deemed salient if they were coded in the delivery discharge file. [Appendix A](#) contains a full list of ICD-9 codes included in our disability definition, along with sample frequencies. The list is divided into broad disability subgroups: physical, hearing, vision, and intellectual/developmental (IDD) disabilities. An individual woman could be in more than one group if she had multiple disability codes recorded on her discharge record. We also created a binary indicator of presence of any of our target disability types versus none.

Our disability algorithm was adapted from sets of codes used in prior research for identifying people with disability or risk of disability. Khoury et al.<sup>20</sup> worked with a disability epidemiologist and a physician to create a list of conditions associated with mobility disability. In consultation with clinicians and disability researchers, we modified the list by removing codes for acute

injuries that may not have lasting impact (e.g. fracture of the spinal column without spinal cord injury) and adding several other diagnoses (e.g. late effects of polio; spinal muscular atrophy; epilepsy; cystic fibrosis; limb amputation) that may be associated with some level of physical disability, although not necessarily a mobility restriction. The addition of these diagnoses was intended to capture a broad range of conditions that may impact physical functioning. We erred on the side of inclusivity to increase generalizability and due to the fact that our data come from the delivery record and not from women's full medical records. Diagnosis codes present in the delivery record may disproportionately reflect the most serious disabilities (obvious enough to be noted at time of delivery), thereby skewing the relationship between disability and cesarean delivery. To help counteract that bias, we included milder conditions as well, if coded. We also conducted a sensitivity analysis in which the physical disability category did not include the codes we had added to the list from Khoury et al.<sup>20</sup> and we instead analyzed them in an "other conditions" category (see [Appendix B](#)).

We drew our initial list of hearing disability codes from Mann et al.,<sup>21</sup> to which we added "other specified forms of hearing loss", "congenital anomalies of ear causing impairment of hearing", and "Deaf, nonspeaking, not elsewhere classifiable". Javitt and colleagues<sup>22</sup> categorized vision loss codes by severity and tested their classification in relation to Medicare costs associated with vision care. We used all codes associated with moderate and severe vision loss and blindness, and added codes for vision conditions that often lead to vision loss (e.g. macular degeneration and other retinal disorders). For IDD, we used the list of codes generated by Lin et al.<sup>23</sup> – with input from clinicians and policy makers – to identify this population in a manner consistent with criteria for service eligibility.

The following pregnancy-related covariates were drawn from the vital statistics birth record: gestational age, which we used to create a preterm birth indicator (<37 weeks gestation); parity of the current pregnancy (nulliparous, indicating a first-time mother versus multiparous, indicating a mother with at least one prior pregnancy lasting longer than 20 weeks); and month of entry into prenatal care, which we used to create a dichotomous indicator of entry to care in the first trimester (<13 weeks) or not. Socio-demographic data extracted from the birth certificate included maternal age, race/ethnicity, and education. A small proportion of age values (0.06%) were missing; in these cases, maternal age was derived from the patient discharge file. We classified race/ethnicity as non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Asian, and Other. We categorized maternal education as those who had completed high school and were at least 16 years of age, and those who had not completed high school.

Additional covariates included comorbidities that have previously been found to be associated with cesarean delivery. These included hypertension, diabetes, and mental health conditions. Chronic hypertension was identified if documented on either the birth certificate or patient discharge file. Gestational hypertension or preeclampsia was extracted in a similar fashion. We identified women with chronic diabetes and gestational diabetes in the discharge file. We identified women with mental health conditions based on diagnoses in the discharge file (see [Appendix A](#) for a list of these ICD-9 codes). Our final covariate was health insurance (public insurance, private health insurance, or no insurance) as indicated in the discharge file.

We used descriptive statistics to characterize the sample overall, assessing demographic and health differences between women with and without disabilities using chi square tests. We then created figures to visualize time patterns in: 1) the proportion of births in which the mother had a code associated with possible disability (overall and stratified by parity); and 2) primary cesarean

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