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# Differences in Prenatal Care by Presence and Type of Maternal Disability

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## Abstract

**Introduction:** Prior studies have found that women with disabilities are less likely to receive adequate prenatal care than women without disabilities. However, little is known about differences in patterns of prenatal care by type of disability. Therefore, this study examined timing and frequency of prenatal care among women with physical, sensory, or intellectual/developmental disabilities compared with women without disabilities.

**Methods:** This was a retrospective cohort study using linked maternal and infant hospital discharge and birth certificate data for all births in California in 2000–2012 (N=6,745,201). Analyses were conducted in 2017–2018. Modified Poisson regression analyses compared women with each type of disability with women without disabilities on trimester of prenatal care initiation and number of prenatal care visits.

**Results:** Women with intellectual/developmental disabilities or with limited hearing had significantly higher RR of delaying prenatal care initiation until the second or third trimester (intellectual/developmental disabilities: adjusted RR=1.21, 95% CI=1.09, 1.33; hearing: adjusted RR=1.11, 95% CI=1.02, 1.21), whereas women with physical disabilities and limited vision had lower risk of delaying care (physical: adjusted RR=0.91, 95% CI=0.88, 0.94; vision: adjusted RR=0.85, 95% CI=0.73, 0.99). Women with limited hearing or vision or intellectual/developmental disabilities had higher risk of receiving fewer prenatal visits than recommended, compared with women without disabilities. Women with physical disabilities or intellectual/developmental disabilities had higher RR of receiving more than the typical number of visits.

**Conclusions:** There were key differences in prenatal care utilization by disability type, reflective of particularly pronounced disparities for women with intellectual/developmental disabilities and women with limited hearing. Delays in receipt of prenatal care and low numbers of

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prenatal care visits may contribute to the poorer birth outcomes that have been observed previously in these groups. Targeted interventions are needed to improve uptake of prenatal care in these vulnerable populations.

## INTRODUCTION

Several recent studies have reported poorer birth outcomes for women with disabilities compared with their counterparts without disabilities. Adverse outcomes include higher proportions of preterm births, low birthweight infants, and stillbirths.[1–11] Women with disabilities are also substantially more likely to deliver by cesarean, with the medical necessity of cesarean delivery not always clear.[3,4,10–14] In addition, women with disabilities are more likely to experience pregnancy complications, such as gestational diabetes and preeclampsia.[2,5,8–11,13] The reasons for these adverse outcomes among women with disabilities are not fully understood. They may be due in part to underlying medical conditions contributing to disability or to aspects of the life circumstances of women with disabilities (e.g., accumulated stress associated with marginalization) that are difficult to fully control for in regression models.[11]

Delayed or insufficient prenatal care may also contribute to disparities in outcomes for women with disabilities. Multiple studies in the general obstetric population have found that inadequate prenatal care is significantly associated with preterm birth, low birthweight, and infants that are small for gestational age.[15–20] Prior studies of women with disabilities overall and women with intellectual and developmental disabilities (IDD) specifically have found that these groups are less likely to receive timely and adequate prenatal care compared with women without disabilities.[3,7,8] However, little is known about how patterns of prenatal care differ by functional category of disability (physical, vision, hearing, and intellectual/developmental) in comparison with women without disabilities. A better understanding of prenatal care utilization patterns among subgroups of women with different types of disabilities is needed in order to effectively target interventions to improve care for these women.

The purpose of this study is to examine and describe the timing and frequency of prenatal care among women with physical, or sensory disabilities, or IDD compared with women without disabilities. It is hypothesized that women with IDD are the group least likely to initiate prenatal care during the first trimester and the group least likely to receive the recommended number of prenatal care visits.

## METHODS

### Study Sample

The study design was a retrospective cohort study using linked maternal and infant hospital discharge and vital records data (birth certificates and death files) for all births in California between 2000 and 2012 (N=6,745,201).[21] This study was approved by the California Office of Statewide Health Planning and Development, and the IRB of Oregon Health & Science University. Analyses were conducted in 2017–2018.

## Measures

Multiple gestations (identified from the birth certificate, *n*=178,135) and births to women with chronic hypertension (identified either from the birth certificate or from ICD-9 codes 410.0, 642.0–642.2, *n*=70,979) or pregestational diabetes (identified from ICD-9 code 250, *n*=43,075) were excluded, as these pregnancies are likely to require more than standard prenatal care. The final analytic sample included 6,453,012 births.

Dependent variables were timing of prenatal care initiation and number of prenatal care visits. Prenatal care initiation was measured as the month of pregnancy in which prenatal care was initiated, determined from the birth certificate. Initiation was then grouped by trimester of pregnancy (months 1–3, 4–6, and 7–9). Number of prenatal care visits was recorded on the birth certificate. For this study, numbers were grouped according to whether women received the typically recommended 11–14 visits,[22] less than that number (zero to ten visits), somewhat more than that number (15–20 visits), or substantially more than that number (≥21 visits).

The key independent variable was disability status and type, which was identified using the ICD-9-CM diagnosis and procedure codes from the mother's discharge file. Disability was classified as either present or absent, and (when present) into subgroups of physical, or hearing, or vision disabilities, or IDD using the coding scheme published by Darney and colleagues[14] (Appendix 1, as well as alternate versions in Appendix 2). An individual woman could be in more than one disability group if she had multiple disability codes recorded on her discharge record.

Sociodemographic covariates included maternal race/ethnicity (non-Hispanic white as referent, non-Hispanic black, Hispanic, non-Hispanic Asian, non-Hispanic other), maternal education (completion of high school/GED and aged ≥16 years as the referent), advanced maternal age (<35 years at birth as referent), insurance status (public insurance as referent, private insurance, none), and parity (nulliparous versus multiparous). Other covariates included maternal comorbidities: gestational hypertension/preeclampsia (ICD-9 codes 642.3–642.5), gestational diabetes (ICD-9 codes 648.0, 648.8), and mental health diagnosis as identified by ICD-9 codes 295–298, 300, or 311.[14] Year of delivery was included as a categorical variable (2012 as referent). Additionally, gestational age (in weeks) was included as a covariate in analyses of number of prenatal care visits.

## Statistical Analyses

Chi-square tests compared the characteristics of mothers with and without disabilities. Multivariable modified Poisson regressions with robust variance estimation were used to examine both trimester of prenatal care initiation and number of prenatal care visits while adjusting for covariates. The regression model examining initiation of prenatal care calculated the RR of women in each disability group (compared with those without disabilities) delaying care until the second or third trimester instead of initiating care in the first trimester (reference level). In the regression models of number of prenatal visits, the typically recommended number of visits (11–14) was the reference level. Two analyses were conducted to calculate the RR of women with disabilities having: (1) fewer visits than

recommended (zero to ten vs 11–14) and (2) more than the typically recommended number of visits (≥15 vs 11–14). Analyses were clustered by woman to account for the possibility that more than one delivery per woman could be included in the dataset. Sensitivity analyses were also conducted with alternate methods of categorizing disability; details and results are presented in Appendix 2. All analyses were performed in Stata, version 14.2. Figure 1 was prepared in R, version 3.4.2.

## RESULTS

Within the analytic sample, deliveries to women with disabilities comprised 0.52% (33,383/6,453,012). Compared with women without disabilities, higher proportions of women with disabilities were non-Hispanic white (40.9% vs 27.5%), high school graduates (78.1% vs 69.8%), aged ≥35 years (23.2% vs 16.8%), and nulliparous (44.3% vs 39.5%). Women with disabilities also had higher proportions of gestational hypertension/preeclampsia (7.8% vs 5.1%), gestational diabetes (8.5% vs 6.2%), and mental health diagnoses (7.4% vs 1.2%) than women without disabilities ($p<0.001$ for all; Table 1).

Overall, a slightly higher proportion of women with disabilities initiated prenatal care during the first trimester (86.7% vs 85.2% of women without disabilities, $p<0.001$). However, patterns of prenatal care initiation differed by disability type (Figure 1A). Women with physical disabilities or with limited vision had significantly higher proportions initiating prenatal care in the first trimester (87.4% and 87.6% respectively) compared with women without disabilities. Women with limited hearing or with IDD were significantly less likely to have initiated care during the first trimester (83.0% and 80.2% respectively). Further, women with IDD had the highest proportion (4.5%) with entry to care delayed until the third trimester (Figure 1A). Associations between disability and prenatal care initiation remained significant when adjusting for covariates. Women with limited hearing and with IDD had significantly higher adjusted risk of delaying care initiation until the second or third trimester, whereas women with physical disabilities or limited vision had significantly lower risk (Table 2).

Number of prenatal visits also differed by disability status and type. Among women with physical disabilities, higher proportions had 15–20 visits (23.1% vs 20.7% of women without disabilities) or ≥21 visits (3.5% vs 1.4%), whereas fewer had zero to ten visits (30.1% vs 32.4%). Conversely, women with hearing or vision disabilities were more likely to have zero to ten visits (36.9% for both) compared with women without disabilities. Women with IDD were overrepresented at both the upper and lower ends of the distribution of number of visits: 26.4% had ≥15 visits whereas 36.4% had zero to ten visits (Figure 1B). In adjusted regression models with the typically recommended number of visits (11–14) as the reference category, women with limited hearing or vision or IDD had greater risk of receiving fewer visits than recommended, compared with women without disabilities. Women with physical disabilities or IDD had higher RR of receiving more than the typical number of visits (Table 2).

## DISCUSSION

Prior research has found that women with disabilities are less likely to receive prenatal care as early or often as recommended,[3,7,8] but there has been limited information about how patterns may vary by type of disability. This study found key differences in prenatal care utilization patterns by disability type, reflective of particularly pronounced disparities for women with limited hearing and women with IDD. Although other research has found that women with IDD are less likely to receive adequate prenatal care compared with women without disabilities,[7] the present study demonstrates that women with IDD not only are disadvantaged relative to women without disabilities, they also experience greater disparities than many other women with disabilities. When adjusting for covariates, significant disparities were apparent in both timing and frequency of prenatal care for women with IDD and women with limited hearing. Disparities on only one of these aspects of care were found for women with vision disabilities, and there was no evidence of late or insufficient care for women with physical disabilities.

Women with IDD were the group least likely to receive care during the first trimester and most likely to wait until the third trimester to initiate care. Delayed entry into prenatal care for women with IDD may be related to delayed recognition of pregnancy in this group.[7] Women with IDD may be less attuned to signs of pregnancy, especially if pregnancies are unplanned.[23]

Unfortunately, women with IDD are also more likely to have modifiable risk factors for adverse pregnancy outcomes (e.g., smoking, obesity)[4,7,24] and thus have a particular need for prompt care in order to have the healthiest pregnancies possible. These issues speak to the need for preconception care that assesses sexual activity and pregnancy desires of women with IDD and directly addresses pregnancy planning and appropriate preparations.

This study also builds on previous indications that women with IDD are overrepresented at both the low and the high end of the prenatal care utilization spectrum.[7] In the main analyses, women with IDD were unique in having this pattern; the pattern was not apparent for women with other types of disabilities. In sensitivity analyses separating out women with multiple disabilities, these women with multiple disabilities exhibited this pattern instead (Appendix 2), suggesting that women with IDD who also have another type of disability are particularly likely to have either low or high numbers of visits. Women with IDD with fewer visits than recommended may constitute a particularly hard to reach subpopulation without well-established connections to healthcare systems or strong patient–physician relationships. Women with IDD who had more than the typical number of visits may have had risk factors other than the ones available as covariates in this dataset; such risk factors may have led their prenatal care providers to believe additional visits were warranted. Utilization of prenatal care among women with IDD may also be closely tied to the level of support women receive from family members or others in scheduling and getting to appointments.[25]

In contrast to women with IDD, women with physical disabilities were the group most likely to initiate care in the first trimester and also most likely to have an ample number of prenatal visits. Women with physical disabilities may anticipate difficulty accessing high quality

prenatal care and be proactive in seeking out care settings and clinicians equipped to address their needs.[26] Early and frequent receipt of prenatal care among women with physical disabilities may be because of maternal or physician concerns about potential pregnancy complications for these women.[27] Although higher numbers of visits may be necessary, they may also be challenging and stressful for mothers with physical disabilities if clinics are not fully accessible. For example, transferring to an exam table that is not height adjustable may be difficult and potentially dangerous for a woman with a physical disability, particularly as pregnancy progresses. Adhering to standards for accessible facilities and equipment[28–30] will help ensure safety and accessibility for patients across the full spectrum of physical abilities and body types.

Women with hearing disabilities had elevated risk of entering care late and of receiving fewer prenatal care visits than recommended. Low health literacy and substantial barriers in communicating with clinicians are common among people who are deaf or hard of hearing.[31] Low health literacy may limit women's understanding of the importance of timely and ongoing prenatal care. Additionally, women who need sign language interpreters may encounter challenges with obtaining interpreter services, which could result in delayed appointments and suboptimal care. Prior research has found that when language barriers are well-addressed (either with providers who sign or with full-time availability of interpreters), receipt of preventive care improves.[32,33] Prenatal care could similarly be improved with routine provision of quality interpretation services, and with incorporation of educational videos in sign language. For women with vision-related disabilities, the elevated risk of receiving fewer prenatal visits than recommended despite initiating care on time raises questions as to whether communication barriers may interfere with optimal delivery of care for this group as well, as women may not be able to read written information about the recommended frequency of visits. Ensuring that key information is presented orally and that return appointments are scheduled at the end of each visit may help address such barriers.

## Limitations

This study was limited to identifying women with disabilities based on diagnosis codes. This is an imperfect science, as the ICD-9 classification system does not provide a comprehensive approach to delineating functional status, and the degree of functional limitation associated with any given diagnosis may vary considerably.[34] Furthermore, the dataset only included ICD-9 codes from the perinatal period and may therefore have missed relevant diagnoses from a woman's prior medical history. The means of ascertaining disability likely resulted in identification of disabilities that were perceived as pertinent to clinical management of pregnancy and delivery. Results of this study may not be generalizable to less obvious or severe disabilities. The dataset also precluded identification of women with mental health diagnoses elsewhere in their medical histories if those diagnoses were not reflected in the hospital discharge record; thus, the analyses may have undercontrolled for the presence of mental health conditions.

Data for this study were not able to provide information about the quality of prenatal care, but only the quantity and timing of care. Qualitative research suggests that obstetricians and midwives have limited training and experience with disability and may not be prepared to

provide care that addresses the needs and concerns of women with disabilities.[35–37] It is also possible that prenatal care for women with disabilities may have improved since 2012, which was the most recent year of data available at the time this study was conducted. It would be relevant for future research to conduct similar analyses with newer data as they become available. An important strength of the present study is the size and inclusiveness of the dataset. California is the most populous state in the country and has one of the most diverse populations.[38] These data are a complete census (rather than a sample) of births in California during the study period. Moreover, pooling multiple years of data yielded sufficient cell sizes to examine differences in patterns for women with different types of disabilities.

## CONCLUSIONS

This study expands on existing literature by examining patterns of prenatal care receipt in relation to type of disability. The findings highlight the particularly pronounced disparities in care for women with IDD and women with limited hearing. Given the increased risk of adverse outcomes among women in both of these groups,[1,2,4–7] the observed delays in receipt of prenatal care and low numbers of prenatal care visits for large proportions of these women are especially worrying. For women with IDD, the number of prenatal visits varied more than was the case in other disability groups, reflecting both underutilization and intensive utilization of prenatal care among women with IDD. Additional research is needed on predictors of low versus adequate or high utilization within this population in order to target interventions to women most at risk of not obtaining adequate prenatal care.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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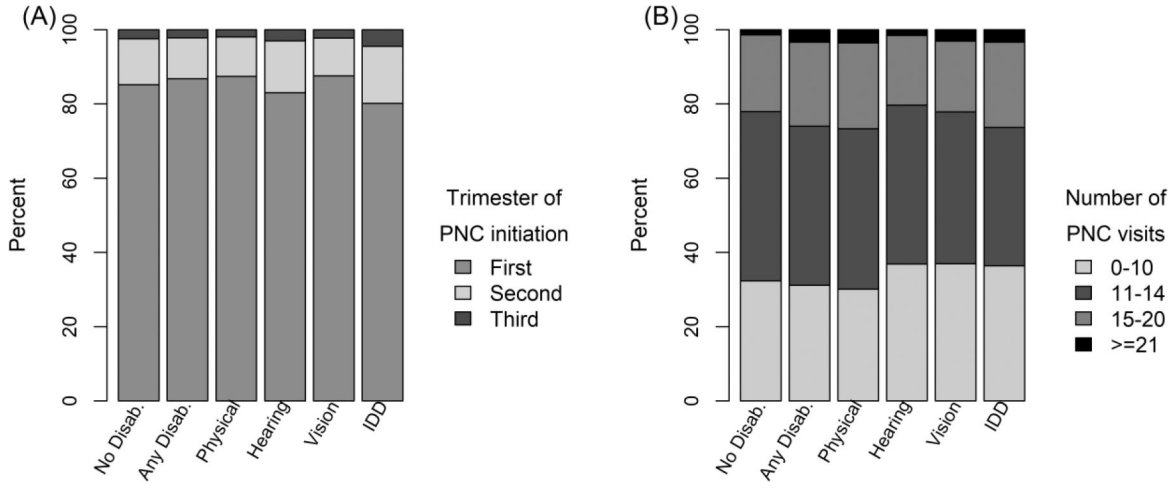


**Figure 1.**

Trimester of prenatal care initiation and number of prenatal visits by presence and type of disability.

*Note*: Column labels refer to type of disability.

No Disab, no disability; Any Disab, any disability, IDD, intellectual and developmental disabilities.

**Table 1.**

Demographic Characteristics of the Analytic Sample

| Characteristics | Cohort | Disability status | | Disability type | | | |
|---|---|---|---|---|---|---|---|
| | | No disability | Any disability | Physical | Hearing | Vision | IDD |
| Total | 6,453,012 | 6,419,629 (99.48) | 33,383 (0.52) | 27,891 (0.43) | 2,790 (0.04) | 1,270 (0.02) | 1,670 (0.03) |
| Race/Ethnicity | | | | | | | |
| White | 1,776,336 (27.53) | 1,762,668 (27.46) | **13,668 (40.94)** | **11,844 (42.47)** | **921 (33.01)** | **415 (31.13)** | **602 (36.05)** |
| Black | 340,194 (5.27) | 337,724 (5.26) | **2,470 (7.40)** | **2,009 (7.20)** | **183 (6.56)** | **126 (9.45)** | **191 (11.44)** |
| Hispanic | 3,464,500 (53.69) | 3,450,659 (53.75) | **13,841 (41.46)** | **11,306 (40.54)** | **1,330 (47.67)** | **589 (44.19)** | **735 (44.01)** |
| Asian | 706,393 (10.95) | 703,906 (10.96) | **2,487 (7.45)** | **1,947 (6.98)** | **295 (10.57)** | **169 (12.68)** | **100 (5.99)** |
| Other | 128,948 (2.00) | 128,221 (2.00) | **727 (2.18)** | **628 (2.25)** | **45 (1.61)** | **26 (1.95)** | **31 (1.86)** |
| Education, at least high school diploma/GED | 4,504,437 (69.80) | 4,478,373 (69.76) | **26,064 (78.08)** | **22,032 (78.99)** | **2,078 (74.48)** | **1,030 (77.27)** | **1,144 (68.50)** |
| Insurance | | | | | | | |
| Public | 3,089,174 (47.87) | 3,074,387 (47.89) | **14,787 (44.30)** | **11,702 (41.96)** | **1,598 (57.28)** | 618 (46.36) | **1,065 (63.77)** |
| Private | 3,224,192 (49.96) | 3,205,999 (50.66) | **18,193 (54.50)** | **15,851 (56.83)** | **1,165 (41.76)** | 697 (52.29) | **583 (34.91)** |
| None | 138,726 (2.15) | 138,324 (2.15) | **402 (1.20)** | **337 (1.21)** | **27 (0.97)** | 18 (1.35) | **22 (1.32)** |
| Advanced maternal age (≥35 years) | 1,085,849 (16.83) | 1,078,091 (16.79) | **7,758 (23.24)** | **6,524 (23.39)** | **619 (22.19)** | **365 (27.38)** | 310 (18.56) |
| Nulliparous | 2,548,932 (39.50) | 2,534,144 (39.47) | **14,788 (44.30)** | **12,226 (43.83)** | **1,182 (42.37)** | **653 (48.99)** | **895 (53.59)** |
| Gestational hypertension/preeclampsia | 331,193 (5.13) | 328,602 (5.12) | **2,591 (7.76)** | **2,015 (7.22)** | **201 (7.20)** | **237 (17.78)** | **178 (10.66)** |
| Gestational diabetes | 399,947 (6.20) | 397,109 (6.19) | **2,838 (8.50)** | **2,331 (8.36)** | **277 (9.93)** | **121 (9.08)** | **135 (8.08)** |
| Mental health diagnosis | 81,441 (1.26) | 78,976 (1.23) | **2,465 (7.38)** | **2,135 (7.65)** | **131 (4.70)** | **74 (5.55)** | **152 (9.10)** |
| Preterm birth | 566,072 (8.77) | 561,747 (8.75) | **4,325 (12.96)** | **3,534 (12.67)** | **319 (11.43)** | **247 (18.53)** | **282 (16.89)** |

*Notes*: Boldface values are statistically significantly different from the no disability group at $p<0.001$. Data presented as n (%).

IDD, intellectual and developmental disabilities; GED, General Education Diploma (high school equivalency certificate).

**Table 2.**

Adjusted Risk Ratios (95% CIs)[a] for Prenatal Care Initiation and Frequency

| Dependent variable | Disability status | | Disability type | | | |
|---|---|---|---|---|---|---|
| | No disability (n=6,080,127) | Any disability (n=31,101) | Physical (n=26,084) | Hearing (n=2,550) | Vision (n=1,231) | IDD (n=1,499) |
| Prenatal care initiation | | | | | | |
| Second/third vs first (ref) (n=6,111,228) | ref | **0.94 (0.91, 0.97)** | **0.91 (0.88, 0.94)** | **1.11 (1.02, 1.21)** | **0.85 (0.73, 0.99)** | **1.21 (1.09, 1.33)** |
| Number of visits | | | | | | |
| Few/none (0–10) vs recommended (11–14, ref) (n=4,589,666)[b] | ref | 1.02 (1.00, 1.03) | 1.00 (0.99, 1.02) | **1.12 (1.07, 1.17)** | **1.08 (1.01, 1.16)** | **1.08 (1.01, 1.15)** |
| Excess (≥15) vs recommended (ref) (n=4,009,424)[c] | ref | **1.13 (1.11, 1.15)** | **1.14 (1.12, 1.16)** | 0.98 (0.91, 1.05) | 1.01 (0.92, 1.12) | **1.23 (1.14, 1.32)** |

*Notes*: Boldface indicates statistical significance at $p<0.05$.

[a]Adjusted for race, education, insurance, age, parity, gestational hypertension/preeclampsia, gestational diabetes, mental health diagnosis, and year. Number of visits also adjusted for gestational age.

[b]Women with ≥15 visits were not included in this analysis.

[c]Women with 0–10 visits were not included in this analysis.

IDD, intellectual and developmental disabilities.