Racial and ethnic disparities in birth outcomes and labor and delivery charges among Massachusetts women with intellectual and developmental disabilities

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Running title: Racial disparities in birth outcomes and labor and delivery charges

Abstract

Understanding the pregnancy experiences of racial and ethnic minority women with intellectual and developmental disabilities (IDD) is critical to ensuring that policies can effectively support these women. This research analyzed data from the 1998-2013 Massachusetts Pregnancy to Early Life Longitudinal (PELL) data system to examine the racial and ethnic disparities in birth outcomes and labor and delivery charges of U.S. women with IDD. There was significant preterm birth disparity among non-Hispanic black women with IDD compared to their non-Hispanic white peers. There were also significant racial and ethnic differences in associated labor and delivery-related charges. Further research, examining potential mechanisms behind the observed racial and ethnic differences in labor and delivery-related charges in Massachusetts' women with IDD is needed.

Keywords: Intellectual Disabilities, Intellectual and Developmental Disabilities; Birth Outcomes; Cesarean Delivery; Preterm Birth, Low Birth Weight; Stillbirth; Hospital Charges; Racial and Ethnic Disparities;

Emerging research suggests women with intellectual and developmental disabilities (IDD) experience increased risk for adverse pregnancy complications and poor birth outcomes (Brown, Cobigo, Lunsky, & Vigod, 2016; M. Mitra et al., 2017; Monika Mitra, Parish, Clements, Cui, & Diop, 2015). Preterm birth, low birth weight, and neonatal mortality rates are markedly higher in women with IDD compared to other women (Brown, Cobigo, Lunsky, & Vigod, 2016; M. Mitra et al., 2017; Monika Mitra et al., 2015; S. L. Parish et al., 2015). These disparities, both in maternal and neonatal outcomes, underscore the complex perinatal and postpartum health care needs of women with IDD and reflect cumulative social and economic disadvantages (Brown, Cobigo, Lunsky, Dennis, & Vigod, 2016; Brown, Lunsky, Wilton, Cobigo, & Vigod, 2016; Magaña, Parish, Morales, Li, & Fujiura, 2016).

Little is known about racial and ethnic variations in birth outcomes among women with IDD. Among nondisabled women, persistent racial and ethnic disparities in preterm delivery, low birth weight and neonatal mortality is observed in non-Hispanic black women (hereinafter "black") compared to non-Hispanic white (hereinafter "white") (Akobirshoev, Parish, Mitra, & Rosenthal, 2017a; Brown, Cobigo, Lunsky, Dennis, et al., 2016; Brown, Cobigo, Lunsky, & Vigod, 2016; Brown, Lunsky, et al., 2016; HÖGlund, Lindgren, & Larsson, 2012; McConnell, Mayes, & Llewellyn, 2008; Monika Mitra et al., 2015; Ncube et al., 2017a, 2017b; S. L. Parish et al., 2015) suggest that infants born to racial and ethnic minority women with IDD may experience heightened risk for poor outcomes. This raises questions about the contribution of differences in health care access, utilization, and quality to disparities in birth outcomes for women with IDD.

Ethnic and racial minority individuals with a disability experience more barriers to health care access and tend to receive lower quality health services than either white individuals with

disabilities or racial/ethnic minority individuals without disabilities (Magaña et al., 2016; 2008; S. L. Parish, J. G. Swaine, E. Son, & K. Luken, 2013; Peterson-Besse, Walsh, Horner-Johnson, Goode, & Wheeler, 2014; Shafi et al., 2007). In a recent study examining health disparities among adults with IDD, Magaña and her colleagues (Magana, Parish, Morales, Li, & Fujiura, 2016) found that black and Hispanic adults with IDD were more likely than their white counterparts to experience poorer overall physical and mental health and report more chronic health conditions.

Research examining birth outcomes, and the costs associated with labor and delivery among racial and ethnicity minority women with IDD is imperative as efforts to improve the quality of care for a vulnerable population, to control costs, and to address healthcare disparities require it to succeed. Annual hospital charges for pregnant women and infants in the US were estimated at nearly 100 billion dollars in 2013 (Truven Health Analytics, 2013). No published research has examined labor and delivery-related charges by race and ethnicity; however, childbirth-associated hospital charges vary by delivery type (i.e., vaginal or Cesarean), phase of perinatal care (prenatal, intrapartum or postpartum), payer, region, facility type and professional service fees (Truven Health Analytics, 2013). Research estimating hospital charges *unrelated* to pregnancy suggests that costs associated with racial and ethnic minority individuals generally exceed those of non-Hispanic whites (Chumney, Mauldin, & Simpson, 2006; Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009; Poulin, July 2016). The complex and multifactorial reasons for these differences are generally attributed to more frequent, complex and costly hospitalizations among ethnic and racial minority patients compared to white patients.

Despite growing knowledge about the perinatal health of women with IDD, almost nothing is known about birth outcomes among racial and ethnic minority women with IDD or the

associated labor and delivery-related charges for this population. This study contributes to an emerging body of research examining the intersections of race, ethnicity, and disability. We analyze longitudinally-linked, population-based, administrative data from Massachusetts to answer two questions: (1) are there differences by race and ethnicity in adverse birth outcomes among women with IDD? and (2) are there racial and ethnic differences in associated labor and delivery-related charges for women with IDD? We hypothesized that the birth outcomes of infants born to black and Hispanic women with IDD, adjusting for sociodemographic and clinical characteristics, would be worse than those of infants born to white women with IDD. Further, we hypothesized that labor and delivery-related charges for black and Hispanic women with IDD relative to white women with IDD, would be significantly different, adjusting for sociodemographic and clinical characteristics.

METHODS

Data source

We analyzed the 1998-2013 Massachusetts Pregnancy to Early Life Longitudinal (PELL) data system. PELL links Massachusetts birth certificates, fetal death reports, and delivery and non-delivery (inpatient visits, observational stays, and emergency department (ED) visits) related hospital discharge records for all infants and their mothers. PELL contains more than 100 data elements for each delivery that occurred in Massachusetts and the subsequent hospitalizations since 1998, including primary and secondary diagnoses and procedures, admission and discharge status, patient demographic characteristics, expected payer, total charges, and length of stay. Detailed information on the PELL design is available elsewhere (Barfield et al., 2007; Clements, Barfield, Kotelchuck, Lee, & Wilber, 2006).

Sample

The sample includes women with IDD with singleton deliveries who gave birth in Massachusetts between January 1998 and December 2013. Women with IDD were identified by analyzing the primary and secondary diagnoses of any hospital admissions before, during or after the delivery, including emergency department (ED) visits, non-delivery hospitalizations and observational stays (any hospital stay for which diagnosis and treatment are not expected to exceed 24 hours but may extend to 48 hours). Women were categorized as having IDD if they had any codes related to IDD in the hospital discharge record. Codes were from the *International Classification of Diseases and Related Health Problems, 9th Revision, Clinical Modification* (ICD-9 CM) codes (Centers for Disease Control and Prevention, November, 2015) (see Table 1 for complete listing). Notably, IDD status may have been established in the record either before or after delivery. For example, if a woman gave birth in 1998 but her IDD status was first noted in a hospital admission record in 2013, she was included in our sample because IDD is lifelong condition with onset during childhood and no cure (Karnebeek C.V., n.d; Miller & Rosenbaum, 2016). Due to relatively few cases of deliveries in women with IDD, we combined data (1998-2013) to increase sample size and statistical power. Among 1,188,656 singleton deliveries in Massachusetts between 1998 and 2013, there were 1,597 deliveries in which women's hospital records identified them as having IDD. Our sample is limited to white, black and Hispanic women; 72 women reporting other racial and ethnic identities were excluded. Thus, the final study sample consists of 1,525 singleton deliveries to women with IDD, including 980 to white women, 228 to black women and 317 to Hispanic women.

<Insert Table 2 about here>

Measures

Dependent variables

The main dependent variables included the following birth outcomes from the birth certificate file: (1) cesarean delivery, (2) preterm birth (delivery less than 37 completed weeks of gestation), (3) low birth weight (birth weight less than 2,500 g) and (4) and total hospital charges for labor and delivery-related admission, excluding physician fees (hereinafter labor and delivery-related charges). To enhance accurate identification of the birth outcomes, as suggested in previous research (Schiff, Doody, Crane, & Mueller, 2017), we linked birth certificate data and ICD-9-CM discharge diagnosis codes to ascertain birth outcomes. All hospital charges were adjusted for inflation using the medical care component of the US Consumer Price Index (Statistic, n.d.) and reported in 2013 dollars.

Independent variable

Race and ethnicity, self-reported by the woman, were derived from birth certificate data and were collapsed into a single variable with the following mutually exclusive categories: non-Hispanic white, non-Hispanic black, and Hispanic of any race.

Covariates

Model covariates for adverse birth outcomes were based on previous studies (Akobirshoev et al., 2017a; Brown, Cobigo, Lunsky, & Vigod, 2016; Cabacungan, Ngui, & McGinley, 2012; Campbell et al., 2017; Inoue et al., 2017; Monika Mitra et al., 2015; S. L. Parish et al., 2015), availability in the PELL data, and sociodemographic and clinical characteristics. Sociodemographic characteristics included maternal age (≤19, 20-34, ≥35), education (< high school, high school graduate, or at least some college), marital status (married or not married), health insurance type (private or public). We chose ≤19, 20-34, and ≥35 maternal age groups because teenage women have a significantly elevated risk for adverse birth outcomes.(de Vienne, Creveuil, & Dreyfus, 2009) Similarly, the American College of

Obstetricians and Gynecologist defined 35 years old as a cut-point for “advanced maternal age” which has been associated with increased risk of maternal and neonatal complications (Gynecologists, 2007), Marital status was included as previous research indicates unmarried women are at an increased risk of adverse birth outcomes compared to married women (Shah, Zao, & Ali, 2011). Clinical covariates included adequacy of prenatal care, characterized as inadequate, intermediate, adequate or adequate plus using the Kotelchuck index (Kotelchuck, 1994, 1997). Previous research demonstrates that pre-pregnancy health conditions and delivery-related complications are significantly associated with adverse birth outcomes (Adams, Smith, & Ruffin, 2000; Brown, Cobigo, Lunsky, Dennis, et al., 2016; Clements, Mitra, Zhang, & Iezzoni, 2016). For pre-pregnancy health conditions or pregnancy-related complications, we included a binary variable as to whether women had none or at least one of the following: diabetes, gestational diabetes, hypertension, gestational hypertension, cardiac disease, hydramnios/oligohydramnios, hemoglobinopathy, renal disease, RH sensitization, rubella infection, seizure disorders, sickle cell anemia, uterine bleeding, weight gain/loss, and other risk factors for pregnancy. For delivery-related complications, we included a binary variable as to whether women had none or one of the following: abruptio placentae, other excessive bleeding, placenta previa, precipitous labor, prolonged labor, rupture of membrane, seizures during labor, anesthetic complications, breech/malpresentation, cephalopelvic disproportion, cord prolapse, dysfunctional labor, fever, fetal distress, meconium moderate to heavy, and other labor and delivery complications. Notably, the binary variables for pre-pregnancy heath conditions or pregnancy risks and delivery-related complications, in addition to the list of specific risk factors and complications, includes cases with discharge records that note ‘other risks for pregnancy’ and ‘other labor and delivery complications’, as defined by the PELL data. The PELL codebook

document, however, does not provide further information about the nature of the diagnoses included in this category. Other clinical characteristics included smoking status during pregnancy and parity (1st pregnancy, 2nd pregnancy, 3rd pregnancy or higher). Finally, since this analysis is based on the combined 1998-2013 PELL data, we included year of delivery as a covariate.

Model covariates for the continuous variables of labor and delivery-related charges were informed by previous research (Hsia, Akosa Antwi, & Weber, 2014; Poulin, July 2016; Singh et al., 2015). In addition to the covariates mentioned above, the model for labor and delivery-related charges included variables related to mode of delivery (cesarean delivery or vaginal delivery), preterm birth (yes/no) and low birth weight (yes/no). Additional continuous variables included the length of hospital delivery stay, number of diagnoses, and number of procedures. The number of diagnoses and procedures were derived from patients' hospital discharge records. The number of diagnoses ranged between 1 and 15 and included one primary diagnosis and a maximum of 14 other secondary diagnoses based on ICD-9 codes. Similarly, the number of procedures ranged between 0 when no procedure was performed and a maximum of 15 procedures performed during the delivery hospitalization.

Analysis

Unadjusted racial and ethnic differences in sociodemographic characteristics, clinical characteristics, adverse birth outcomes, and labor and delivery-related charges were compared within the sample. Frequencies and proportions were reported for categorical variables and Rao and Scott Chi-square tests (Rao & Scott, 1984) were used to test significance. Mean, standard deviation, and median were reported for continuous variables; significance was tested using independent sample Student's t-tests when normally distributed, and Wilcoxon-Mann-Whitney (WMW) test when not normally distributed (Moses, 2005). Multivariate logistic regression

models were used for the bivariate dependent variables: (1) cesarean delivery, (2) preterm birth, and (3) low birth weight. Linear regression models estimated labor and delivery-related charges because this was a continuous variable. As the hospital charges were right-skewed, we transformed them to log form which allowed us to interpret the log form regression coefficients ($\ln(\beta)$) as percent change. Recognizing that the sample could include more than one delivery to the same woman during the study period, our analyses adjusted for individual-level clustering by using the robust clustered sandwich estimator method (Wooldridge, 2003). All analyses were performed using STATA 15 (StataCorp, 2015).

This study was approved by the authors' university Institutional Review Board.

Results

<Insert Table 2 about here>

Hispanic women with IDD, compared to their white peers, were more likely to be younger, unmarried, report fewer years of education and have public health insurance (see **Table 2**). Similarly, black women with IDD were more likely than their white counterparts to have less education, be single and have public health insurance. Maternal age at delivery was not significantly different between black and white women with IDD.

<Insert Table 3 about here>

Table 3 presents bivariate, unadjusted contrasts of clinical characteristics, birth outcomes, and labor and delivery-related charges by race and ethnicity within the study sample of women with IDD. Hispanic women with IDD, compared to their white peers, did not have significantly different clinical characteristics (adequacy of prenatal care or Kotelchuk index, pre-pregnancy health conditions, length of stay, and a number of procedures) or birth outcomes (cesarean delivery, preterm birth, and low birth weight). Hispanic women with IDD did have

lower rates of smoking during pregnancy and higher parity compared to white women with IDD. Similarly, black women with IDD did not have significantly different clinical characteristics compared to white women with IDD. Black women with IDD had lower rates of smoking during pregnancy, had more extended hospital stays and number of diagnoses but fewer procedures than their white peers with IDD. Consistent with previous research on racial differences in birth outcomes in the general population (Crawford et al., 2017), black women with IDD had higher rates of preterm birth compared to white women with IDD (18.4% vs. 12.2%).

There were significant racial and ethnic disparities in hospitalization charges for the delivery-related admissions. The average labor and delivery-related charges for black and Hispanic women with IDD ($16,172 and $14,075 respectively) exceeded those for white women with IDD ($11,778) or by 37% and 20% respectively. Median labor and delivery-related charges for black and Hispanic women with IDD ($10,010 and $10,170 respectively) exceeded those for white women with IDD ($8,702), or by 15% and 17% respectively.

<Insert Table 4 about here>

Table 4 presents the multivariate regression results that examined racial and ethnic differences in adverse birth outcomes and delivery-related charges among women with IDD. Research question 1 addressed whether there were racial and ethnic disparities in birth outcomes among women with IDD. After adjusting for sociodemographic and clinical characteristics, black women with IDD were more likely to have preterm birth compared to white women with IDD (OR=1.69, 95%CI: 1.13 - 2.53, $p<0.01$). We found no differences in the risk of having a cesarean delivery or low birth weight infant between black and white women with IDD. We did not find any differences in the risk of cesarean delivery, preterm birth, and low birth weight between Hispanic and white women with IDD. Research question 2 addressed whether there

were differences in labor and delivery-related charges based on race/ethnicity. In adjusted regression analyses, hospital labor and delivery charges for black and Hispanic women with IDD were 15% higher compared to white women with IDD ($\ln(\beta)=0.14$, 95%CI: 0.02 - 0.27, $p<0.05$ and $\ln(\beta)=0.14$, 95%CI: 0.06 - 0.22, $p<0.01$ respectively) (Table 4).

Discussion

To the best of our knowledge, this is the first investigation of racial and ethnic differences in birth outcomes and labor and delivery-related charges among women with IDD. We found significant racial disparities in the risk for preterm birth. Black women with IDD were more likely to experience preterm birth than their white counterparts after controlling for all available covariates. However, we did not observe a disparity in the risk for preterm birth among Hispanic women with IDD. These findings align with research examining racial/ethnic disparities in preterm birth among the general population (Burris, Collins, & Wright, 2011; Culhane & Goldenberg, 2011; Hogue, Menon, Dunlop, & Kramer, 2011; Misra, Slaughter-Acey, Giurgescu, Sealy-Jefferson, & Nowak, 2017; Spriggs, 2007; Xu, Grigorescu, Siefert, Lori, & Ransom, 2009).

The rate of preterm delivery observed in our sample were elevated compared to the Massachusetts' obstetric population overall: 64% higher for black women with IDD (18.4% vs. 11.2%); 60% higher for Hispanic women with IDD (14.6% vs. 9.1%) and; 44% higher for white women with IDD (12.2% vs. 8.5%) (Massachusetts Department of Public Health, December 2014). These findings are consistent with previous research (Akobirshoev et al., 2017a; Brown, Cobigo, Lunsky, & Vigod, 2016; Monika Mitra et al., 2015; S. L. Parish et al., 2015) suggesting that women with IDD are generally at higher risk for preterm birth.

We cannot draw conclusions about the mechanisms behind the differences in preterm birth we observe. Previous research (Peterson-Besse et al., 2014) has demonstrated that racial or ethnic minority individuals with disabilities face greater barriers to health care access and receive lower quality services than either white women with disabilities or black women without disabilities. Parish and colleagues (Susan L. Parish, Jamie G. Swaine, Esther Son, & Karen Luken, 2013) found that African-American women with IDD were significantly less likely to receive mammography than their white counterparts. Similarly Magaña and colleagues (2008) found that minority adults with IDD and their caregivers experienced a greater number and intensity of challenges in accessing health care relative to white peers, including: lack of knowledge of the health system, dissatisfaction with services, lack of services in the area, lack of transportation, and high costs of services. Other studies (Peterson-Besse et al., 2014; Shafi et al., 2007) have demonstrated that even when black and white adults with disabilities have similar health insurance coverage, education, or income, black people with disabilities are less likely than their white counterparts to have access to adequate health care services. Recent health disparities (Magana et al., 2016) research among adults with IDD also found that black adults were more likely than their white peers to be in fair or poor health and fair and poor mental health. It is likely that healthcare professionals, including obstetricians and midwives who provide prenatal care to women with IDD in general, and women of color with IDD in particular, lack awareness of their elevated potential for adverse pregnancy outcomes. Further, health care professionals may well lack training on how to personalize prenatal care for women with IDD, therefore providers might need more time with their patients with IDD and the visits may need to be more frequent for these patients to motivate adherence to medical advice. One study on satisfaction with prenatal care among women with a physical disability (M. Mitra et al., 2017)

found that providers lacked training and education regarding the prenatal care needs of women with physical disabilities and how their disability can impact their pregnancy. Insufficient awareness and training among health care professionals, coupled with persistent racial and ethnic health disparities (Cox, Zhang, Zotti, & Graham, 2011; Gavin, Adams, Hartmann, Benedict, & Chireau, 2004) may increase the risk of preterm birth among black women with IDD.

We found no support for our hypothesis that racial/ethnic minority women with IDD were more likely to have low birth weight infants A higher proportion of black and Hispanic women with IDD had low birth weight infants (15.9% and 13.9%, respectively) than white women with IDD (11.7%), however, after adjusting for sociodemographic and clinical characteristics, these differences were not significant. Nevertheless, these findings do support results from prior studies suggesting that women with IDD are significantly more likely to have low birth weight infants than women without IDD. Akobirshoev et al. (2017b) used HCUP data and observed that women with IDD had 1.6 times higher odds of having low-birth weight infants compared women without IDD. . The rate of cesarean delivery among women with IDD in our sample was comparable to women in the general Massachusetts obstetric population (32.9% vs. 31.4% for white women, 37.4 % vs. 34.2% for black women and 30.0% vs. 30.3% for Hispanic women, respectively) (Massachusetts Department of Public Health, December 2014). This finding is contrary to previous research. Using nationally representative HCUP data, Parish et al. (Susan L. Parish et al., 2015) found that the rate of cesarean delivery was 49% among women with IDD and 33% among women without IDD. Similarly, Mitra et al. (2015) used Massachusetts PELL data and found that 36.3% women with IDD in Massachusetts had cesarean delivery versus 27.1% of women without IDD in the general obstetric population.

We cannot draw inferences about why we did not detect significant racial/ethnic disparities in the rate of cesarean delivery or low birth weight among women with IDD in this study. Relatively strong health care quality in Massachusetts, in concert with near-universal health insurance coverage (Massachusetts Budget and Policy Center, 2014) may have attenuated the risks observed in nationally-representative data.

A noteworthy finding of this study is the evidence of marked racial and ethnic differences in labor and delivery-related charges among women with IDD. Namely, black and Hispanic women with IDD had 37% and 20% higher unadjusted labor and delivery-related charges than their white counterparts with IDD. Racial and ethnic differences in these charges were robust and remained statistically significant after adjusting for a variety of covariates including: a woman's sociodemographic characteristics, clinical characteristics, adverse birth outcomes, number of diagnoses, number of procedures, length of hospital stay and birth year. Market characteristics (i.e., patient flow, number of hospitals in an area, percent uninsured and percent below the poverty line in the county) have been shown to influence hospital charges and costs (Ginsburg, 2010; Hsia et al., 2014; Mutter, Wong, & Goldfarb, 2008; Wong, Zhan, & Mutter, 2005). However, owing to PELL data restrictions, we were unable to control for market characteristics in this study. Racial and ethnic differences in labor and delivery charges may be confounded by clinical complexity. For example, black and Hispanic women with IDD might have more complex diagnoses requiring more intensive procedures during labor and delivery; all of which may increase the cost of care. To address the potential for confounding, we adjusted for the number of procedures and number of diagnoses during labor and delivery, however, significant differences remained. It is possible that unmeasured differences between the populations, including individual disease burden and access to care remain. The determinants of health status

and health outcomes are complex and interrelated; however, initiatives that facilitate access to services across a variety of sectors may help to modify and ameliorate observed differences.

Limitations

Several limitations warrant consideration. First, some women with IDD who gave birth were likely not coded by the ICD-9 as having an intellectual or developmental disability, as labor and delivery were the focus of the hospitalization. As such, the final analytical sample may represent an undercount of deliveries in women with IDD. Second, there is the potential for omitted variable bias. As noted above, owing to PELL data restrictions, the study could not account for income, hospital or market-level characteristics, factors that may account for some of the observed racial and ethnic differences in labor and delivery-related charges. Further, lack of information on residential setting is another factor that have been shown to impact access to preventive care for people with IDD (Bershadsky et al., 2012). Third, combining multiple years of data presents an additional challenge in terms of controlling for potential confounding factors related to perinatal policy and practice changes between 1998 and 2013. Fourth, although these data represent the entire population of Massachusetts women who delivered between 1998-2013, the findings may not generalize to women living in other states. Finally, causality cannot be established due to the cross-sectional nature of the data (Baron & Kenny, 1986). Further longitudinal studies are needed to better understand the mechanisms associated with higher labor and delivery-related charges for black and Hispanic women with IDD.

Despite these limitations, the study has important strengths. It does not rely on self-reported data regarding clinical conditions or characteristics, but instead includes data from high-quality clinical and birth certificate records. Second, it is population-based, so the sample is not subject to selection bias, which is a concern in samples that are drawn from disability service

organizations or voluntary participation. Another strength is the use of longitudinally-linked administrative data to identify women with IDD and examine their risk for adverse birth outcomes and differences in labor and delivery-related charges.

Conclusions

This is the first investigation of racial and ethnic differences in birth outcomes and labor and delivery-related charges among women with IDD in Massachusetts. Our findings underscore the need for an integrated approach to the delivery of comprehensive perinatal services for black women with IDD. Additionally, further research is needed to examine birth outcomes and delivery charges in other states or regions of the country. Research is also needed to understand the reasons for racial and ethnic differences in labor and delivery-related charges we observed in women with IDD. These findings contribute to an emerging body of work on reproductive health outcomes among women with IDD and may contribute to state-level public health planning and surveillance efforts to ensure equity in access, utilization, and quality of health care services for this population.

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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

Table 2: Sociodemographic characteristics of PELL 2002-2013 sample, N=1,525 women with intellectual and developmental disabilities

Characteristics	Non-Hispanic White N=980 n (%)	Non-Hispanic Black N=228 n (%)	Hispanic N=317 n (%)	P values
Maternal age				b
<20	97 (9.9)	24 (10.5)	44 (13.9)	
20-34	749 (76.4)	176 (77.2)	252 (79.5)	
>35	134 (13.7)	28 (12.3)	21 (6.6)	
Maternal Age, Mean (SD)	27.4 (0.2)	26.6 (0.4)	24.9 (0.3)	b
Maternal education				a,b
Less than high school	249 (25.4)	75 (32.9)	174 (54.9)	
High school or GED	490 (50)	130 (57)	117 (36.9)	
Some college	84 (8.6)	14 (6.1)	10 (3.2)	
College and higher	153 (15.6)	7 (3.1)	13 (4.1)	
Missing	4 (0.4)	2 (0.9)	3 (0.9)	
Marital Status				a,b
Married	413 (42.1)	23 (10.1)	62 (19.6)	
Not married	565 (57.7)	205 (89.9)	254 (80.1)	
Missing	2 (0.2)	0 (0)	1 (0.3)	
Health insurance				a,b
Private	326 (33.3)	19 (8.3)	25 (7.9)	
Public	651 (66.4)	208 (91.2)	292 (92.1)	
Missing	3 (0.3)	1 (0.4)	0 (0)	

Note: a – indicates statistically significant difference at $p<0.05$ between non-Hispanic white and non-Hispanic black women. b – indicates statistically significant difference at $p<0.05$ between non-Hispanic white and Hispanic women.

Table 3. Clinical characteristics, birth outcomes, and hospital charges, PELL 2002-2013, N=1,525 women with intellectual and developmental disabilities

Characteristics	Non-Hispanic White N=980 n (%)	Non-Hispanic Black N=228 n (%)	Hispanic N=317 n (%)	P values
Kotelchuck Index				
Inadequate	22 (2.3)	<11(1.9)	<11 (2.9)	
Intermediate	91 (9.5)	15 (7)	37 (11.9)	
Adequate	353 (36.7)	85 (39.5)	90 (28.9)	
Adequate Plus	496 (51.6)	111 (51.6)	175 (56.3)	
Pregnancy related complications[c]	572 (59)	142 (63.1)	184 (58.8)	
Labor complications[d]	467 (48.2)	114 (50.7)	162 (51.6)	
Smoking during pregnancy	205 (20.9)	28 (12.3)	49 (15.5)	a,b
Parity				b
First pregnancy	491 (50.3)	102 (44.9)	137 (43.4)	
Second pregnancy	278 (28.5)	65 (28.6)	85 (26.9)	
Third or higher	208 (21.3)	60 (26.4)	94 (29.7)	
Cesarean delivery	322 (32.9)	85 (37.4)	95 (30)	
Preterm birth	120 (12.2)	42 (18.4)	46 (14.6)	a
Low birth weight	114 (11.7)	36 (15.9)	44 (13.9)	
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	
Number of diagnoses[e]	4.7 (0.1)	5.1 (0.2)	5.2 (0.2)	a,b
Number of procedures[f]	2.4 (0.04)	2.1 (0.09)	2.5 (0.08)	a
Length of stay, days	3.4 (0.1)	3.8 (0.2)	3.3 (0.2)	a
Labor and delivery related charges	$11,778 ($462)	$16,172 ($2,028)	$14,075 ($843)	a,b
	Median (IQR)	**Median (IQR)**	**Median (IQR)**	
Number of diagnoses	4(3;6)	5(3;7)	5(3;7)	
Number of procedures	2(1;3)	2(1;3)	2(1;3)	
Length of stay, days	3(2;4)	3(2;4)	3(2;4)	
Labor and delivery related charges	$8,702 ($5,993; $13,622)	$10,010 ($6,428; $17,834)	$10,170 ($6,897; $16,856)	

Note: a – indicates statistically significant difference at p<0.05 between non-Hispanic white and non-Hispanic black women; b – indicates statistically significant difference at p<0.05 between non-Hispanic white and Hispanic women; [c]Pregnancy related complications include one of the following pre-existing chronic and pregnancy-related comorbidities: diabetes (gestational or chronic), hypertension (pregnancy-related and chronic), cardiac disease, hydramnios/oligohydramnios, hemoglobinopathy, renal disease, RH sensitization, rubella infection during pregnancy, seizure disorders, sickle cell anemia, uterine bleeding, weight gain/loss, and other complications recorded. [d]Delivery-related complications include one of the following: abruptio placentae, other excessive bleeding, placenta previa, precipitous labor, prolonged labor, rupture of membrane, seizures during labor, anesthetic complications,

breech/malpresentation, cephalopelvic disproportion, cord prolapse, dysfunctional labor, febrile, fetal distress, meconium moderate to heavy, and other complications of labor and delivery. [e]The number of diagnoses ranged between 1 and 15 and included one primary diagnosis and a maximum of 14 other secondary diagnoses based on ICD-9 codes. [f] The number of procedures ranged between 0 indicating no procedure was performed and a maximum of 15 procedures performed during the delivery hospitalization based on ICD-9 codes.
To maintain confidentiality, cells with <11 cases for non-missing outcomes cannot be reported.

Table 4. Association between race/ethnicity, birth outcomes and labor and delivery-related charges among women with intellectual and developmental disabilities, Massachusetts, N=1,525

Outcomes	Unadjusted				Adjusted[a]			
	black vs. white		Hispanic vs. white		black vs. white		Hispanic vs. white	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Cesarean delivery	1.22	(0.91 - 1.65)	0.87	(0.66 - 1.15)	1.03	(0.75 - 1.41)	0.84	(0.62 - 1.13)
Preterm birth	1.62**	(1.10 - 2.38)	1.22	(0.85 - 1.76)	1.69**	(1.13 - 2.53)	1.32	(0.90 - 1.94)
Low birth weight	1.43*	(0.95 - 2.14)	1.22	(0.84 - 1.78)	1.28	(0.74 - 2.23)	1.03	(0.62 - 1.72)
	ln (b)	**95% CI**	**ln (b)**	**95% CI**	**ln (b)**	**95% CI**	**ln (b)**	**95% CI**
Delivery charges,[b] $, Mean (SD)	0.18***	0.08 - 0.29	0.17***	0.09 - 0.25	0.14**	0.02 - 0.27	0.14***	0.06 - 0.22

Data source: Pregnancy to Early Life Longitudinal (PELL) Data System, 1998-2013

*p<0.05; **p<0.01; ***p<0.001.

Acronyms: OR=Odds Ratios; CI=Confidence Intervals.

[a] Adjusted for maternal age, education, marital status, Kotelchuk index, pregnancy complications, labor complications, smoking during pregnancy, parity, and birth year. [b] Delivery-related charges model, additionally adjusted for Cesarean delivery, preterm birth, low birth weight, number of diagnoses, number of procedures, and length of hospital stay.