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The (dis)ability to be pregnant: how sensory, developmental, and reproductive disabilities among women of reproductive age influence pregnancy outcomes using 2017-2019 NSFG data.

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Thesis Committee Chair: Subasri Narasimhan, PhD, Emory University

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
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Abstract

The (dis)ability to be pregnant: how sensory, developmental, and reproductive disabilities among women of reproductive age influence pregnancy outcomes using 2017-2019 NSFG data.

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Women with disabilities (WWD) in the U.S. are a vulnerable population with disproportionate lack of access to healthcare. Pregnancy outcomes for this population are understudied in public health research, both due to stigma from healthcare providers and low quantity and quality of consistent data. Existing literature suggests higher rates of miscarriage and negative maternal health outcomes among WWD compared to women without disabilities (WWOD). Using a biopsychosocial framework of disability, this secondary, cross-sectional analysis uses data from the 2017-2019 U.S. National Survey of Family Growth to examine miscarriage, abortion, and livebirth outcomes among WWD compared to WWOD (n = 9,794), and women with one of three disease categories (sensory (SD), developmental (DD), or reproductive-related non-communicable (RRD)) compared to women with one of the remaining two disease categories (n = 2,681). After adjusting for sociodemographic factors, binomial logistic regressions found increased odds of miscarriage among WWD compared to WWOD (OR: 1.58, $p < 0.0001$, 95% CI: 1.28 – 1.95) and in women with RRD compared to women with SD or DD (OR: 1.35, $p = 0.04$, 95% CI: 1.01 - 1.81). These results add to the growing body of literature calling for increased and improved data collection and research about women with disabilities in the U.S., including standard definitions of different types of disability, and improved, consistent data collection questions. The results also help to contextualize the disparity that WWD face in accessing appropriate reproductive healthcare. Lastly, they signal the need for consideration of vulnerable populations in changing U.S. healthcare policy and in reproductive and family planning resources.

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Finally, to anyone working and researching in the reproductive and disability justice space – thank you for continuing to fight the good fight.

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Positionality Statement

The first author Hannah Anolik is a Master of Public Health Student and intern at a global health non-profit. She identifies as Caucasian, cis-gender, female. She identifies as someone with a chronic autoimmune disorder. She acknowledges that her membership in these groups has influenced her research question to some extent, and has sought help to appropriately cover the topic, include and reference diverse research, and abide to the outlined frameworks of disability and reproductive justice.

The committee chair Dr. Subasri Narasimhan is a cis-gender Asian-identifying female. She has worked on issues of reproductive health for more than one decade, including in partnership with academics and community groups. She identifies as a person with a reproductive disability.

The committee member Johnathan Edwards is a cis-gender Caucasian-identifying male. He has worked on issues of reproductive health and HIV for seven years including in partnership with hospital and clinical staff in KwaZulu-Natal South Africa. He identifies as a person with neurocognitive disability.

Abbreviations

CDC: Center for Disease Control and Surveillance

DD: Developmental disability

IDD: Intellectual and developmental disability

NHANES: National Health and Nutrition Examination Survey

NSFG: National Survey of Family Growth

MEPS: Medical Expenditure Panel Survey

PWD: People with disabilities

RRD: Reproductive related disability

SD: Sensory disability

WWD: Women with disabilities

WWOD: Women without disabilities

I. Introduction

Women with disabilities (WWD) make up 12% of the global population but are largely excluded, explicitly and/or implicitly, in sociological and medical research on reproductive health despite clear needs for autonomy-centered services and accessible and appropriate healthcare (Kitchin, 2000). One area of research that is understudied among WWD is pregnancy outcomes and the confounding factors that influence these outcomes, including pre-, peri-, and postnatal care in the U.S, stigmas, physical barriers, and socioeconomic factors.

In existing literature there is lack of consensus about the prevalence of pregnancy, pregnancy related complications, and birth outcomes in WWD (Ward et al., 2022). The literature has captured that WWDs are as likely as nondisabled peers to desire pregnancy, though fewer report desire for future pregnancy in intention data (Signore et al., 2021). Additionally, WWD are more likely to have negative birth outcomes and experiences of stigma from physicians surrounding pregnancy, compared to their non-disabled counterparts (WWOD) (Blair et al., 2022; Tarasoff et al., 2020). In particular, the odds of miscarriage among WWD are higher than among WWOD, exacerbated by certain disabilities and socioeconomic factors. However, the shortage of information explaining higher odds of negative maternal and birth outcomes in WWD and inconsistency in results necessitates an understanding of the health of marginalized populations that is crucial for ensuring the reproductive health of WWD (Dissanayake et al., 2020).

While the quantity of research at the intersection of pregnancy and disability has increased since years past, research on people with disabilities (PWD), a vulnerable research population, is often of low validity, reliability, and quantity due to shortcomings in standard methods for collecting and reporting data. For example, the National Survey for Family Growth (NSFG) is one of the only nationally representative surveys in the U.S. that collects information about both pregnancy and disability. Further, research that utilizes past NSFG data cycles have no consistent definition of the different categories of disability to base analyses on, which further contributes to lack of consensus in the literature. Thus, the need for greater examination of pregnancy outcomes for WWD using datasets intended to capture maternal health experience is apparent. To that point, there is no recent, focused analysis of pregnant WWD from the most recent survey cycle of NSFG (2017-2019) (Powell, 2022).

This unique study will use a biopsychosocial framework of disability and the United Nation's (UN) framework for reproductive justice to examine pregnancy outcomes, specifically livebirth, abortion, and miscarriage, among women with sensory (SD), developmental (DD), and reproductive-related disabilities (RRD) in the US using data from the Center for Disease Control (CDC)'s 2017 – 2019 NSFG dataset. These findings are presented as the odds of each pregnancy outcome among WWD compared to WWOD, and among women with SD, DD, and RRD compared to each other. Finally, results are framed in the context of existing literature and public health implications. This study will examine the questions: "Is there a higher risk of negative birth outcomes for WWD compared to WWOD?" and "Are pregnancy outcomes different between women with different types of disabilities, as opposed to only between WWD and WWOD?".

II. Literature Review

A. Pregnancy among women with disabilities

Existing literature about WWD and pregnancy is limited to recent years and suggests greater negative birth outcomes for WWD compared to nondisabled counterparts. These negative outcomes can be examined in the context of rates and intentions of pregnancies, barriers and facilitators to accessing healthcare before, during, and after pregnancy, the theoretical frameworks that explain how disability and reproductive health are treated in the U.S., and methodological needs and concerns in existing data about WWD.

1. Pregnancy rates and intentions

WWD and WWOD have similar rates of pregnancy desirability (61% and 60%, respectively). However, fewer WWD have an intention to become pregnant. Higher rates of unintended pregnancy prevail among WWD compared to WWOD. According to 2011 – 2013 NSFG data of 5,601 WWD and WWOD, 43% of WWD reported an intention to become pregnant compared to 50% of WWOD (Bloom et al., 2017). Additional analysis of 3,089 WWD from the 2011 – 2015 NSFG datasets showed that WWD were 42% more likely to have an unintended pregnancy compared to WWOD. The authors of this study theorized that societal views of WWD as asexual paired with insufficient reproductive education for WWD contributed to this statistic (Horner-Johnson et al., 2020).

Research on WWD may suffer from data collection issues including a lack of representativeness of types of PWD, inconsistent data collection across national surveys and local clinics, incorrect comparison groups, mis-categorization of disability types, and small sample sizes, all leading to an unstable picture of the prevalence of pregnancy in WWD (Zhang et al., 2019). According to an analysis of women ages 18-44 from the 2011-2015 NSFG, WWD were less likely to be pregnant than were WWOD (Zhang et al., 2019). In contrast, studies such as an analysis of women ages 20-44 from the 2015-2016 National Health and Nutrition Examination Survey (NHANES) claimed that there were no significant differences in pregnancy rates, number of pregnancies, or number of unsuccessful pregnancies in WWD and WWOD (Ward et al., 2022). Some analyses have found that pregnancy rates among WWD became more similar as more recent data is collected and when comparing samples by demographic factors, specifically age and income group (Signore et al., 2021). Therefore, updated literature with more nuanced comparisons suggest that the gap in pregnancy prevalence between WWD and WWOD is narrowing, with recent data reporting a pregnancy rate of 1.2 – 1.3 births per women in WWD and WWOD alike (Horner-Johnson et al., 2020).

2. Pregnancy outcomes

The relatively few existing studies on pregnancy outcomes in WWD have found higher rates of miscarriage and lower rates of live birth among WWD compared to WWOD. An analysis of 3,843 women from the 2011 – 2015 NSFG data cycle showed that 32% of WWD compared to 22% of WWOD had a miscarriage (Dissanayake et al., 2020). Another secondary analysis of 4,513 women using Medical Expenditure Panel Survey (MEPS) data from 1996 – 2007 found higher rates of miscarriage among women with complex activity limitations and lower rates of livebirth among women with any disability (Horner-Johnson et al., 2017). Similarly, a 2017 cross sectional analysis of 268 women in U.S. hospitals and private physician practices found that women with endometriosis had 1.97 times higher risks of miscarriage compared to women without endometriosis (Kohl Schwartz et al., 2017). Thus, the odds of miscarriage among WWD, using data from different datasets and years, is consistently higher than the odds among WWOD. Continuously, findings from analyses of outcomes among women with specific disabilities compared to people with other disabilities or WWOD suggest that some disabilities have stronger influences on birth outcomes than others.

Additional studies have found that WWD have increased risk of cesarean section (c-section) births compared to WWOD. For example, a 2021 secondary analysis of a nationwide cohort study of 223,385 women found that WWD had 1.34 times the risk of c-section than did WWOD (Gleason et al., 2021). Another retrospective cohort study using birth and hospital data in California from 2000 – 2010 found that WWD had double the odds of c-section than WWOD had (Darney et al., 2017). Continuously, in secondary analysis of 2015-2016 National Health and Nutrition Examination Survey (NHANES) data, 182 women with difficulties hearing or seeing, or with functional limitations (making decisions, walking, dressing, or doing errands) were more likely to have a c-section than were women without any functional limitations (Ward et al., 2022). Yet, an analysis of 13,361 WWD and WWOD from the 2002-2011 Rhode Island Pregnancy Risk Assessment Monitoring System (RI PRAMS) showed no significant difference in the odds of c-section in WWD compared to WWOD (Mitra et al., 2015). Researchers did not hypothesize why this difference did not exist.

Gleason et al. and Darney et al. used The International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) to categorize WWD, whereas Mitra et al. and Ward et al. used surveys that collected data utilizing the standard CDC questions and categorized answers based on previous literature. Thus, if the difference in outcomes is due to data, it might be one example of the results of inconsistencies in data collection and categorization. If the different outcomes are assumed to both be true, then they might also demonstrate the need to have more nuanced understandings of the health of marginalized populations, including the disparities and discrepancies that exist in healthcare access and outcomes within disability categories.

a. Physical disabilities

For women with physical disabilities, the effect on functional activity is typically what is measured when disability is measured in a survey using CDC standard questions, underscoring the theory that limitations to daily life appear to be the main driver of discrepancies in pregnancy outcomes rather than the presence of physical disability itself.

Women with physical disabilities that impacted independent living were more likely to have more than two miscarriages compared to WWOD, as well as more hysterectomies and c-sections, according to Ward et al.'s 2015-2016 NHANES analysis (Ward et al., 2022). Other research such as Horner-Johnson et al.'s (2017) analyses of Medical Expenditure Panel Survey (MEPS) data from 1996 – 2007 agreed with this finding. They reported that women with complex physical activity limitations that restricted their ability to participate in social roles or self-care activities were more likely to have miscarriages, preterm births, babies with low birth weight, and babies in the NICU than were women who did not have these limitations (Horner-Johnson et al., 2017). Further supporting this, pregnancy prevalence seems to fall as severity of physical disability increases, according to a cross sectional analysis of 6,043 women with chronic physical disabilities interviewed in the 2006 – 2011 National Health Interview Survey (NHI) (Iezzoni et al., 2013). Evidenced by this diverse range of data, there is consensus in the literature that functional limitations impact birth outcomes.

Some specific physical disabilities, however, such as multiple sclerosis (MS) or epilepsy, appear to have no strong evidence of effect on birth outcomes. A cross sectional analysis of 10,055 pregnancies in the Nationwide Inpatient Sample and Healthcare Cost and Utilization

Project (HCUP) showed no significant differences in birth outcomes between women with MS or epilepsy and women without either (Kelly et al., 2009). Another systematic review of papers examining pregnancy in women with MS from 1995 – 2019 found no significant differences in pregnancy outcomes among women with MS and women without (Canibaño et al., 2020). Literature examining functional activity limitations in women with MS and epilepsy would help to compare results across studies and better understand why some studies show differences in birth outcomes and some do not.

b. Intellectual and developmental disabilities

There are mixed results in existing literature regarding pregnancy outcomes for women with intellectual or developmental disabilities (IDD) (also referred to as cognitive disabilities in some studies). However, most studies, especially those using survey data as opposed to hospital discharge data, find negative birth outcomes among women with IDD compared to those without.

In Parish et al.'s cross-sectional analysis of 340 women with IDD compared to 776,986 women without IDD using 2010 HCUP data, women with IDD had 1.78 times the odds of preterm labor (Parish et al., 2015). Another analysis of 2011-2019 NSFG data showed that 307 women with cognitive disabilities had statistically significant risks for preterm birth compared to WWOD (Horner-Johnson, Dissanayake, et al., 2022). Yet, in a cross sectional analysis of 103 women with IDD and 10,300 women without IDD from 1987 – 2012 Washington state hospital discharge data, no significant difference in the rate of preterm delivery was found (Mueller et al., 2019). Whether or not this discrepancy is because of analysis of hospital data as opposed to survey data is unclear but notable.

Parish et al.'s same 2015 analysis of HCUP data also found that women with IDD had 2.13 times the risk of caesarean delivery (Parish et al., 2015). Further analysis of the same data from Washington State hospital discharge data, while disagreeing with Parish's analysis of preterm birth weight, agreed with findings on cesarean delivery and found that women with IDD had 1.43 times the risk of c-section than did those without (Mueller et al., 2019).

Horner-Johnson et al.'s same 2022 analysis of NSFG 2011 – 2019 data also found significant associations between low birth weight among infants and mothers with cognitive disability (Horner-Johnson, Dissanayake, et al., 2022), while Mueller et al.'s analysis of Washington State hospital discharge data did not find association with low birth weight (Mueller et al., 2019), again highlighting the differences when comparing between studies using survey data and studies using hospital data.

c. Reproductive-related disabilities

Women with RRD have also been seen to have more negative pregnancy outcomes than women without these disabilities. Endometriosis is known to increase the odds of miscarriages, and Kohl Schwartz et al.'s cross sectional analysis showed that even mild endometriosis may be a large risk factor for miscarriage (Kohl Schwartz et al., 2017). A meta-analysis of pregnancy among 720 women in 15 studies from 1990 to 2005 with polycystic ovary syndrome (PCOS) showed correlations with c-section, low birth weight, and neonatal complications, though the validity of studies and presence of strong potential confounders made some results questionable (Boomsma et al., 2006). Another meta-analysis describing 49 pregnancies from 34 studies after 1971 among women with pelvic inflammatory disease (PID) found high proportions of miscarriages and intrauterine fetal demises compared to women without PID, and found that c-section was the most common delivery method across many studies in women with PID

(Marcinkowski et al., 2022). Though a wide range of disabilities and amount of impact on functional limitation falls in the category of RRD, there appears to be an overall correlation among women with RRD with higher odds of negative birth outcomes when compared to women without RRD.

3. Associated health outcomes

In addition to correlations with negative birth outcomes, WWD have also been more likely to have negative maternal health outcomes resulting from pregnancy. For example, the risk of severe maternal mortality in WWD has been found to be three times that of WWOD according to a retrospective cohort study of 33,044 women in California (Horner-Johnson, Garg, et al., 2022). This is consistent with findings from other studies, such as Gleason et al.'s 2021 retrospective cohort study of 223,385 women with and without disabilities at 12 U.S. clinical centers from January 2002 to 2008 (Gleason et al., 2021) and Mitra et al.'s 2021 cross sectional study of 32,324 deliveries to women with IDD using 2004 – 2017 HCUP data (Mitra et al., 2021), that both showed increased risk of severe maternal mortality among WWD. These results further highlight the need to better understand reproductive healthcare needs of WWD.

a. Physical disabilities

Among women with physical disabilities, risk of maternal complications is agreed upon in literature to be high.

According to Mitra et al., women with physical disabilities from the 2011 RI PRAMS data were more likely to experience medical problems during pregnancy including blood transfusions, high blood pressure, vaginal bleeding, kidney/bladder infections, and nausea, than were WWOD. Mitra et al. discussed that since women with physical disabilities had higher rates of cesarean delivery, they also had higher chances of infection during/after pregnancy (Mitra et al., 2015).

Among women with spinal cord injury, one cohort study of 22 women found a 100% prevalence rate of urinary tract infections (UTIs) in pregnant women during pregnancy, and according to a 2021 systematic review of women with different types of disabilities, studies of women with spinal cord injury showed overall increased risk of UTIs in pregnancies (Signore et al., 2021). These results underscore the increased risk for infections during pregnancy in women already predisposed to an infection.

In Horner-Johnson et al.'s aforementioned retrospective cohort study of 33,044 WWD in California, women with vision disabilities had the highest risks for acute renal failure, respiratory distress, cardiac rhythm conversion, eclampsia, pulmonary oedema, and ventilation, and severe maternal mortality was highest for women with injury related physical disabilities (Horner-Johnson, Garg, et al., 2022). While the presence of physical disabilities is strongly correlated with maternal complications in these studies, it is unclear if these correlations are between the presence of disability or functional limitations.

The consensus of a high prevalence of maternal complications among women with physical disabilities should be both acknowledged, but also more closely examined.

b. Intellectual and developmental disabilities

In women with IDD, unlike with pregnancy outcomes, it is mostly agreed on in existing literature that maternal health outcomes are negative. In a retrospective cohort study of 3,932 women with IDD in Ontario, Canada from 2002 – 2011, risks for negative maternal health outcomes (preeclampsia, peripartum hemorrhage, abruptio placentae, cesarean delivery, venous thromboembolism, and overall maternal complications) were higher in women with IDD than in the general population (Brown et al., 2017). Continuously, a 2007-2016 analysis of Wisconsin Medicaid data showed that women with IDD had higher risks hypertension, gestational diabetes, preeclampsia, peripartum hemorrhage, and abruptio placentae than WWOD did (Rubenstein et al., 2020; Signore et al., 2021) In Horner-Johnson's 2022 California cohort study, women with IDD were the second most likely group of WWD to receive blood transfusions and to have heart and pericardium operations, and had the greatest overall risk of maternal health effects among WWD (Horner-Johnson, Garg, et al., 2022).

c. Reproductive-related disabilities

In women with RRD, high odds of negative maternal outcomes are also typically agreed on in existing literature. An example of this is seen in women with PCOS, who had significantly higher odds of overall complications when compared to women without PCOS in multiple studies, including in Kollmann et al.'s 2015 retrospective matched cohort study of 885 women with PCOS in the U.S (Kollmann et al., 2015). In Lalani et al.'s 2018 systematic review of 33 cohort and case control studies from January 1990 to December 2017, risks for pre-eclampsia, placenta previa, antepartum hemorrhage, antepartum hospital admission, malpresentation, labor dystocia, cesarean section, and gestational hypertension, diabetes, and cholestasis, were all higher in women with endometriosis than women without (Lalani et al., 2018). Additionally, women with uterine fibroids (UF) were found to have higher risk for placenta previa, placental abruption, and for postpartum hemorrhage according to a 2016 systematic review of outcomes among women with UF in various countries (Parazzini et al., 2016).

While the quality of the studies and diagnostic definitions varies, general agreement of increased risk for maternal complications among women with RRD, specifically PCOS, endometriosis, and UF, is evidenced.

B. Potential confounders on birth outcomes

The presence of a disability alone was not the only cause of negative birth outcomes or maternal complications in any mentioned studies. Covariates in analysis that measured other factors such as access to healthcare services, socioeconomic status, and stigma associated with disability, are a few variables that help to explain disparities in birth and maternal health outcomes.

1. Stressors

WWD have been more likely to experience stress before pregnancy compared to WWOD. Compared to WWOD, WWD were more likely during pregnancy to engage in risky behaviors (such as smoking), report a medical complication, experience stressful life events and physical abuse, and report feeling unsafe in their neighborhood than WWOD were to, according to data from the previously described 2002 – 2011 Rhode Island (RI) PRAMS analysis. 13.6% and 3.6% of WWD reported sometimes and almost always feeling unsafe during their pregnancy respectively, compared to 5.1% and 1.1% of WWOD respectively. WWD also reported higher overall levels of emotional, partner-related, financial, and traumatic stress (Mitra et al., 2015). According to 2007 – 2008 Massachusetts PRAMS data, the rate of physical abuse was over three times as high in the year before birth and during pregnancy in WWD than it was in WWOD (Mitra et al., 2012). Additional findings from the Behavioral Risk Factor Surveillance System analyzing 67,790 women from the U.S. showed that WWD had significantly higher odds of preconception frequent mental distress and inadequate social support compared to WWOD (Horner-Johnson et al. 2021).

Regardless of the cause, stress during pregnancy is correlated with negative birth outcomes (Horner-Johnson, Akobirshoev, et al., 2021). Therefore, higher levels of prenatal and perinatal stress might influence the effect of disability on pregnancy outcomes shown in studies. The increased presence of stress might also be something to take into consideration when providing reproductive health services to WWD.

2. Access to quality reproductive and family planning health services

WWD have reported significantly lower health care utilization before, during, and after pregnancy compared to WWOD, which leads to poorer birth and maternal health outcomes and suggests disproportionate access to reproductive healthcare across the lifespan.

Regarding reproductive health before pregnancy, WWD ages 15 – 44 in 2011 – 2015 NSFG data were significantly less likely to have received a method of birth control or birth control counseling, and significantly less likely to have used any family planning services compared to nondisabled counterparts (Mosher et al., 2017). This was affirmed through focus groups of 17 women with different types of disabilities in 2016 in Oregon that described challenges visiting their obstetrics-gynecology (OBGYN) physicians (Horner-Johnson, Klein, et al., 2021), and through individual interviews with 31 women with different disabilities in the U.S. describing system, financial, and healthcare barriers to accessing family planning services (Alhusen et al., 2021). Both results showed that participants felt that it was difficult to have an OBGYN appointment and access these services.

During pregnancy, Mitra et al.'s RI PRAMS study reported that WWD did not access reproductive care during the first trimester as much as WWOD (Mitra et al., 2015). However, Deierlein et al.'s 2021 systematic review of 16 studies reported that women with physical disabilities accessed more intensive perinatal care than WWOD (Deierlein et al., 2021). These different results might be explained by difficulties accessing services, increased attention to higher risk pregnancies, the impact of functional limitation, stigma, and more. The impact of these factors on reproductive care should be further examined.

In postpartum, WWD reported having less people than WWOD did to help them if they were sick, to help take care of their baby, and to drive them to the doctor if needed. They also reported less frequent checkups and contact with healthcare workers than did WWOD, according to RI PRAMS (Mitra et al., 2015). Similarly, according to an analysis of Massachusetts PRAMS 2016 – 2020 data, WWD had a statistically significant lack of partner, financial, and social support after giving birth, compared to WWOD (Chen et al., 2023).

Physical, socioeconomic, educational, and stigma-based factors can help to explain these differences in stressors and access to quality reproductive healthcare/family planning services from preconception to postpartum.

a. Physical Barriers

One major barrier to accessing care among WWD has been shown to be the physical inaccessibility of offices, exam rooms, transportation, and treatments, which delay or prevent WWD from making doctor's appointments, or limit the effectiveness of a doctor's appointment.

In one qualitative study of ten women with physical disabilities in Texas, women described never being weighed at physician office visits due to inaccessible scales, being physically lifted onto non-adjustable exam tables, and some only being examined in a wheelchair. Aside from being scary and embarrassing, these events led to effects like incorrect dosing and a lack of a quality exam (Becker et al., 1997).

In individual interviews with 31 women with many disabilities, adolescent women with physical disabilities claimed that they often had a caretaker, often a parent, at a healthcare visit with them who they did not feel comfortable discussing reproductive care around. This prevented discussions around family planning and was correlated with unintended pregnancies (Alhusen et al., 2021).

Additionally, women in both qualitative studies described delays trying to find a physician's office that was physically accessible which further delayed when they might first discuss reproductive healthcare with a doctor (Alhusen et al., 2021; Becker et al., 1997). Making physician offices more physically accessible was the main way that interviewees suggested eliminating physical barriers to accessing reproductive healthcare.

Birth control options can also be limited by mobility disabilities. For example, a NuvaRing requires someone to fully bend, intrauterine devices (IUD) require a specific sitting position for insertion, weight gain side effects from birth control pills can be more serious in people with mobility issues, and risks of blood clots that accompany hormonal methods can be compounded for people who use wheelchairs. However, in Alhusen's qualitative study, women with physical disabilities reported no discussion with their prescribing physician about alternate options when these methods posed problems. As a result, women with mobility disabilities had lower rates of voluntary use of contraception (Alhusen et al., 2021). This prevalence rate has been confirmed in other studies as well, such as Mosher et al.'s 2018 secondary analysis of 7,505 women at risk of unintended pregnancy from 2011-2015 NSFG data that found significant odds of not using birth control pills and elevated odds of non-use of any contraception among women with physical disabilities compared to WWOD (Mosher et al., 2018). Effective methods for mitigating the effects of mobility limitations on birth control usage should be further studied. Physical barriers to using birth control among WWD, lack of knowledge and discussion from physicians, and disuse by WWD because of misinformation about fertility were some factors discussed in these studies as potential influences on the results.

b. Socioeconomic Status and Intersectionality

Socioeconomic factors also influence how WWD access reproductive health services. Disparities in access to family planning services were most pronounced among WWD reporting low education, low income, and unemployment when compared to WWOD, according to previously mentioned interview data (Alhusen et al., 2021). Additional related barriers, such as not enough accessible providers accepting Medicaid/Medicare which WWD use more than WWOD, resulted in less access to physicians and was correlated with higher rates of unintended pregnancy (Alhusen et al., 2021). When comparing WWD in minority racial and ethnic groups to WWOD in the non-Hispanic white group in the Massachusetts Pregnancy to Early Life Longitudinal (PELL) database, all risk factors for maternal complications were higher for WWD. These factors included no check up in the past year, no pap smear in the past 3 years, no health insurance, obesity, never being tested for HIV, and no flu vaccine in the past year (Horner-Johnson et al., 2021). As with other conclusions about WWD, more evidence is needed to understand how reproductive health services can be offered in ways that ensure equitable access and prenatal care.

Racial and ethnic groups also impact birth outcomes. Literature shows that most negative birth outcomes and maternal complications are higher among marginalized groups than among non-marginalized groups. For example, a cross-sectional analysis of 2,110 women with IDD from the 2004 – 2011 HCUP sample showed significantly higher odds of stillbirth, longer hospital stays, and higher labor and delivery-related costs among non-Hispanic Black and Hispanic women with IDD compared to non-Hispanic White peers (Ransohoff et al., 2022). This finding was further confirmed by a cohort study in Wisconsin from 2007 – 2016 using Medicaid data to examine birth outcomes among women with IDD that found Black women with and without IDD had higher odds of not receiving first trimester prenatal care and of having gestational diabetes and hypertension compared to White women (Rubenstein et al., 2020). The authors of this paper described that the difference between Black and White women with and without IDD was not big, implying that the difference might be more due to race than the combined effect of race and disability together. Therefore, strong evidence suggests a difference in pregnancy outcomes by race among WWD, implying greater access disparities by race.

c. Stigma, Reproductive Coercion, and Violence

Stigma from healthcare providers has also impacted the ability to access care and the quality of care received by WWD. In Alhusen et al.'s qualitative study with 31 women with disabilities, women stated that providers often assumed WWD were asexual and did not talk about reproductive healthcare with these patients. Compounding the existence of this stigma was that WWD said they often feared a negative experience because of physician stigma, so they delayed seeing an obstetric doctor until after the first 12 weeks of pregnancy (Alhusen et al., 2021). This is consistent with other studies, such as Streuer et al.'s qualitative study of 25 women with spina bifida and Khanna et al.'s qualitative study of women with IDD, which both showed that WWD had difficulties communicating with their physicians and experienced stigma from physicians regarding pregnancy (Khanna et al., 2022; Streur et al., 2019). Becker's qualitative study of 10 women with physical disabilities found that WWD reported "negative attitude of health care providers" as the most difficult barrier to accessing care even when compared to physical and financial barriers (Becker et al., 1997).

Additionally, despite reproductive coercion more commonly occurring in WWD than in WWOD, providers for WWD rarely screened for violence according to Alhusen et al.'s study (Alhusen et al., 2020). Fifty young women with reproductive disabilities in a secondary analysis in 2019 said they feared being pressured into decisions not medically indicated, injuries related to anesthesia, and doctors who would underestimate their pain (Gomez et al., 2019).

This stigma appeared to stem from a deep-rooted history of the myth of asexuality among WWD, especially among those with visible and/or developmental disabilities (Khanna et al., 2022). Continuously, a history of a lack of bodily autonomy among WWD in the U.S., resulting in forced sterilization (which is still legal for WWD in some U.S. states) (Kallianes & Rubenfeld, 1997) and a stigma that WWD were unfit for parenthood (Khanna et al., 2022) might have contributed to these beliefs among physicians.

d. Educational

In addition to the stigma imposed from physicians, WWD also lack appropriate education surrounding family planning and reproductive health services, and physicians also sometimes lack appropriate tools to provide such education.

In Horner-Johnson et al.'s focus group study of 17 women of reproductive age, women with physical disabilities reported that their care provider knew little or nothing about the impact that their physical disability would have on their pregnancy (Horner-Johnson, Klein, et al., 2022). A systematic analysis of studies examining women's experiences with maternity care also showed that women were more likely to report unmet prenatal care needs including not receiving appropriate information throughout their pregnancy because their provider lacked disability knowledge (Blair et al., 2022). In a secondary analysis of qualitative data from 12 adolescents with fertility issues, many reported that their physician did not adequately explain their risk of pregnancy (Smeltzer et al., 2018). As a result, adolescents in multiple studies, including this one and Trent et al.'s cross sectional study of 97 adolescents with PCOS, expressed concerns about fertility or health status while pregnant (Smeltzer et al., 2018; Trent et al., 2003).

Other studies showed that physicians did not effectively communicate with their patients. In Kirkpatrick et al.'s interviews with 16 neurology providers who typically discussed reproductive planning with their patients, neurologists told patients with epilepsy to wait until they were transferred to an adult practice to discuss reproductive healthcare (Kirkpatrick et al., 2020). In another qualitative study, a blind patient explained being handed pamphlets with written material about birth control that they could not read, and a patient with IDD explained that "Doctor language is like in one ear and out the other" (Horner-Johnson, Klein, et al., 2022).

In a cross sectional survey of 1,000 OBGYNs in America, only 19% felt comfortable managing pregnancy in WWD, and only 17% reported training on providing healthcare to WWD (Taouk et al., 2018). In a 2018 qualitative study of 14 OBGYNs from across the U.S who work with women with physical disabilities, none received formal training on working with WWD (Smeltzer et al., 2018). A lack of knowledge from physicians creates overall misinformation and another barrier to care for WWD.

C. Significance of the Problem

Existing literature points to evidence of negative health outcomes for pregnant WWD compared to nondisabled counterparts and within different types of disabilities and/or functional limitations. Overall, it appears that miscarriage rates are typically higher among WWD compared to WWOD and that risk of c-section is higher among women with some types of disabilities, with discrepancies in results existing between studies using survey as opposed to hospital data. High risk of negative birth outcomes is more consistently agreed on in existing literature about women with physical and RRD, though not as much in research about women with IDD. Consensus also typically exists in results about high maternal and neonatal health risks for WWD across studies. Researchers discussed that some factors influencing these outcomes might be accessibility of healthcare, and physical, socioeconomic, educational, and stigma barriers.

Differences in study design regarding disability classification and data collection methods are two potential, substantial influences on discrepancies in results. Specifically, there is a lack of consensus in the literature about pregnancy outcomes in WWD. To better understand the outcomes and needs of the population of WWD in the U.S., improved, consistent, and substantial data and research about pregnancy and disability is needed.

D. Theoretical Frameworks

Most literature around disability and reproduction in the U.S. centers on child or fetal disability, not maternal disability. Specifically, much of the literature debates if abortion is ethical in the case of fetal abnormalities. However, the theoretical frameworks that exist to conceptualize the influence of disability on health and reproductive rights can be applied in our research context.

1. Disability Framework

Two frameworks for studying disability and ensuring human rights for people with disabilities have been mainstreamed since the 1970s: the medical and social models of disability. The medical model of disability - the original framework of disability - viewed disability as a medical issue that can be cured when treated by a doctor. It made disability and its outcomes, such as lack of employment, an individual issue that can be solved medically. This model viewed PWD as “others” and “not normal” in society (Petasis, 2019).

The proceeding social model of disability, first coined in the 1980s, viewed disability as the barriers that people and society place on a person because of their impairment. The social model of disability views the exclusion placed on disabled people by society as the main contributor to their lack of privilege and inferior position in the world, rather than barriers faced because of the manifestation of disability itself. The social model of disability was the prevailing way of thinking about disability by the World Health Organization (WHO) and other scholars since its conceptualization. It ignited thinking that PWD can overcome barriers with correct support from society and led to legislation and activism to ensure human rights for PWD (Horner-Johnson, Akobirshoev, et al., 2021).

Finally, the biopsychosocial model was eventually created to incorporate the medical and social influences that create the experience of disability for a person. This model was most recently used for the foundation of the WHO's International Classification of Functioning, Disability, and Health (ICF). Though it has been criticized as combining both models without acknowledging the different levels of impact that one might have versus another in different people, and is not as widely used or known as the social model, it is an approach that encompasses medical and social influences to justify a person's experience and work towards equity (Petasis, 2019). As the most integrative approach and the basis for the WHO's ICF, and because this thesis examines medical outcomes influenced by social factors, the biopsychosocial framework is used throughout this paper.

Due to the existence of various frameworks, there is no universal definition of "disability" in research. In some ways, this is beneficial because it does not limit disability by a definition and allows someone with an impairment who feels inferior in society either due to access or medically, regardless of diagnosis, to identify as disabled. In other ways, this can harm research because it makes comparing across studies difficult. It can also harm PWD because without a definition or label, someone who feels blocked by barriers in society or medically may not be able to access the tools and resources needed for equity (Petasis, 2019).

2. Disability and reproductive health justice

Disability justice as defined by Patty Berne and Mia Mingus in 2005 recognizes that “[a]ll bodies are unique and essential” and, simultaneously, that “[a]ll bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them.” (*Disability Justice — Woodhull Freedom Foundation*, n.d.) Reproductive health justice, as defined by the UN, states that all people deserve the right to choose “freely and responsibly on the number and spacing of their children” (*Sexual and reproductive health and rights | OHCHR*, n.d.). Achieving disability and reproductive health justice in society requires work in both, as disability influences reproductive freedom and reproductive freedom influences disability.

3. Interconnectedness

Both disability and reproductive justice are in jeopardy in the U.S.. In 2022, Roe vs. Wade was overturned in the U.S. Supreme Court, reversing a precedent that protected the right to abortion nationwide, and handing the power to ban abortion to the states. Since then, 19 states have banned or restricted access to abortion in some form. This disproportionately affects minorities, such as trans women, women of color, women experiencing violence, and women with disabilities, who typically have less access to abortion, health insurance, income, and transportation (Powell, 2022). A ban on abortion is a direct threat to a person’s right to choose to reproduce or not, and therefore a threat to reproductive health justice. It separates sex and ability, making it a threat to disability justice as well.

Additionally, over 30 states still have compulsory sterilization laws still in effect after the Supreme Court decision of Buck vs. Bell in the 1970s allowed for involuntary sterilization of people with disabilities (Powell, 2022), and only 3 have disability inclusive sex ed curriculums (Powell, 2022). Therefore, these decisions also threaten disability and reproductive justice.

Ensuring the right to bodily autonomy and safe access to healthcare are pillars of both reproductive and disability justice. However, until the overturning of Roe vs. Wade, the two movements rarely joined forced. This is because much of the literature about disability rights and pregnancy revolve on the ethics of selective abortion based on genetic testing that may reveal a genetic abnormality in a fetus, which normally aligns the pro-life and disability rights sides to prevent abortion. These movements are not typically aligned, as the pro-life school of thought generally aligns with conservative viewpoints and disability rights generally align with progressive viewpoints (Jesudason & Epstein, 2011). However, as displayed through threats to bodily autonomy and safe spaces, reproductive health and disability justice are inherently interconnected.

E. Measurement of disability in the U.S.

1. General measurements used

The typical questions used to examine disability in U.S. national surveys, including in NSFG, come from the CDC's guidance on measuring disability, which are based on the six questions recommended by the Washington Group on Disability Statistics (WG) and align with the WHO's ICF (Washington Group on Disability Statistics (WG), n.d.). These questions measure functionality and effect on daily life, rather than the diagnosis of a disability itself. This approach has been both praised for focusing on impact rather than trying to categorize people, but it has also been condemned for ignoring unique perspectives of people with diagnosed disabilities, at the same time (Hall et al., 2022)..

2. Problems with measurement

The six WG questions do not ask if the functional limitations indicated are due to specific barriers, such as if difficulty walking or dressing is due to physical or developmental disability.

This makes categorization based on disability when needed and the creation of reasonable accommodations difficult to create based on the data. All data is also self-reported, and since the questions measure functional limitations, the answers are subjective. Many scholars agree that the questions do not adequately identify people with intellectual and development disabilities, communication disabilities, or distinguish psychiatric, learning, and intellectual disabilities (Hall et al., 2022). Studies that analyze results from surveys utilizing these questions often make categories of disability without any standard or mainstream definition of different types of disability. This makes comparing across studies difficult.

Most data collected about maternal disability and pregnancy also does not indicate time, so researchers cannot discern if disability preceded pregnancy or not. This is especially important when studying disability because maternal outcomes from pregnancy can result in disability, which would mean that disability is being correlated with a pregnancy experience and with birth outcomes when it may not have been present at the time of pregnancy. This was shown in one study to have a substantial effect on the results, which indicated that many people were classified as having a disability during pregnancy when they actually did not (Krahn, 2019).

Additionally, many national and local data sets do not collect data on disability at all. If they do, it is often inconsistent with other data sets, unless it is nationally representative using the WG questions. In the US, only Rhode Island and Massachusetts include questions to identify disability in pregnant mothers in PRAMS (Mitra et al., 2015). This problem exists for local clinics as well, where it is often not feasible due to limited resources to collect or report sufficient or consistent data. As a result, many studies use hospital or claims data which consistently indicate lower levels of maternal disability than population level surveys do (Horner-Johnson, Dissanayake, et al., 2022).

3. Best Practices

Many scholars argue that a mix of functional and diagnostic information is necessary in measuring disability. PWD have also well received answering additional questions about their disability and their physician visit while leaving doctors' offices because of the greater public goal to tackle barriers they face, despite doubt by researchers that PWD would not want to share confidential information or opinions that might potentially impact further care. Ensuring confidentiality and explaining the use of data was important to ensure privacy and accuracy in this study. Additionally, including measurements for factors such as temporality, severity, and diagnoses, as well as standard definitions have been found to improve data consistency and depth (Kitchin, 2000).

F. Summary

The experiences of 12% of a population should not and cannot be ignored. Yet, the lack of participatory research, valid and reliable data, and conclusive literature examining pregnancy outcomes among WWD does just that. Until better data is collected and can be analyzed, existing research points to negative pregnancy and health outcomes for pregnant WWD. Disparities in pregnancy prevalence, intent, outcomes, and treatment exist. Stigma and physical, socioeconomic, attitudinal, and educational barriers contribute to these experiences and disparities. Using the most up to date nationally representative survey in the U.S. that collects data on both pregnancy and maternal disability, the 2017-2019 NSFG, the pregnancy outcomes for women with sensory, developmental, and reproductive disabilities will be compared. This analysis is important to understand the most recent barriers and pregnancy outcomes in WWD. Amid threats to disability and reproductive justice nationally, understanding outcomes and barriers to marginalized populations like WWD is important to maintaining equity and focusing policy and programmatic efforts in public health.

III. Methods

A. Data Source

This cross-sectional secondary analysis used the “Female Respondent” and “Pregnant Female Respondent” datasets from the 2017-2019 National Survey of Family Growth (NSFG).

NSFG is a complex, nationally representative survey that collects data regarding reproductive and family health in the United States. In the 2017-2019 data collection cycle, samples were selected in five stages; primary sampling units (PSU), secondary sampling units (SSU), housing units, eligible household members, and those selected for follow-up.

The first stage of sampling created 2,149 PSUs from metropolitan statistical areas (MSAs), counties, or groups of counties. These PSUs were stratified using probability proportionate to size (PPS) based on attributes such as census division and MSA status. This allowed underrepresented subgroups in the population to be oversampled. The second stage of sampling used PPS to select neighborhoods within the PSUs, creating Secondary Sampling Units (SSUs). SSUs with larger populations of underrepresented groups had higher probabilities of selection as an SSU. Next, a list of housing units within each SSU was created. Housing units were selected, and interviewers then determined household members’ eligibility via household screening surveys. If household members were eligible, they were contacted for an interview. Eligible respondents were females and males ages 15-49 living in households in the U.S.. The final, fifth stage of sampling was two-fold. A subset of the sample that did not respond to the screening or study survey was selected and flagged for follow up during weeks 11 and 12 of data collection.

All interviews were completed in English and Spanish by trained interviewers using computer assisted personal interviewing software. Interviews were conducted from late September 2017 through early September 2019. Respondents received a $40 incentive for completing the household screening survey and another $40-$45 for completing the interview. Interviews were conducted in households in person, with respondents only inputting answers themselves for a subset of sensitive questions. The overall response rate for respondents was 63.4% for a total of 12,647 female respondents. The female pregnancy survey was conducted if a woman indicated they had ever been pregnant during the initial survey, with a total of 10,215 women responding to the Female Pregnancy Survey (*2017-2019 National Survey of Family Growth (NSFG): Sample Design Documentation*, n.d.)

B. Data preparation and variable selection

The analytic sample for this study were women who had ever experienced a livebirth, miscarriage, or abortion, ages 15-49, who lived in households in the US, resulting in a total analytic sample of 9,794 women. A subsample of this sample comprised of women with sensory, developmental, and reproductive disabilities was also created. This subsample comprised of 2,681 females. This analytic selection process is displayed in Figure 1.

Respondents who met the inclusion criteria of having ever been pregnant were recorded as observations in both the pregnancy database and the respondent database. To prevent double counting of observations when datasets were merged, the variables were labeled differently in the two original datasets. Therefore, in this analysis, variables were kept primarily from the pregnancy dataset, and secondarily from the respondent database if the variable was not recorded in the pregnancy dataset.

Variables selected for this analysis are listed in Table 2. Data came from the Female Respondent and Female Pregnant Respondent publicly available datasets, which were downloaded, imported, formatted, and merged using publicly available codebooks and program syntax from NSFG. The analysis for this paper was generated using SAS software, Version 9.4 (SAS Institute, Cary NC). Tables and figures were generated in Microsoft Word (Microsoft® Word for Microsoft 365 MSO (Version 2302)).

Variables were reverse coded to ensure that yes = 0 and no = 1. This ensured that the reference group for analysis was automatically "yes" in SAS software. Responses of "Do not know" or "Refused" were treated as missing data. Missing data were not included in the analysis.

A binary variable for the main exposure, disabled or not disabled, was created from the entire analytic sample. Affirmative answers for the NSFG variables measuring if respondents had difficulty seeing, hearing, walking, making decisions, or doing errands, and if they were ever diagnosed with polycystic ovary syndrome (PCOS), ovulation problems, endometriosis, or uterine fibrosis (UF) were used to measure if a respondent had a disability. Another variable with 3 levels was created from the subsample of people with a disability, with a level for each disability (SD, DD, RRD). DD, SD, and RRD were categorized as described in Table 1. Respondents without a disability, with more than one disability, or with a different type of disability besides the three being analyzed were treated as missing data for this variable. Dummy variables for people with DD, SD, or RRD were created.

A new variable for the main outcome was created from the original NSFG pregnancy outcome variable. This new variable had three levels - livebirth, miscarriage, and abortion. "Stillbirth", "currently pregnant", and "ectopic" were removed as values and treated as missing values due to the low percent of the sample that they comprised which could have potentially led to type one error (n=105 [1.03%], n=193 [1.89%], and n=123 [1.20%] respectively). Missing values were not included in the analysis. Dummy variables were also created for the three pregnancy outcomes.

Covariates were selected based on previous literature. Covariates that were included from NSFG measured respondent age, respondent age at pregnancy, if the respondent wanted another child, total income, level of education, marital status, religion, race, and current insurance status. Highest level of education and total income variables were recoded to consolidate responses into fewer categories.

Weights, strata, and cluster variables were applied using the original NSFG variables.

C. Analysis

Descriptive statistics were created for all variables in the analytic sample including frequency, mean/proportion, and standard error. Descriptive statistics were then created to measure the frequency and mean/proportion of all variables by disability status and by disaggregated disability type.

Covariates were tested as potential confounders, effect modifiers, and mediators based on a dependent variable of pregnancy outcome composed of all 3 levels of potential outcomes, and independent variables of disability and type of disability composed of the 3 types of disabilities identified. Additionally, correlation tests were conducted (Table 4). Despite some variables being correlated, the covariates were included in the final adjusted regression models because of their known significance on pregnancy outcomes from previous literature. For this reason, both unadjusted and adjusted regressions were conducted and displayed in the results.

Analytic statistics were then conducted to measure if pregnancy outcome differed by disability status. One-way analysis of variance (ANOVA) tests were run to measure if there was a significant difference in the means of at least two pregnancy outcomes in WWD or not and in women with disaggregated disabilities. Tests for assumptions of ANOVA including equal variance of variables were also conducted.

Next, unadjusted and fully adjusted (with significant covariates and effect modifiers) binomial logistic regression models were run to calculate the probability that having a disability or not, or having a specific type of disability or not, would increase or decrease the odds of having a specific pregnancy outcome.

Further sensitivity analysis was conducted after the interpreting the results of this predetermined analysis. This sensitivity analysis determined if the odds or significance of the results changed when only comparing women with developmental and sensory disabilities. This analysis was conducted based on the biopsychosocial theoretical framework which suggests that the social and medical impacts of disability are combined to create the experience of disability. As RRD explicitly emphasizes more of the medical impact of disability relative to pregnancy than do DD and SD, sensitivity analysis included unadjusted and adjusted binomial logistic regressions without RRD included in the disability variable. Another analysis was also run including the variable “Doctor advised me not to become pregnant again” in the confounding variables, to see if this influenced the results of a miscarriage. The results of this sensitivity analysis can be found in Appendix A.

Results were reported using odds ratios, 95% confidence intervals, and p-values, communicated via tables and figures created in Microsoft Word (Microsoft® Word for Microsoft 365 MSO (Version 2302)). Tables 2 and 3 list descriptive statistics. Table 4 reports correlations between covariates. Table 5 reports ANOVA results. Tables 6 and 7 report results of unadjusted and adjusted binomial logistic regressions. Interpretation of these results are included in the Results section of this thesis.

IV. Results

A. Descriptive Statistics

1. Eligible sample

Of the eligible sample of women who ever had a livebirth, miscarriage, or abortion (n = 9,794), 27% (n = 2,681) reported having a disability and 73% (n = 7,113) had no disability or two or more disabilities. 0% (n = 31) were younger than or equal to 18 years old, 5% (n = 494) were ages 19-24, 37% (n = 3,584) were ages 25-32, 39% (n = 3,839) were ages 35-44, and 19% (n = 1,846) were ages 45+. The most common race was white, consisting of 67% (n = 6,562) of the sample, while 27% (n = 2,615) of the sample was black and 6% (n = 617) was other races. Regarding birth outcomes, 74% (n = 7,199) had a livebirth, 10% (n = 941) had an abortion, and 17% (n = 1,654) had a miscarriage (Table 2).

2. Disability subset

Of those with a disability (Table 2), the sample was mostly white, between the ages of 35-44, single, and had private or Medi-Gap health insurance. 67% (n = 1,792) were white, 25% (n = 679) were black, and 8% (n = 206) were other races. Regarding age, 0% (n = 8) were under the age of or exactly 18 years old, 3% (n = 70) were between the ages of 19-24, 29% (n = 787) were 25–34 years old, 43% (n = 1,147) were 35–44 years old, and 25% (n = 669) were 45+ years old. Almost half of the sample (48% [n = 1,276]) had private health insurance or Medi-Gap, while 31% (n = 829) had Medicaid, CHIP, or a state-sponsored health plan, 7% (n = 177) had Medicare, military health care, or other government health care, and 15% (n = 389) had a single-service plan, Indian Health Service, or no insurance. More women (60% [n = 1,596]) were single than married (40% [n = 1,085]). 35% (n = 913) wanted more children and 63% (n = 1,697) did not. 44% (n = 1,178) had a high school or lower education, 20% (n = 555) had some college education, 11%'s (n = 308) highest level of education was an associate or bachelor's degree, and 24% (n = 640) had earned an advanced degree. 19% of the sample (n = 500) identified as Catholic, 52% (n = 1,383) as Protestant, 22% (n = 592) as having no religion, and 8% (n = 206) as other religions. The most common income brackets were \$25,000 - \$49,999 (27% [n = 725]) and \$50,000 - \$99,999 (25% [n = 672]). Among remaining income brackets, 6% (n = 167) earned under \$5,000, 12% (n = 325) earned \$5,000 - \$12,499, 15% (n = 394) earned \$12,500 - \$24,999, and 15% (n = 398) earned \$100,000 or more. In this sample of WWD, 68% (n = 1,862) had a livebirth, 10% (n = 266) had an abortion, and 21% (n = 553), had a miscarriage. Most descriptive statistics of people with disabilities were within 1% - 3% of the descriptive statistics of the sample of females who ever had a livebirth, miscarriage, or abortion.

3. Disaggregated by disability type

Of those with one of the three types of disabilities, 9% (n = 233) had a developmental disability, 21% (n = 564) had a sensory disability, and 70% (n = 1,884) had a reproductive related disability (Table 3).

The most common pregnancy outcome in those with developmental, sensory, and reproductive-related disabilities was livebirth, consisting of 76% (n = 164), 69% (n = 397), and 71% (n = 1,300) of the samples respectively. This was always followed by miscarriage (DD: 17% [n = 47], SD: 22% [n = 110], RRD: 20% [n = 397]) and abortion (DD: 7% [n = 22], SD: 10% [n = 57], RRD: 10% [n = 187]). Among all three disaggregated disabilities, white was the most common race (DD: 79% [n = 185], SD: 66% [n = 1235], RRD: 66% [n = 1235]), while black was second (DD: 15% [n = 34)], SD: 25% [n = 136], RRD: 27% [n = 509]), and other races was least common (DD: 6% [n = 14], SD: 10% [n = 56], RRD: 7% [n = 140]).The most common age group was ages 35 – 44 years old (DD: 50% [n = 116], SD: 34% [n = 190], RRD: 44% [n = 841]). The second most common age group was 25-34 years old (DD: 32% [n = 75], SD: 33% [n = 184], RRD: 28% [n = 528]. In women with DD, 1% (n = 3) were younger than or exactly 18 years old, 6% (n = 13) were 19-24 years old, and 11% (n = 26) were older than 45 years old. 1% (n = 5) were younger than or exactly 18 years old, 5% (n = 30) were 19-24 years old, and 27% (n = 155) were older than 45 years old among those with SD. In women with RRD, 0% (n = 0) were younger than or exactly 18 years old, 1% (n = 27) were 19-24 years old, and 26% (n = 488) were older than 45 years old.

B. Confounding and effect modifiers

No covariates showed a significant interaction between disability or disability type and pregnancy outcome, based on the resulting odds ratios. Therefore, all covariates were used as confounders. No significant differences between unadjusted and adjusted regressions were found, and results of both were reported.

C. Parametric testing

Results of the ANOVA tests showed that variables met the assumptions of ANOVA and that there was a significant difference between the means of at least two pregnancy outcomes in those with a disability and those without a disability (F=67.87; p<0.0001). However, disaggregation by disability type resulted in no significant difference (Table 5).

D. Regression testing

Based on unadjusted and adjusted binomial regressions, significant associations were observed between disability status and between RRD status with livebirth and miscarriage.

1. Statistically Significant Effects

Having a disability as opposed to not having a disability had a significant effect on the odds of having a livebirth. The 95% CI of 0.59 – 0.84 did not span 1, so the decreased odds (OR 0.7) of livebirth among WWD reached statistical significance. This is further indicated with a p-value of 0.0002, as shown in Table 7. Conversely, WWD had significantly higher odds (OR: 1.59, (95% CI: 1.28 – 1.97, $p < 0.0001$) of having a miscarriage than did WWOD. People with RRD also had significantly higher odds of miscarriage (OR: 1.43, 95% CI: 1.06 – 1.93, $p = 0.02$) compared to the odds of miscarriage in people with DD or SD (Table 7).

E. Patterns and Trends

Significant results were found when comparing the odds of miscarriage and livebirth, and when comparing WWD to WWOD and women with RRD to women with DD or SD. No pregnancy outcomes were significantly different among those with DD or SD compared to those with the two other disabilities in any comparison. Additionally, no odds of abortion were significantly different in any comparisons (Table 7).

Though not statistically significant, the odds of having a miscarriage in WWD and when disaggregated by disability type were higher in every comparison – that is, the odds of miscarriage in the analytic group were always higher than the odds of miscarriage in the comparison group (Table 7).

IV. Discussion

These findings add an up-to-date analysis to the limited but growing body of literature regarding WWD (Horner-Johnson et al., 2016), and agree with past findings about pregnancy outcomes – specifically livebirth and miscarriage - among WWD (Blair et al., 2022; Tarasoff et al., 2020). While our data do not tell us why the observed differences exist, literature suggests that the biopsychosocial impact of disability and limitations in data collection among PWD are the main drivers (Horner-Johnson, Dissanayake, et al., 2022). Our results have implications for future healthcare delivery, policies for WWD, and research studies.

A. Significant Findings

1. Likelihood of miscarriage among women with disabilities

Higher odds of miscarriage and lower odds of livebirth among WWD compared to WWOD indicate that WWD may experience differences in treatment before and during pregnancy. This aligns with existing literature that says that WWD have higher chances of negative birth outcomes, specifically miscarriages, than do WWOD (Dissanayake et al., 2020) due to a variety of accessibility reasons spanning from lack of provider awareness of disabilities (Alhusen et al., 2021) to physically inaccessible healthcare visits (Blair et al., 2022).

Since this specific finding compares all WWD to all WWOD without disaggregating by disability type or severity, the result might also be reflecting the health effects of disability that are medically associated with pregnancies (Parish et al., 2015) in addition to the aforementioned social experiences of pregnant PWD (Horner-Johnson et al., 2016). That is, while SD or DD may not be significantly associated with higher odds of negative pregnancy outcomes individually, the aggregated psychological and social experiences of pregnancy for all PWD, with the biological experiences associated with some pregnancies (Alhusen et al., 2021; Horner-Johnson, Garg, et al., 2022), might explain the overall higher risk for miscarriage in WWD compared to WWOD. For example, higher levels of stress during pregnancy (Mitra et al., 2015), less options for and discussions around birth control (Mosher et al., 2018), later prenatal care compared to WWOD ("Women with developmental disabilities may be at risk of poor pregnancy outcomes.," 2015), stigma around ability to become pregnant or raise a child (Alhusen et al., 2021), and socioeconomic status limiting the ability to visit physicians or maintain health status (Alhusen et al., 2021) that are shown to affect all PWD according to existing literature are a few experiences that might explain our results, and are in line with the biopsychosocial model of disability.

2. Likelihood of miscarriage among women with reproductive-related disabilities

Women with RRD in the sample were more likely to have a miscarriage and less likely to have a livebirth compared to women with DD or SD. This is supported by individual studies on physician care (Taouk et al., 2018), perceptions about pregnancy among women with RRD (Trent et al., 2003), and associated health outcomes (Boomsma et al., 2006; Kohl Schwartz et al., 2017; Marcinkowski et al., 2022) that point to increased odds of maternal health complications for pregnant women with RRD compared to pregnant women without RRD, and to a lack of education among pregnant women with RRD that impact their ability to maintain proper prenatal and perinatal health.

Our results underscore the biopsychosocial model of disability. Research such as Taouk, et al.'s and Smeltzer, et al.'s 2018 studies suggest that physician training to provide quality care to people with RRD is lacking (Smeltzer et al., 2018; Taouk et al., 2018). This is additionally supported by data that show that women with RRD face more barriers to recognizing a pregnancy or receiving pregnancy-related education due to a lack of information communicated by physicians (Trent et al., 2003). For example, women with RRD often report not knowing they can get pregnant when they actually can, carrying potentially dangerous pregnancies out of fear it is the only time they will ever get pregnant, and experiencing the downplaying of the severity of their condition or pain by doctors (Whelan, 2007).

Women with RRD may also be impacted by stressors in their pregnancies (Mitra et al., 2012) which are correlated with negative health outcomes such as preeclampsia and low birth weight in pregnancies (Traylor et al., 2020), further underscoring the biopsychosocial model of disability. Additionally, negative pregnancy risks medically associated with an RRD can mean that results are naturally skewed to higher odds of miscarriage in this population (Dokras et al., 2017).

3. The impact of developmental and sensory disabilities

Finally, females in this sample with SD or DD had no significantly different odds of pregnancy outcomes compared to women with DD or RRD, or with SD or RRD, respectively. Although limited updated data exists surrounding pregnancy outcomes for women with SD and DD, existing literature suggests a difference in maternal complications which our study did not examine. Studies show higher risks of preeclampsia, peripartum hemorrhage, and abruptio placentae in women with intellectual disabilities (Signore et al., 2021) and higher risks for preterm births, low birth weights, cesarean section, and perinatal mortality in women with DD (Nahar, 2019) compared to women without any disability. This highlights the need to no longer examine pregnancy outcomes in silos, but rather in tandem with variables measuring accessibility and the impacts of pregnancy complications on maternal experiences and further on birth outcomes, again highlighting the biopsychosocial perspective.

Additionally, existing studies do not use a standard definition of DD, SD, or ID, which makes it difficult to compare our results across existing results in the literature.

B. Strengths

A major strength of this research is that multiple disabilities were examined. Much of existing research about disabilities looks at one category of disability (physical, mental, emotional, developmental) compared to people without disabilities, rather than people with different disabilities compared to each other and to people without disabilities (Horner-Johnson et al., 2017; Horner-Johnson, Akobirshoev, et al., 2021; Mosher et al., 2017; Mueller et al., 2019). Further research requires studies to include specific analysis of many disabilities, rather than specific analysis of one disability or nonspecific analysis of many disabilities.

Additionally, this analysis compared disability type to disability type, rather than disability type to not disabled. Many programs view "disability inclusive" as one overarching goal, but as we learn more and look at healthcare access from a biopsychosocial framework, it is important to recognize that "inclusive" might be more complex than only physical accessibility (Organization & United Nations Population Fund, 2009). Measuring outcomes comparatively between disability type is important to understanding gaps in achieving disability inclusivity. Comparing disability types is just the start of creating inclusive healthcare for people with disabilities, as other factors such as severity, temporality, and intersectional influences will impact this research and goal.

C. Limitations

1. NSFG measurements

NSFG is the only up-to-date, comprehensive, nationally representative survey collecting data on both pregnancy/birth related outcomes and maternal disability among females of reproductive age. While this provides valuable information into pregnancy outcomes for WWD in the US, there is still an overall lack of data available about this topic.

a. Pregnancy outcomes and complications

Although data is collected for some pregnancy complications, such as hypertension, other data that might be more prevalent in women with certain disabilities such as urinary tract infection, eclampsia, and hemorrhaging, is not collected. A birth outcome might be the same for WWD and WWOD, but one might have hemorrhaged while the other did not, which changes the experience of pregnancy. Even though variables that were collected about maternal complications were not examined directly in our analysis, these variables are important to collect in their entirety so that future studies can include them in analysis.

Additionally, as a cross-sectional study, there was no way to determine if a disability came before or after a pregnancy outcome. Data about dates were collected for pregnancy outcomes but not for the various disability status-related questions. This also meant that if there was more than one pregnancy outcome reported by a respondent, there was no way to tell if disability status changed between pregnancies. This is especially important in studying pregnancy-related outcomes since chronic maternal disability can be a result of pregnancy.

b. Disability status

The questions measuring disability in NSFG are based on the Health and Human Services (HHS) Implementation Guidance on Data Collection standards, which require the six questions in the NSFG survey to be the minimum set of questions administered in a national survey where it is applicable to measure disability. However, many researchers have noted that the questions do not fully encapsulate disability status, make it difficult to distinguish between different disabilities, are often triple or double barreled, and do not ask about chronic conditions or a person's perception of their disability status (Horner-Johnson, Dissanayake, et al., 2022). While NSFG questionnaires ask a few more questions about specific RRDs, it does not collect information about the severity of SD or DD, chronic diseases impacting daily life, and other social barriers caused by or impacting disability status.

c. Accessibility measurements

Continuously, while NSFG measures if a female had a pap smear or HPV screening, it does not measure additional potential barriers to OBGYN care, such as distance travelled, time waited, whether the visit was inclusive of disability status, how much doctors knew about disability status, and the time frame in which patients were able to obtain inclusive care. Thes variables might have helped to frame pregnancy outcomes in a biopsychosocial context.

d. Self-report of diagnoses vs. functionality

RRD were self-reported by respondents based on diagnosis, whereas DD and SD were recorded and categorized during analysis based on respondent reports of functional limitation. Analyses should examine if the results of this analysis which only found significance among those with RRD, the only diagnostic related self-report, might be influenced by these data collection methods.

Additionally, these self-reports were based on questions that ask about functionality without asking about cause. A person may have difficulty walking due to sensory, physical, or developmental disabilities, all of which may require different accommodations. However, NSFG only asks, “Do you have serious difficulty walking or climbing stairs?”. Similarly, standard definitions should exist to assist with framing these results in relation to existing literature, where researchers may have categorized variables differently.

D. Future Directions and Additional Research

1. Sensitivity analyses

Sensitivity analysis examining differences between livebirth and miscarriage for specific disabilities (more specific than developmental, sensory, and reproductive-related NCD) should be conducted to see if a difference continues to exist or if new differences are found. Sensitivity analyses should also examine if results change depending on the severity and temporality of the condition, as well as with additional confounding variables measuring accessibility for women with disabilities.

Additionally, the fact that no differences were found in SD or DD pregnancy outcomes compared to other disabilities highlights the need for further analysis. It also reinforces the idea that this thesis only examined birth outcomes confounded by sociodemographic factors, and did not examine maternal complications, even though the results are discussed here using the biopsychosocial model of disability. Sensitivity analyses that disaggregate by specific disability, severity, and temporality, and that include measures of accessibility, can help examine if a difference exists that was not identified in women with SD or DD because of a true lack of a significant difference in pregnancy outcome, or because the data was not available.

These results can be further examined by using existing NSFG variables about treatment access, as discussed earlier. Variables such as "When was your last HPV test?" or "Have you ever had a pap smear?", and accessibility variables such as distance travelled, time waited, and whether the visit was inclusive of a patient's disability status should be added to data collected and/or analyzed. This was completed at a basic level in our sensitivity analysis, as explained in Appendix A, with the addition of the confounding variable, "Has a doctor ever advised you that it might be dangerous for you to get pregnant?".

Lastly, this analysis compares WWD to WWD, and women with a specific type of disability to women with other types of disabilities. It does not compare women with a specific type of disability to women without disabilities, though this analysis should be conducted.

2. Generalizability

This analysis conducted focuses on females who were pregnant and women with disabilities, confounding for certain socioeconomic variables such as race, income, and insurance status. While pregnancy outcomes are influenced by these socioeconomic variables, the experiences of LGBQT+ people who were not interviewed who can be pregnant or because they did not meet certain inclusion criteria (such as living in a house) and the influences of intersectionality on our results should not be ignored or forgotten. Variables assessing these experiences should be added to NSFG, and further analyses stratifying by socioeconomic status, interviews with wider inclusivity criteria, and an analysis of existing literature examining representativeness of the population should be conducted.

V. Conclusion

Updated data from NSFG 2017-2019 show increased odds of having a miscarriage and decreased odds of having a livebirth among women with disabilities as opposed to women without disabilities, and among women with reproductive related disabilities compared to women with developmental and sensory disabilities. No significant differences in pregnancy outcomes were found among women with DD and SD compared to women with different types of disabilities, or among any group having an abortion. While exact comparisons to the previous NSFG round (2015-2017) do not exist for pregnancy outcomes for women with disabilities, the findings are consistent with previous existing literature that show higher odds of negative pregnancy outcomes among WWD compared to WWOD from NSFG 2011-2015 data (Horner-Johnson, Dissanayake, et al., 2022).

This analysis implies some disadvantage in treatment among WWD compared to WWOD, and higher odds of negative birth outcomes in WWD. However, the entire story is not told in these findings. The results of this analysis prompt further research into examining these outcomes with different accessibility variables, with more specific data about SD and DD, and relative to disaggregated and standardized data about WWD. Existing literature exists examining pregnancy outcomes among women with physical disabilities and RRD, but less exists for women DD. Additional research is needed examining the larger context of pregnancy outcomes in specific populations and the barriers and facilitators that they face. To achieve this, surveys about maternal and child health need to begin including questions about disability that are specific and disaggregated.

VI. Public health implications

A. Individual

On an individual level, WWD and WWOD should be empowered to advocate for accommodations and inclusivity in healthcare. Questionnaires for women with physical disabilities to help them decide if they should have children are being tested, and should be created for women with other disabilities as well (Kalpakjian et al., 2023). Using predicted pregnancy and maternal outcomes from existing studies (or future studies with more comprehensive data), WWD can use these questionnaires as tools to make decisions regarding their pregnancy based on fact. Additional resources educating people with disabilities with the knowledge they need to have a healthy pregnancy and to speak up for the accommodations they need, and resources providing legal information or explaining rights for people with disabilities, are also not yet easily accessible.

B. Provider/clinicians

There is a need for providers to discuss reproductive health with their patients. As discussed in the literature review, doctors are often hesitant to discuss family planning with patients with disabilities. Whether this is due to bias about a person with disability’s sexuality or lack of training as to how to discuss reproductive health with PWD, physicians should strive to have the same conversations with patients with disabilities as they do with patients without disabilities when necessary. Providers and clinicians need to distribute information about pregnancy among WWD in many formats and in many spaces, including at healthcare visits, online, through insurance companies and community centers for WWD, and in other communications with patients.

The National Center on Disability (NCD) recommended forming an expert working group to develop disability competencies that healthcare providers should have before graduation (*Chapter 17: Findings and Recommendations | NCD.gov*, n.d.). Additionally, groups such as the Society of Reproductive Technologies and American Society for Reproductive Medicine have been tasked by NCD to provide recommendations and training to physicians about assisted reproductive technology (*Chapter 17: Findings and Recommendations | NCD.gov*, n.d.). Medical professionals should advocate for more comprehensive training about treating patients with varying disabilities and work to address bias and misconceptions about people with disabilities.

C. Policy

1. The Overturning of Roe vs. Wade

As an under-researched, substantial part of the population with less access to healthcare and higher odds of high-risk pregnancies, the recent overturning of Roe vs. Wade (which allows state to determine rights to abortion and takes away a federal right to abortion) disproportionately impacts WWD. Access to abortions is a medical necessity for WWD who might face complications from pregnancies, are at higher risk of sexual abuse than non-disabled women, and face a history of a lack of bodily autonomy. Any accessibility barriers that existed for WWD in accessing healthcare, specifically healthcare such as voluntary or forced abortions, are compounded by the overturning of Roe vs. Wade.

Transportation to abortion clinics or OBGYNs allowed to/willing to provide reproductive healthcare is now longer and more expensive, which pose additional barriers to WWD who generally have lower income than WWOD and a harder time using transportation. Additionally, the closing of many reproductive healthcare clinics due to doctors moving to areas where abortion is legal makes accessing a disability-inclusive healthcare office even more rare and harder. Doctors may be unclear as to what they are able and not able to provide for someone medically, especially in the case of abortion, contraception, and in the face of existing medicine or treatments that might interfere with pregnancies (Bezyak & Samour, 2022).

This all puts WWD at higher risk for facing barriers in accessing abortion and prenatal and perinatal care overall, which makes monitoring and evaluating pregnancy outcomes even more important than before.

2. Implications from distal policy

Policies and programs that do not directly center on healthcare accommodations, such as transportation policy and assistive technology, are also integral in improving pregnancy outcomes for WWD. Increasing accessibility for public transportation, cell phone and online use, and other factors that influence a person's ability to access healthcare, can all play a part in pregnancy outcomes. NCD recommends that public service agencies increase accommodation efforts. For example, they recommend that public housing agencies make 50% of their housing accessible, the Department of Transportation creates guidance on transporting passengers with disabilities, and Social Security improves their benefits for PWD. NCD also recommends the Department of Justice (DOJ) and HHS increase monitoring and enforcement of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act for healthcare facilities (*Chapter 17: Findings and Recommendations | NCD.gov*, n.d.).

D. Data collection

Continuing with research that lacks specificity about disability type, temporality, and severity leads to a standstill in the extent of findings possible. To better understand and improve health outcomes for people with disabilities, more than six standard questions must be asked in nationally representative surveys, questions about disability status should be included in more surveys, and standardized definitions of disability type should be mainstreamed.

Tables and Figures

Table 1 Composite variables created to classify types of disability.

Composite variable	Question 1	Question 2	Question 3	Question 4
Developmental Disability	HD-16: Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?	HD-13: Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering or making decisions?	HD-15: Do you have difficulty dressing or bathing?	
Sensory Disability	HD-11: Do you have serious difficulty hearing?	HD-12: Do you have serious difficulty seeing, even when wearing glasses or contact lenses?	HD-14: Do you have serious difficulty walking or climbing stairs?	
Reproductive Related Disability	HD-10b: (You may have already told me this, but) Has a doctor or other medical care provider ever told you that you had Polycystic Ovarian Syndrome, also known as PCOS?	HD-10: (You may have already told me this, but) Has a doctor or other medical care provider ever told you had problems with ovulation or menstruation?	HD-8: (You may have already told me this, but) Has a doctor or other medical care provider ever told you had fibroid tumors or myomas in your uterus?	HD-1: Have you ever been treated for an infection in your fallopian tubes, womb, or ovaries, also called a pelvic infection, pelvic inflammatory disease, or P.I.D.?

Note: Answering affirmative to any of the above questions classified someone as having a disability.

Table 2. Frequencies and weighted percentages of disability status and covariates by disability status (n = 9,794)

Characteristics	**Has disability (n=2,681)**		**No disability (n=7,113)**		**Total (n=9,794)**	
	n	%	n	%	n	%
Outcome						
Livebirth	1862	69	5,337	75	7,199	74
Abortion	266	10	675	9	941	10
Miscarriage	553	21	1101	15	1654	17
Race						
Black	679	25	1,936	27	2615	27
White	1792	67	4,770	67	6562	67
Other	210	8	407	6	617	6
Religion						
Catholic	500	19	1,698	24	2198	22
Protestant	1383	52	3,256	46	4639	47
No religion	592	22	1,649	23	2241	23
Other	206	8	510	7	716	7
Age at Screening						
<=18	8	0	23	0	31	0
19-24	70	3	424	6	494	5
25-34	787	29	2,797	39	3584	37
35-44	1147	43	2,692	38	3839	39

45+	669	25	1,177	17	1846	19
Education Level						
High school or less	1178	44	3,551	50	4729	48
Some college	555	21	1,362	19	1917	20
Associate or Bachelor's Degree	308	11	667	9	975	10
Advanced Degree	640	24	1,533	22	2,173	22
Total Income						
Under $5000	167	6	351	5	518	5
$5000 - $12,499	325	12	732	10	1057	11
$12,500 - $24,999	394	15	1,260	18	1654	17
$25,000 - $49,999	725	27	2,024	28	2,749	28
$50,000 - $99,999	672	25	1,764	25	2,436	25
$100,000 or more	398	15	982	14	1,380	14
Type of Insurance						
Private	1276	48	3,373	47	4649	47
Medicaid	839	31	2,286	32	3125	32
Medicare	177	7	334	5	511	5
Other Public	389	15	1,120	16	1509	15
Marital Status						
Single	1596	60	4,241	60	5837	60
Married	1085	40	2,872	40	3957	40
Age at Pregnancy						
<=18	378	14	907	13	1285	13
19-24	976	36	2,735	38	3711	38
25-34	1105	41	2,954	42	4059	41
35-44	218	8	509	7	727	7
45+	4	0	8	0	12	0
Wants more children						
Yes	913	35	2,433	35	3346	34
No	1697	65	4,509	65	6206	63

Table 3. Frequencies and weighted percentages of birth outcomes and covariates disaggregated by disability (n = 2,681)

Characteristics	Developmental (n=233)		Sensory (n=564)		Reproductive (n=1884)	
	n	%	n	%	n	%
Pregnancy Outcome						
Livebirth	164	76	397	69	1300	71
Abortion	22	7	57	10	187	10
Miscarriage	47	17	110	22	397	20
Race						
Black	34	15	136	24	509	27
White	185	79	372	66	1235	66
Other	14	6	56	10	140	7
Religion						
Catholic	50	21	122	22	328	17
Protestant	102	44	263	47	1018	54
No religion	63	27	127	23	402	21
Other	18	8	52	9	136	7
Age at Screening						
<=18	3	1	5	1	0	0
19-24	13	6	30	5	27	1
25-34	75	32	184	33	528	28
35-44	116	50	190	34	841	45
45+	26	11	155	27	488	26
Education Level						
High school or less	146	63	322	57	710	38
Some college	58	25	98	17	399	21
Associate / Bach.	13	6	55	10	240	13
Advanced Degree	16	7	89	16	535	28
Total Income						
Under $5000	18	8	69	12	80	4
$5000 - $12,499	64	27	80	14	181	10
$12,500 - $24,999	43	18	95	17	256	14
$25,000 - $49,999	67	29	150	27	508	27
$50,000 - $99,999	28	12	108	19	536	28

$100,000 or more	13	6	62	11	323	17
Type of Insurance						
Private	36	15	216	38	1024	54
Medicaid	106	45	207	37	526	28
Medicare	31	13	33	6	113	6
Other Public	60	26	108	19	221	12
Marital Status						
Single	102	44	313	56	1181	63
Married	131	56	251	45	703	37
Age at Pregnancy						
<=18	32	14	91	16	255	14
19-24	114	49	200	35	662	35
25-34	82	35	237	42	786	42
35-44	5	2	36	6	177	9
45+	0	0	0	0	4	0
Wants more children						
Yes	87	39	211	39	615	33
No	134	61	335	61	1228	67

Table 4. Significant p-value correlations between covariates

	Race	**Insurance**	**Religion**	**Want children**	**Education**	**Married**	**Age**	**Age at pregnancy**	**Income**
Race					<0.001	0.048	<0.001	<0.001	<0.001
Insurance	<0.001				<0.001	<0.001	<0.001	<0.001	<0.001
Religion	<0.001						<0.001		<0.001
Want children					<0.001	<0.001	<0.001	<0.001	<0.001
Education	<0.001	<0.001		<0.001		<0.001	<0.001	<0.001	<0.001
Married	<0.001	<0.001		<0.001	<0.001		<0.001	<0.001	<0.001
Age at pregnancy	0.0011	<0.001	<0.001	<0.001	<0.001		<0.001	<0.001	<0.001
Age	<0.001	<0.001		<0.001	<0.001	<0.001		<0.001	<0.001
Income	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001		<0.001	<0.001

Table 5. One-way unadjusted ANOVA examining mean differences of selected birth outcomes among women with disabilities and different types of disabilities (n =3,158)

	Disability vs. no disability (n = 9,794)		**DD vs. SD or RRD (n = 2,681)**		**SD vs. DD or RRD (n = 2,681)**		**RRD vs. SD or DD (n = 2,681)**	
	f-value	p-value	f-value	p-value	f-value	p-value	f-value	p-value
Outcome	**67.87**	**<0.0001**	**2.69**	0.10	0.01	0.92	2.91	0.09

Table 6. Unadjusted binomial logistic regression estimates exploring odds ratio and confidence intervals of selected birth outcomes among all women and among women with different types of disabilities

	Disability vs. no disability (n = 9,794)		**DD vs. SD or RRD (n = 2,681)**		**SD vs. DD or RRD (n = 2,681)**		**RRD vs. SD or DD (n = 2,681)**	
	OR (p)	95% CI	OR (p)	95% CI	OR (p)	95% CI	OR (p)	95% CI
Livebirth	**0.69 (0.0002)**	**0.57 – 0.83**	1.06 (0.72)	0.76 – 1.48	0.81 (0.19)	0.58 – 1.12	0.76 (0.07)	0.56 – 1.02
Abortion	1.06 (0.77)	0.71 – 1.58	0.84 (0.52)	0.50 – 1.44	1.12 (0.62)	0.70 – 1.81	1.09 (0.79)	0.57 – 2.12
Miscarriage	**1.58 (<.0001)**	**1.28 – 1.95**	1.01 (0.97)	0.71 – 1.42	1.24 (0.26)	0.85 – 1.80	**1.35 (0.04)**	**1.01 – 1.81**

Abbreviations: OR = Odds Ratio, CI = Confidence Interval

Table 7. Adjusted binomial logistic regression estimates exploring odds ratio and confidence intervals of selected birth outcomes among all women and among women with different types of disabilities

	Disability vs. no disability (n = 9,794)		**DD vs. SD or RRD (n = 2,681)**		**SD vs. DD or RRD (n = 2,681)**		**RRD vs. SD or DD (n = 2,681)**	
	OR (p)	95% CI	OR (p)	95% CI	OR (p)	95% CI	OR (p)	95% CI
Livebirth	**0.70 (0.0002)**	**0.59 – 0.84**	1.01 (0.47)	0.74 – 1.38	0.86 (0.73)	0.64 – 1.16	0.76 (0.08)	0.57 – 1.03
Abortion	0.97 (0.88)	0.68 – 1.49	0.84 (0.65)	0.53 – 1.35	1.07 (0.45)	0.72 – 1.61	1.01 (0.99)	0.60 – 1.68
Miscarriage	**1.59 (<.0001)**	**1.28 – 1.97**	1.07 (0.94)	0.79 – 1.46	1.16 (0.33)	0.78 – 1.72	**1.43 (0.02)**	**1.06 – 1.93**

Abbreviations: OR = Odds Ratio, CI = Confidence Interval

*Adjusted for age, age at pregnancy, race, religion, education, want more children, marital status, insurance type, and total income

Figure 1. Analytic sample from NSFG 2017-2019

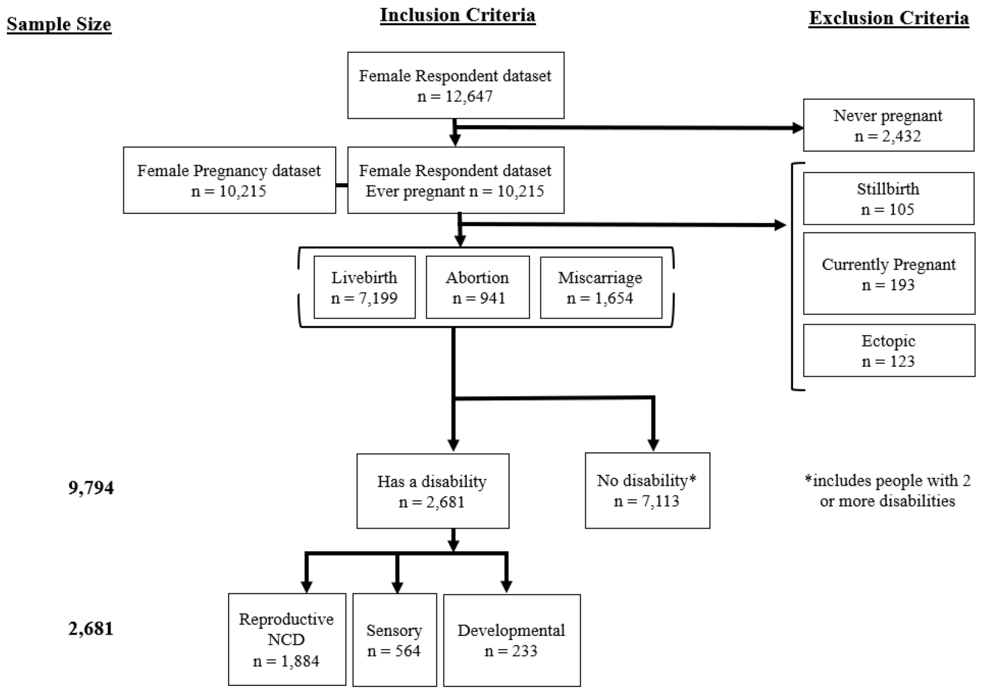
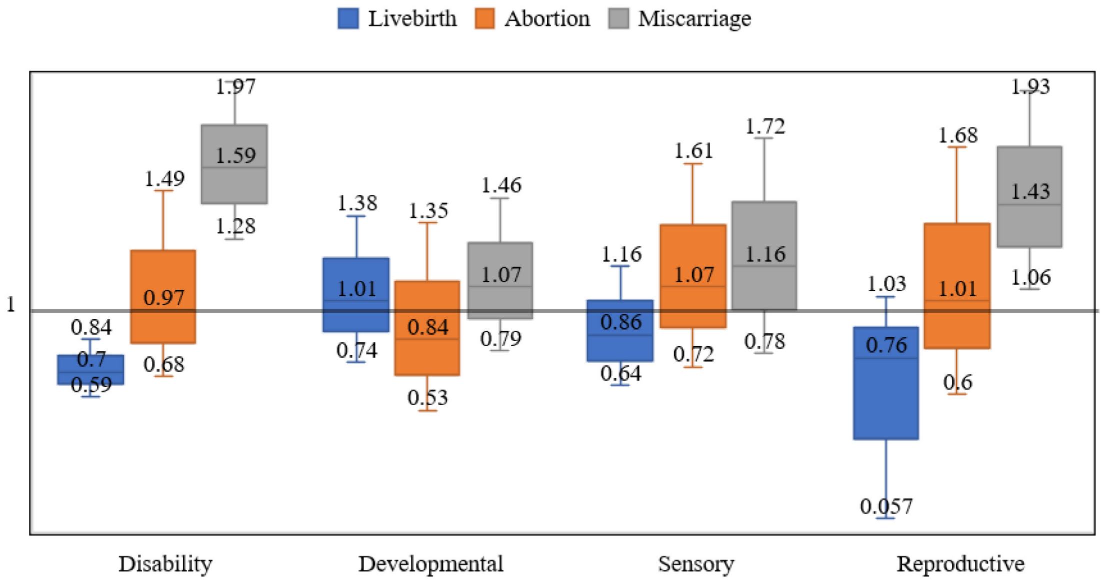


Figure 2. OR of pregnancy outcome and 95% CI among people with disability and no disability, and among people with specific disability compared to people with different disabilities.



Appendix A

A. Disability variable without reproductive related disability

Variables were created to define disability as having a sensory or developmental disability, thus including RRD in the non-disabled category. This was conducted based on the biopsychosocial model of disability framework, to further examine if disabilities that were not directly related to pregnancy had a different impact on pregnancy outcomes than all disabilities together did. An adjusted binomial logistic regression was run to test if the odds of livebirth, abortion, or miscarriage differed among those with developmental and sensory disabilities compared to those with RRD or no disabilities.

In this analysis, the odds of miscarriage were higher among those with DD and SD compared to those without disabilities or with RRD, as they were in the original analysis. However, in this analysis, the odds of a livebirth among those with a DD or SD compared to those without a disability or with an RRD did not reach statistical significance whereas they reached significance in the original analysis. Results of this analysis are shown in Table A1.

These results might indicate higher odds of negative birth outcomes but not lower odds of positive birth outcomes for people with DD or SD compared to those with RRD or no disability. This might indicate that the psychosocial barriers to prenatal and perinatal care that are more often associated with people with DD or SD when combined might have a greater effect on birth outcomes than they do individually or when compared the health barriers that are specific to those with RRD or no disability. However, this was an initial analysis and should be further examined by analyzing these results relative to different accessibility covariates.

Table A1. Adjusted binomial logistic regression including RRD in non-disabled category, showing odds of pregnancy outcomes among those with disabilities compared to those without disabilities (n = 9,794).

	Disability vs. no disability	
	OR (p)	95% CI
Livebirth	0.77 (0.08)	0.57 – 1.03
Abortion	0.70 (0.25)	0.38 – 1.30
Miscarriage	**1.67 (0.007)**	**1.16 – 2.40**

B. Severity of disability

Analyses were recreated with the added confounding variable "Doctor advised me to never become pregnant again". The results of this analysis were almost identical to the original analysis, implying that this variable did not have a great effect on the odds of pregnancy outcomes among those with disabilities and those without. Results are shown in Table A2.

Table A2. Adjusted binomial logistic regression including "Doctor advised me to never become pregnant again" in covariates, showing odds of pregnancy outcomes among those with disabilities compared to those without disabilities (n = 9,794).

	Disability vs. no disability	
	OR (p)	95% CI
Livebirth	**0.78 (0.04)**	**0.62 – 0.99**
Abortion	0.98 (0.94)	0.63 – 1.53
Miscarriage	**1.41 (0.03)**	**1.03 – 1.91**

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