Disability and Pregnancy: Research from NIDILRR and NICHD

Persistent maternal health disparities related to race, ethnicity, and income have garnered recent national policy attention. A growing body of research examining women with disabilities' experiences with reproductive health reveals that disparities also exist between women with and without disabilities. The purpose of this brief is to summarize findings about reproductive education, experiences, and outcomes among women with long-term disability from research funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD).[1]

This brief considers the accessibility of motherhood for women with disabilities and related outcomes within the social model of disability[2] over the life course. This model views the experience of disability as created by an interaction between person and environment in which attitudinal, community, physical, policy, programmatic, social, and transportation barriers limit the full participation of people with disabilities. The social model contrasts with models that frame the body of a person with a disability as something to "fix." Identifying and removing barriers can improve health outcomes, including maternal health outcomes for women with disabilities.

The brief focuses on research funded by NIDILRR and NICHD only. It does not represent the comprehensive list of published research in this area. A central theme across the literature on pregnancy and women with disabilities is that many gaps exist in relevant consumer education, clinician training, research, and appropriate interventions.

Disclaimer

All statements in this publication are solely those of the authors and do not necessarily represent the views of the NICHD, NIDILRR, Administration for Community Living (ACL), or Department of Health and Human Services (HHS). Questions or comments may be sent to Dr. Amanda Reichard at amanda.reichard@acl.hhs.gov.

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[1] NIDILRR defines disability through Title II of the Rehabilitation Act, as "…any person who has a physical and mental impairment which substantially limits one or more of such person's daily life activities…"
NICHD covers research on physical, intellectual, developmental, and learning disabilities.
[2] Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society, 28(7)*, 1024-1026.

Women with disabilities are just as likely as women without disabilities to intend to have a child (Bloom et al., 2017) and as likely to report pregnancy (Horner-Johnson et al., 2016; Iezzoni et al., 2013). Simultaneously, compared to women without disability, women with disabilities have a greater risk for unintended pregnancies (Horner-Johnson et al., 2020c); perinatal complications (Tarasoff et al., 2020); unjustified labor induction, and cesarean sections (Biel et al., 2020; Darney et al., 2017; Smeltzer, 2017); and adverse pregnancy outcomes (Crane et al., 2019; Dissanayake et al., 2020; Tarasoff et al., 2020). Thus, it is not surprising that women with disabilities also report more uncertainty about motherhood than women without disabilities.[3] Other barriers include physical inaccessibility of providers' offices and medical equipment, appointment times and insurance reimbursement constraints, and limited clinician knowledge (Shandra et al., 2014; Mitra et al., 2017a).

Many health care facilities do not have adequate physical accessibility for women with disabilities. Inaccessible environments and equipment at health care providers' offices and hospitals can impede women with physical disabilities from receiving routine prenatal examinations, weight measurements, and care (Iezzoni et al., 2013, 2015a, & 2017). For example, bassinets and changing tables in hospitals during the postpartum period are often too high, limiting the mother's ability to effectively and independently care for their newborn after delivery (Mitra et al., 2016a). Additionally, only 17% of deaf or hard-of-hearing women who use a sign language interpreter reported regularly being provided with one in health care settings. The resulting poor communication often contributes to various adverse outcomes, including reduced treatment adherence, inappropriate use of health services, and less awareness of healthy behaviors (Mitra et al., 2020).

Further, few clinicians receive training or education on identifying or addressing the needs of women with disabilities during their undergraduate or medical education, residencies, or fellowships. This limited exposure and preparation likely contribute to women with disabilities describing their clinician's lack of knowledge, awareness, sensitivity, and respect, as well as stereotyping, as factors compromising their receipt of prenatal (Mitra et al., 2017a), labor and delivery (Smeltzer et al., 2017), and perinatal care (Smeltzer et al., 2016). These findings highlight the need to develop evidence-based maternity practice guidelines, training, and clinician education specific to the unique needs of women with disabilities during pregnancy (Mitra et al., 2017a). There is also a pronounced need for increased opportunities and improved preconception education for adolescent and adult women with disabilities.

PRECONCEPTION AND CONTRACEPTION

Research indicates that women with disabilities have poorer preconception health than women without disabilities. Women who self-reported having a disability were twice as likely to smoke, less likely to exercise, and less likely to receive routine preventive medical care. Women with disabilities were also more likely to report poor pre-pregnancy health status, with an 80% increased prevalence of diabetes, 40% increased prevalence of obesity, and 90% increased prevalence of asthma than women without disabilities (Mitra et al., 2016a).

Despite the commonly accepted benefits of adequate preconception knowledge in reducing pregnancy-related complications and adverse infant outcomes,[4] recent studies have found that women with disabilities are less likely to have accurate knowledge about contraception and to use contraception than women without disabilities (Mosher et al., 2017 & 2018). Additionally, the type of contraceptives used varies by disability type (Horner-Johnson et al., 2019b). One study found that women with physical disabilities and those with cognitive disabilities were more likely than women with no disability to use female sterilization (Mosher et al., 2018).

[3] Shandra, C. L., Hogan, D. P., & Short, S. E. (2014). Planning for motherhood: fertility attitudes, desires and intentions among women with disabilities. *Perspectives on Sexual and Reproductive Health*, *46*(4), 203-210.
[4] American College of Obstetricians and Gynecologists. (2019). Pre-pregnancy counseling. ACOG Committee Opinion No. 762. *Obstetrics and Gynecology, 133*, e78–89.

Another study confirmed these findings, showing that compared to women without disabilities and women with other disabilities, women with cognitive disabilities were most likely to have had hysterectomies and sterilizations. Women with disabilities who received these procedures at younger ages than women without disabilities received them at a younger age (Li et al., 2018). Other studies have shown that women with IDD (Wu et al., 2018) and those with physical or sensory disabilities (Wu et al., 2017) were less likely to receive long-acting reversible contraception (i.e., intrauterine device or subdermal implant) and moderately effective contraceptive methods (i.e., pill, patch, ring, shot, or diaphragm) than women without a disability. As one might predict, given these findings, women with disabilities had greater odds of unintended pregnancy than women with no disabilities (Horner-Johnson et al., 2020c).

Verlenden et al. (2019) identified obstacles to contraceptive use from their literature review on contraceptive practices and reproductive health among women with IDD. These include drug interactions for women with comorbid health conditions, difficulty with prescription adherence, physical side effects, decision-making, and consent-related legal and ethical concerns. They also found that adolescent and adult women reported difficulty obtaining reproductive health services and guidance with contraception.

Breast and Cervical Cancer Screenings. Women with disabilities have long been shown to have much lower rates of timely and appropriate breast and cervical cancer screening than women without disabilities (Rivera Drew & Short, 2010; Horner-Johnson et al., 2014 & 2015). One study showed that women with disabilities had lower screening rates than women without disabilities and that women with more complex or severe disabilities had the lowest rates compared to women with less complex disabilities and women without disabilities (Horner-Johnson et al., 2014). Another study found that women with disabilities in rural areas experienced geographic disparities in access to care that compounded the disparities associated with disability (Horner-Johnson et al., 2015). Additionally, a 2019 study by Kushalnagar et al. (2019) found that deaf women were less likely to have received cervical cancer screenings than hearing women when controlling for covariates despite their importance to preconception and overall health care.

Reproductive Health Education. Women with disabilities have also reported a lack of access to reproductive health education (Long-Bellil et al., 2020; Horner-Johnson et al., 2020c). The limited evidence available on research and intervention development in this area further highlights the lack of importance and focus placed on providing education on reproductive health to adolescent girls and women with disabilities, increasing their risk of health disparities. Studies of women with intellectual disabilities show that they may have particularly limited access to accurate reproductive health information.

Intimate Partner Violence. Notably, intimate partner violence disproportionately influences prenatal care and pregnancy experiences for women with disabilities because they experience such violence at higher rates than women without disabilities. For example, deaf or hard of hearing women have a proportional rate of intimate partner violence double that of the general population (Mitra et al., 2016b). Additionally, an estimated 68% to 83% of women with intellectual and developmental disabilities (IDD) experience sexual assault in their lifetime. As a result, women with disabilities have an increased risk for unintended pregnancy which carries social, economic, and health consequences for the women and their families (Alhusen et al, 2019). Women with intellectual and developmental disabilities are also less likely to know or document the paternity of their infants and are fearful of reporting assault because sexual activities are often prohibited by residential facilities and families (Mitra et al., 2015a).

PRE-PREGNANCY AND PREGNANCY-RELATED COMORBIDITY DISPARITIES

Recent studies have examined pre-pregnancy comorbid conditions and pregnancy-related health conditions among women with disabilities that can increase their risk of adverse outcomes. The prevalence rates of these conditions (i.e., chronic diabetes, chronic hypertension, gestational diabetes, gestational hypertension , and mental health conditions) are higher among women with disabilities than women with no disability (Mitra et al.,

2017a; Horner-Johnson et al., 2017a; Horner-Johnson et al., 2020b), often vary by disability type (Darney et al., 2017; Tarasoff et al., 2020), and are even higher among women from minority race/ethnic groups (Horner-Johnson et al., 2020a). Examples of comorbidities by disability type include:

- ***Spinal Cord Injury***. Several health conditions can negatively affect functional abilities during pregnancy (and the postpartum period) for women with spinal cord injuries. These include greater likelihood of developing pressure ulcers, lower extremity edema, weight gain, urological complications, gastrointestinal dysfunction, postural hypotension, and autonomic dysreflexia (Iezzoni et al., 2015a).
- ***Deaf and Hard of Hearing***. In a national study, Mitra et al., (2020) found that deaf and hard of hearing women had greater risk than women without hearing loss to have one or more chronic conditions (e.g., pre-existing diabetes, hypertension) and pregnancy-related complications (e.g., preeclampsia, placental abruption) (Mitra et al., 2020).
- **IDD**. Compared to those without IDD, women with IDD were found to have increased prevalence of gestational diabetes and preeclampsia (Mueller et al., 2019) and other chronic conditions (Mitra et al., 2018a, 2018b, & 2019).

Despite these findings, many women reported no substantial impact of their disabling condition on their pregnancy (Long-Bellil et al., 2017a).

PRENATAL CARE DISPARITIES

Mitra et al. (2015a) found that when compared to women with no disabilities, women with disabilities were less likely to have received timely prenatal care, defined as care beginning in the first trimester (Mitra et al., 2015a). More recent studies have shown that the use of prenatal care varies by type of disability. Women with IDD were less likely to have timely initiation of prenatal care and more likely to have received inadequate prenatal care throughout their pregnancy than women without disabilities (Mitra et al., 2015b; Mitra et al., 2019), and women with other types of disabilities (Horner-Johnson et al., 2019a). They were also almost twice as likely as women without disabilities to have used an emergency department visit during their pregnancy, and more likely to have non-delivery hospital stays (Mitra et al., 2018b).

Women with physical disabilities, however, had somewhat different patterns of prenatal care utilization. They had a lower risk of delaying prenatal care than women with other types of disabilities and women with no disabilities (Horner-Johnson et al., 2019a). Women with spinal cord injuries, for example, were more likely than those without them to receive intensive prenatal care (Crane et al., 2019). In another study, women with physical disabilities reported having positive prenatal care experiences overall. Still, these experiences were moderated by providers' negative reactions about their pregnancy and their lack of knowledge about disability and pregnancy (Mitra et al., 2017a). Further, women with physical disabilities often reported barriers to accessing some elements of prenatal care due to inaccessible weight scales and exam tables (Iezzoni et al., 2015a; Mitra et al., 2016c).

LABOR AND DELIVERY

Research on the birth experience of women with disabilities reveals several themes. First, women with disabilities have reported dissatisfaction with their labor and delivery experiences. Reasons for such dissatisfaction included having too little involvement in advanced labor and delivery planning (Long-Bellil, 2017b; Smeltzer et al., 2016), and having limited input into the mode of delivery (Mitra et al., 2017a), length of stay (Horner-Johnson et al., 2020b), and pain management during labor (Long-Bellil et al., 2017b; Smeltzer et al., 2017). Second, studies have highlighted disparities between women with and without disabilities in rates of induction of labor and cesarean deliveries, with and without medical justification (Biel et al., 2020; Crane et al., 2019; Darney et al., 2017). Studies have also shown that these disparities vary by disability type (Crane et al.,

2019; Darney et al., 2017; Horner-Johnson et al., 2019a; Mitra et al., 2015a). One state-level study found that the proportion of deliveries by primary cesarean for women with disabilities was twice that of women without disabilities, with women with physical disability due to injuries having the highest proportion of this type of delivery (Darney et al., 2017). Akobirshoev et al (2019) also found birth outcomes vary by race and ethnicity, especially with stillbirth prevalence rates higher among non-Hispanic Black and Hispanic women with disabilities.

Third, surgery and anesthesia may present increased risks for women with disabilities, and recovery from surgery may be more complicated (Darney et al., 2017; Horner-Johnson et al., 2017a). Fourth, compared to women with no disability, women with disabilities overall had a significantly higher likelihood of prolonged length of stay after delivery. One study found a mean length of stay for women with disabilities of about half a day longer for vaginal delivery, nearly three-fourths of a day longer for primary cesarean delivery, and nearly two-thirds of a day longer for repeat cesarean delivery (Horner-Johnson et al., 2017a). In another study, women with spinal cord injury also had significantly longer hospital stays than women with no disability (Crane et al., 2019).

PREGNANCY AND BIRTH OUTCOMES

Although many women with disabilities give birth to healthy babies, several studies have identified disparities in these outcomes. Using the Medical Expenditures Panel Survey (MEPS), Horner-Johnson, and colleagues (2017b) found higher rates of miscarriage among women with complex activity limitations. However, they found few differences in rates of miscarriage and live birth for women with other types of disabilities. In contrast, Dissanayake et al. (2020), using the National Survey of Family Growth data, reported higher adjusted odds of women with all disabilities experiencing miscarriage than women without disabilities.

Other recent studies have reported that women with disabilities have a greater likelihood of adverse birth outcomes than women with no disabilities (Mitra et al., 2017b). Moreover, the possibility of adverse outcomes varies by mother's disability type. Examples include:

- **Deaf and Hard of Hearing**. Babies of deaf and hard of hearing women had an increased risk for preterm birth, low birth weight or very low birth weight, and low 1-minute or low 5-minute Apgar score. However, no significant differences were found in size for gestational age, fetal distress, or stillbirth (Mitra et al., 2020).
- **IDD**. Women with IDD had an increased risk for preterm birth, low birth weight, low Apgar scores, and stillbirths (Akobirshoev et al., 2017; Mitra et al., 2015a). Women with IDD received an equal number of postpartum visits as women without disabilities, but were more likely to use outpatient visits for other concerns during the postpartum period (Clements et al., 2020).
- **Spinal Cord Injury**. Women with SCI had a higher prevalence of comorbidities and preterm birth and cesarean delivery than women with no disability. However, infants of women with SCI did not appear to have an increased risk for long-term morbidity (Crane et al., 2019).

POSTPARTUM MORBIDITY AND CARE

Adequate postpartum care and supports can help women adapt to a life caring for a new infant. Mitra et al. (2015) found that women with disabilities have an increased risk of postpartum depression than women without

disabilities. Other research has shown disparities in postpartum morbidities and receipt of postpartum care among specific subgroups of disability. For example:

- **IDD**. Following delivery, women with intellectual and developmental disabilities have higher rates of postpartum hospital utilizations than women with no disability, including observational stays, emergency department visits, and non-delivery hospital stays (Mitra et al., 2017c, 2018a & 2019).
- **Spinal Cord Injuries**. Women with SCI were found to have significantly higher risk for postpartum depression and injury than women without disabilities (Crane et al., 2019).

GAPS AND OPPORTUNITIES

Gap: Several factors likely contribute to contraceptive use patterns among women with disabilities, including higher odds of sterilization. These may include lack of accessible health care facilities, limited knowledge among women with disabilities, and insufficient clinician training. However, the field needs more robust studies to better understand all of the factors influencing contraceptive use among women with disabilities.

> **Opportunity**: Preconception counseling provides an opportunity for clinicians to address the modifiable risk factors common among women with disabilities and to optimize health before pregnancy, as well as time to prepare for potential complications that may result due to a particular disability. The value and benefits of preconception counseling highlight the importance of implementing better clinician education in recognizing and addressing the unique reproductive health needs of women with disabilities (Mitra et al., 2017b).

Gap: Adolescent girls and women with disabilities experience barriers and challenges to obtaining necessary reproductive health information and services. These gaps stem, in part, from the fact that maternal health policies and programs have historically excluded women with disabilities.

> **Opportunity**: Using an integrated life course approach, maternal and child health policy can address education and knowledge gaps among women with disabilities by increasing their access to appropriate reproductive health care and accurate information.

Gap: There is only limited research addressing the reproductive health needs and experiences of women with disabilities. Some of the remaining questions include:

- What are the relationships between comorbidity, access to care, and pregnancy outcomes and experiences among women with disabilities?
- Why are cesarean section delivery rates higher among women with disabilities than women without disabilities, even without medical justification?
- Why is there such a high rate of sterilization of women with disabilities?
- What factors lie behind the disparities in prenatal care?

Having such a limited evidence base prevents the implementation of evidence-based interventions and developing clinical practice guidelines about unique needs, risks, and preferences of women with disabilities that can improve quality of care to reduce the disparities women with disabilities experience.

> **Opportunity**: Several actions can help improve the quality and frequency of research regarding the reproductive health and pregnancy experiences of women with disabilities. Most importantly, adding disability identifiers to the state and national databases used to study maternal and child health will enable comparisons between women with and without disabilities and between women with different types of disabilities with greater precision and ease (Brown et al., 2020; D'Angelo et al., 2020; Horner-Johnson et al., 2017b). Additionally, increasing the number of measures available to study the needs

and preferences of women with disabilities would further expand our knowledge base. For example, a group of researchers recently created a conceptual framework for developing new patient-reported outcome measures (PROMs) for women with physical disabilities (Kalpakjian et al., 2020).

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