

Intellectual and Developmental Disabilities

Pregnancy Experiences of Women With Intellectual and Developmental Disabilities

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Abstract

Today women with intellectual and developmental disabilities (IDD) are more likely than ever to live in the community and are increasingly likely to give birth. However, they are at increased risk of adverse maternal and infant outcomes. This qualitative study explored pregnancy care experiences of women with IDD. Semi-structured interviews were conducted with 16 U.S. mothers with IDD in 2016–2017 (analysis in 2020–2022). A content analysis approach revealed that perinatal care, social and economic, psychosocial, and environmental factors impacted pregnancy experiences. Some participants reported exceptional care. This study centers the voices and experiences of U.S. women with IDD. Findings demonstrate a need to improve care through clinician training and to develop accessible programs and services.

Keywords: maternal health care, intellectual and developmental disabilities, perinatal care, clinician training

Introduction

Eugenic practices during the 20th century, such as institutional segregation and involuntary sterilization of women with intellectual and developmental disabilities (IDD), were widely accepted in the U.S. and elsewhere (Agaronnik et al., 2020; Kallianes & Rubenfeld, 1997; Tilley et al., 2012). Today, women with IDD generally live in the community, and institutional settings are less common (McCarron et al., 2019). Some persons with IDD desire to have sexual experiences, to become parents, and to bear children (Brown, Cobigo, et al., 2016; Brown, Lunskey, et al., 2016; Horner-Johnson, 2019; Horner-Johnson et al., 2016). However, recent studies have highlighted their increased risk for adverse birth and maternal outcomes compared to women without IDD (Agaronnik et al., 2020; Akobirshoev et al., 2017; Mayes et al., 2006; Mitra, Parish, Clements, et al., 2015). In addition, women with IDD report experiencing myriad barriers, unmet perinatal care needs, and negative experiences with healthcare providers (Höglund & Larsson, 2013; Khan et al., 2021; Malouf et al., 2017; Potvin et al., 2019, 2020; Walsh-Gallagher et al., 2012).

IDD refers to significant limitations in both intellectual functioning and adaptive behavior used in conceptual, social, and practical adaptive skills. IDD can be expressed to varying degrees in conditions or syndromes, for example, Down syndrome (Schalock et al., 2007). An estimated 820,000 women of childbearing age have one or more IDD in the U.S. (Howden & Meyer, 2011). Though birth rates for women with IDD have not been formally established in the U.S., studies done in Ontario, Canada have estimated 20.3 live births for every 1,000 women with IDD in 2009, compared to 43.4 among women without IDD (Brown, Cobigo, et al., 2016; Brown, Lunskey, et al., 2016). In the U.S., the birth rate in the general population is 58.3 births for every 1,000 women (Martin et al., 2020) and studies have demonstrated that individuals with any disability are just as likely to have been pregnant as individuals without disabilities; women with cognitive disabilities were less likely to have been pregnant than women with no disability (Horner-Johnson et al., 2016). Some fertile women with IDD have reported they desire to be parents or engage in sexual activity (Agaronnik et al., 2020; Potvin et al., 2019, 2020), but concomitantly, they lack adequate support, resources, and sexual health knowledge (Abells et al., 2016; Potvin et al., 2020).

People with IDD are more likely to experience poverty (Emerson, 2007; Roebuck, 2021), violence, mental illness and chronic illness, and barriers accessing health care (Krahn et al., 2006), which are indicators known to predict adverse perinatal outcomes (Laditka et al., 2005).

A growing body of research documents disparities in numerous maternal and infant health outcomes for women with IDD. Compared to infants born to women without IDD, infants born to women with IDD are more likely to be born preterm, be born with low or very low birthweight, be stillborn, and be admitted to the ICU after birth (Akobirshoev et al., 2017; Brown, Cobigo, et al., 2016; Mitra, Parish, Clements, et al., 2015; Mitra, Parish, Son, et al., 2015). Women with IDD are also at higher risk for severe maternal morbidity and maternal mortality (Horner-Johnson et al., 2022; Mitra et al., 2021; Signore et al., 2020). Furthermore, women with IDD are less likely to receive appropriate prenatal screenings throughout pregnancy (Brown, Cobigo, et al., 2016; Horner-Johnson, 2019; Mitra, Parish, Clements, et al., 2015; Mueller et al., 2019), and have higher rates of complications throughout pregnancy, such as preeclampsia or early labor (Brown, Cobigo, et al., 2016; Mitra, Parish, Son, et al., 2015; Mueller et al., 2019).

Qualitative research reports that pregnant women with IDD experience prejudiced attitudes and stigma towards their disability, age, sexuality, and reproductive rights (Mayes et al., 2006; Potvin et al., 2019; Xie & Gemmill, 2018). Women with IDD have reported stress due to involvement with child-protective services and custody of their children (Potvin et al., 2019; Ptacek et al., 2023; Xie & Gemmill, 2018); it is often during interactions with the healthcare system or social services when women with IDD are referred to child-protective services (Lightfoot & DeZelar, 2016). They also report difficulty communicating with their providers (Barnett et al., 2016; Khan et al., 2021; Malouf et al., 2017), lack of accessible pregnancy and parenting resources (Khan et al., 2021; Walsh-Gallagher et al., 2012), lack of choice in medical decision-making, and abortion suggestions from providers (Barnett et al., 2016; Mayes et al., 2006; Walsh-Gallagher et al., 2012). These negative healthcare experiences act as potential deterrents to women with IDD engaging in help-seeking behaviors throughout their pregnancies (Mitra, Parish, Clements, et al., 2015), and may

contribute to adverse maternal or infant health outcomes or a lack of satisfaction with perinatal care (Khan et al., 2021).

Examining pregnancy from the perspectives of women with IDD is critical to understanding potential factors contributing to these pregnancy-related disparities. Using qualitative data gathered from individual interviews with women with IDD, this study aimed to uncover the pregnancy and perinatal care experiences of this population. Specifically, we wanted to explore the following research questions: What barriers did women with IDD experience in accessing adequate perinatal care in clinical settings? What other unmet needs did they experience during pregnancy, outside of clinical settings? How did any unmet needs outside of clinical settings impact access to perinatal care?

Methods

We conducted semi-structured qualitative interviews with 16 women with IDD between February 2016 and October 2017 as part of a larger investigation on improving pregnancy outcomes among women with IDD in the U.S.

Investigators adapted the interview guide based on one used for a previous study (Mitra et al., 2016), Mitra et al.'s perinatal care framework (Mitra, Long-Bellil, Smeltzer, et al., 2015), and available research (Mitra, Parish, Clements, et al., 2015). Investigators cognitively tested the interview guide with two women with IDD to assess how participants may understand and respond to the questions and to identify potential sources of confusion or misunderstanding (Bowen, 2008). A member of the research team asked the questions on the interview guide and then probed to understand the thought process of the participants while they were answering the questions. The interview guide was revised based on the cognitive tests, and it included questions about pregnancy planning, care experiences, interactions with providers, and recommendations to providers and other women with IDD. The interview guide was developed according to best practices for conduct of research with people with IDD, including plain language for accessibility and graphics to support comprehension (Rosenthal et al., 2022; Swaine et al., 2011; Swaine et al., 2014). Interviews were conducted in English, either in-person or by telephone, and lasted up to one hour.

Author positionality: The authors all identify as non-disabled cis-gender women. Two of the authors have a doctorate degree, one has a master's degree, and one has an undergraduate degree.

Recruitment

Recruitment was conducted throughout the U.S. using a combination of purposive and convenience sampling methods (Etikan et al., 2015). We used various recruitment strategies, such as distribution of study flyers through community organizations and agencies providing services to people with IDD, advocacy organizations, independent living centers, parenting programs (e.g., groups, trainings, supports), and individuals active in the disability community (e.g., self-advocates, community leaders). All study materials were in plain language to ensure accessibility for women with IDD. Potential participants were able to contact study staff directly via information on the flyer if they chose to, or a "consent-to-contact" protocol was also used. The consent-to-contact was used for potential participants to give permission for an agency staff person to give the person's contact information to study staff. Study staff then contacted the potential participant either directly or with assistance of a service provider or caregiver, based on the potential participant's preference.

Data Collection

Study staff screened potential participants for eligibility over the phone. To be eligible, a woman must have had an intellectual disability (e.g., learning disability) or autism, been living in the U.S., been at least 18 years old, given birth to a child within the last 18 months, and been able to respond verbally to interview questions either over the phone or in-person. Intellectual disability was either self-identified by the participant or was identified by a caregiver or support person, such as an agency staff member; we did not screen by specific diagnoses. The screening process was designed to make screening and participation as accessible as possible; clinical confirmation of diagnoses was not feasible and the researchers recognized that people refer to IDD in a variety of non-clinical ways. People with only developmental disabilities (e.g., cerebral palsy) were not eligible unless they also had an intellectual disability. In-person interviews were conducted with women located within 4 hours driving distance of the research institution at a private location convenient to the

participant (e.g., the participant's home, a private room in a local library); all others were conducted over the phone. Research staff read the informed consent form to eligible people over the phone at the time of screening and provided the opportunity for them to ask questions. During the screening process, study staff asked about the women's guardianship status. Participants with a guardian provided verbal assent over the phone, and guardians were contacted subsequently to provide informed consent. Participants without a guardian provided informed consent verbally over the phone. The informed consent process was repeated a second time immediately prior to the interview. In-person participants signed the informed consent form and phone participants provided verbal consent or assent. All study documentation, including informed consent, was developed using plain language, simple sentence structure, and illustrations to support comprehension. Study staff were trained to assess whether a potential participant understood the informed consent, and the woman was not enrolled if the researcher determined that the woman did not understand the research procedures or informed consent; however, no participants were excluded for this reason.

Interviews were conducted by one of three study staff trained in study protocols, including a protocol for how to respond if the participant disclosed any abuse during the interview (Sammet Moring et al., 2019). They had extensive experience with interviewing people with IDD and were trained to monitor participants for any signs of fatigue or distress and to offer breaks as needed. All study procedures followed established recommendations for recruiting and obtaining consent from people with IDD (Swaine et al., 2011; Swaine et al., 2014). Participants were paid \$50 as a thank-you for their time. Interviews were audio-recorded and transcribed by a professional transcription service.

All study procedures were approved by the Brandeis University Institutional Review Board under protocol number 15013.

Analysis

This study used a qualitative content analysis approach. Content analysis is a flexible and widely used method for analyzing text for content and contextual meaning and was appropriate for this study's goal to gain understanding of participants' experiences during pregnancy. This study started using a conventional approach by extracting themes from the

content of the data (Hsieh & Shannon, 2005; Maxwell, 2012). The researchers started by reviewing three transcripts followed by group discussion to identify themes in the data. Themes developed into codes, which were documented in a codebook. One primary researcher conducted a first round of coding based on the codebook and a second researcher reviewed coded data. The researchers met periodically to discuss and resolve any coding discrepancies and revised the codebook iteratively to reflect coding decisions. The researchers then used inductive and deductive techniques to analyze coded data for larger themes and relationships between categories. Mitra et al.'s perinatal health framework (Mitra, Long-Bellil, Smeltzer, et al., 2015) was used to understand and organize the findings. Interview guide questions were related mostly to health care access and experiences based on the overall study goals. Despite the interview's focus on health care, analysis confirmed the prominence of other factors from the framework and demonstrated ways in which they impacted health, healthcare access, and overall pregnancy experiences of participants.. Analysis took place in 2020–2022. The researchers used Dedoose web-based qualitative analysis application to facilitate analysis (Dedoose Version 8.3.17, 2020).

Findings

Out of the 16 study participants, the majority identified as non-Hispanic, White and the mode age category was 30–34 (Table 1). Women reported a range of experiences during pregnancy; some involved direct interactions with healthcare providers or the healthcare system but many were around other related factors, such as housing instability or the need for other kinds of services and support. These findings reflect a broad lens through which we examined participants' experiences during pregnancy, since factors like housing and economic security are somewhat inextricable and contribute to overall health and wellbeing. Our findings reflect a number of factors that were perceived by the mothers to have influenced their experiences of pregnancy: perinatal care experiences and satisfaction; social and economic factors; and psychosocial factors. These factors can either positively or negatively impact participants' pregnancy experiences. We also discuss environmental factors which included things related to the external context in which these women's experiences took place, such as societal views about people with IDD having children. A

table of themes with additional example quotations can be found in Table 2.

Perinatal Care Experiences and Satisfaction

Provider Communication

Participants discussed communication with their providers that impacted their pregnancy experiences, including decision-making and perceived provider attitudes. Communication played an important role across participants' reported care experiences, including both effective and ineffective communication with providers.

Effective communication included providers listening to participants' concerns, taking time to answer questions, and slowing down to explain things. One participant reported her provider's willingness to answer all of her questions, even beyond clinical encounters:

I felt that [my provider] was open ears and comfortable. He always said, if I ever had any other questions, just call his office. His secretary will talk to me or they'll have him on the phone and he'll talk to me.

One participant stated that she found her providers to be effective communicators when they explained concepts in non-medical terms: "[I liked that] they actually explained things in normal terms, not medical."

Many participants, however, described experiences of unsatisfactory communication with providers, which included providers not explaining things slowly enough and becoming frustrated when the participant struggled to understand. One participant suggested providers slow down and be more patient when communicating with women with IDD: "They need to slow down when they talk to you. They need to make things easier to understand ... If you don't understand something, they need to not get frustrated with you."

Participants discussed decision-making and its importance in the context of perinatal care. Women in the study described sometimes feeling excluded from decision-making and that their clinicians did not explain options for medical procedures clearly.

One participant reported she did not always feel providers communicated clearly about what her choices were for her care: "It's hard for me [to] understand I have choices in my healthcare; sometimes I don't feel that way."

A majority of participants reported experiencing judgement, stigma, and biases from providers related to their disabilities. One participant expressed feeling judged after disclosing that she receives social security income benefits to her provider:

[The providers] need to be more understanding or acknowledge what I was saying. I tell them I get SSI. I feel like if I tell somebody I got SSI, they are going to think that I am special ed. I feel like I am normal.

Another participant recalled how she felt disrespected for being unable to sit in a typical way for a cesarean delivery:

During my C-section they were awful. They didn't respect me at all. I can't sit the way they wanted, they got very frustrated with me, and it's like I'm sorry.

Nothing I can do about it. Some of the things they were saying, it was awful.

One participant described feeling like providers treated her differently by speaking down to her because of intersecting characteristics including disability, race, and history of substance use:

With the shots or this or that. [They asked me] "Do you fully understand?" "Yes, I fully understand what you're saying to me. Yes I do." They wouldn't say that if a couple went in there, married, in their 30s, good jobs, they wouldn't talk to them in that type of manner.

She also described how her partner's race and her drug use contributed to providers' treatment of them during care:

We have two separate kids. He's black, I'm white. I was using drugs. They had asked him if he had ever been to jail and he said no. I don't know why that was ... It just felt really judgy.

Another woman felt ignored because of her disability status when she reported to providers that she felt sick after giving birth:

They ignored me when I felt really sick ... I felt so sick I couldn't eat my food. ... They just told me it was just nausea and they ignored it. ... I felt like I was going to die.

Perinatal Care Satisfaction

This theme includes aspects of perinatal care such as care coordination and comprehensiveness. One participant described asking her provider many questions related to feeding and caring for her baby and her provider gave her all the information she was looking for:

I had questions about ... breast feeding ... or pumping. And like, mixing the formula and the pumps. ... And just like, most stuff I would need for the babies. ... And just a whole lot of things. ... And they answered [everything].

Another participant described her provider giving her techniques to move labor along: "I had to walk ... It was interesting actually. I didn't know there were so many different ways to, you know, try to dilate more and to push it to go faster." Another participant described feeling that she was not adequately attended to after giving birth, saying, "The treatment ... after birth they were awful. Like if you were asking for a drink or something, they took almost two hours to get you a drink."

Many participants spoke very highly about their providers; they described situations where their providers went out of their way to provide supportive care that went beyond the woman's medical needs.

One participant spoke about an app her provider put on her phone to help her track her exercise and nutrition:

[My doctor] made me take pictures of everything I ate. She put this app on my phone to help me because I had to walk a lot. So ... having the phone in my pocket or anything, it tracks how much I walk. I take pictures of what I eat and it tells me how far I am weekly. She did a lot for me.

Another participant reported that her doctor assisted her with ensuring restraining orders were properly in place to protect the woman. She said, "[My doctor] helped me make sure that my restraining orders were out there and in the right places, and the right people were informed. She was just good in every situation."

Across findings, women expressed a desire to be respected as a person and to have quality care. Listening to the women's needs and taking extra time to explain information in

an accessible way and answering questions patiently were important to participants' care experiences. One participant described her positive and meaningful birth experience:

[Giving birth] was really intense and it was really painful. But at the same time, right when she came out, it was like this really beautiful feeling of relief. And hearing her cry and stuff was like oh my goodness. I just created this thing and she was really cute. It was a beautiful moment.

Economic and Social Factors

Nearly all participants gave examples of how economic factors, particularly low income, impacted their pregnancy experiences. One participant reported that she only ate once a day during her pregnancy because she could not afford any more than that:

The problem was that I couldn't afford to eat more than once a day. Even now I can't. I am lucky if I eat once a day because I don't get enough food stamps. ... My rent is only \$200, but my gas and electric bills, I have \$300. ... Now I have to buy diapers. I have to buy wipes. I have to get her clothing because she outgrows everything within a week.

Closely related to economic stability is housing stability. Some participants described living with family members for financial reasons and some spent time living in shelters. One participant described challenges finding an apartment:

I am looking for an apartment. It is hard finding an apartment with my income. I do not make enough. ... And they want first, last, and security. It is like twice what I make ... you have to have proof of it. If you just come with a bunch of money and show them, they are like that is not enough proof. We need to know how much you make.

Transportation to medical appointments during pregnancy came up repeatedly during interviews. Some participants received services that transported them to appointments. Others received rides from family members or they walked. One woman took her children with her to appointments by riding public transportation. In this example, a participant talked about transportation services she received: "[Service provider] pays for taxi rides for me. I get \$300 a month ... to get the taxi where I need to go." On the other hand, another participant did not

receive such services, despite needing them: “My outreach program can’t do basically anything for me because they can’t give me [transportation], which is the main thing that I need.”

Participants’ reports of social support varied. Some received support from the father of their baby, for example:

I could not eat. I could not even drink water. I was throwing up and my husband was so concerned about me. Try to eat anything, even a little bit. He took care of the boys because I was always sleeping. I was always so weak and then he would get the money for daycare and I would just be sleeping.

Others reported receiving support from friends, family, or other community members. Examples of support included emotional support, transportation, and accompaniment at medical appointments.

All participants reported some form of social support, although some did not have as much as they would have liked. One participant described being alone in the hospital for labor and delivery without a support person:

I made it [in an ambulance] to [the hospital] into the labor and delivery room. ... I didn’t have anybody with me. ... It was just me. I was actually quite scared. ... I would’ve wanted somebody with me.

Almost all participants reported receiving some formal supports to varying degrees. Formal supports included transportation services and assistance planning for taking care of the baby. For example, a participant described a program where someone came after the baby was born to track the baby’s growth and progress:

And then I also liked after when I had [my service provider] how she came out to the home every week and brought a little scale with her and we would weigh [my baby] to see how much she was growing because when I had her she was so tiny. She was only five pounds, 2.2 ounces. So it was a big deal for her to gain weight.

The same participant described an annual meeting through the same program where she sets goals and she can get assistance with various needs.

Psychosocial Factors

Participants described a variety of psychosocial issues that impacted their pregnancy experiences, including substance use, involvement with child-protective services, stress, and identity as a disabled parent.

A few participants described using substances during their pregnancy. One woman shared her experience seeking smoking cessation support, a need which went unmet:

I am smoking being pregnant. Can you guys at least help me because it is a struggle for me especially being stressed and I do not want to be doing this to the baby? I have even asked here for this pregnancy, can you please help me because I am a smoker of cigarettes and I want to quit but every time I am stressed, I get antsy or something, I smoke cigarettes. ... I said I want to stop and she told me well, it is bad for the baby. That is all. I was like that is no help for me.

On the other hand, another participant reported her providers supported her in going off her medication and did not report her to child-protective services:

I was using [medication] and they knew that. ... They helped me get into clean slate. They didn't call [child-protective services] on me. They said they weren't going to file as long as they could tell in the levels when I would use.

All participants except for one reported having had some involvement with child-protective services. Some reported having had children previously removed from their care. In the following example quotation, a participant discusses her awareness of the likelihood of people with IDD being referred to child-protective services:

[People with disabilities] are automatically going to wind up having [child-protective services] involved and investigating you and interrogating you all because you were born the way you were, which in my opinion is completely unfair. Where they sort of judge someone just because they are them. They have difficulties doing or thinking or feeling a certain way.

Several participants described stress that impacted their pregnancy. One participant described how her child's father repeatedly called the police on her throughout her pregnancy and created a great deal of stress:

[My child's father] sent the cops out to our home a couple of times and I cried. It was very hard for me because I knew I wasn't doing nothing wrong. And he was being this psycho and I did have [my baby] three weeks early because she stopped growing in me. And my mom thinks it's because of the stress that my daughter's dad put me through when I was pregnant with her.

Finally, several participants spoke about their identity as a disabled parent. Identity had an impact on care experiences as it allowed women to advocate for themselves and seek supports. One participant described maintaining her self-efficacy as a parent with a disability despite other people's views:

Because as much as people may complain about me and say I am a bad parent and say I am not able to take care of her and whatnot, I know how to be a good parent. I put her health and her safety first.

Environmental Context

Environmental context factors discussed included challenges navigating the healthcare system, societal stigma related to disability or other aspects of identity, or a combination of both.

In this example, a participant discussed challenges obtaining contraception without a referral:

They want a referral now for everything. You want to have a referral for birth control and then if I don't get that referral right away and I get pregnant, then you want a referral because I'm pregnant.

One participant's challenges navigating pregnancy care were mitigated by a midwife who helped coordinate her care:

[My midwife] was very understanding... I explained how I wanted things and she was very on top of it; very, very understanding and everything. [At the end of her shift] she told the other midwife, "She likes things this way." She was explaining how I liked things and to explain things specifically so I would understand it ... like, just explaining exactly what I wanted and how I wanted everything. She explained to me

every little thing that they are going to do, like if they are going to check me or give me medicine or something. She would just like be very forward and get right to it.

Most participants spoke in some way about societal stigma regarding people with disabilities. One person described, “I just feel like I’m always being judged constantly.” Another discussed society’s views that people with IDD can’t or shouldn’t be parents, but having supportive people helped strengthen her identity:

There were some people that would tell me I couldn’t be a parent. There were a lot of people in my childhood that didn’t think that I would be a mother. But I also had people in my life that did say that I could be a mother, that I could be a parent.

Discussion

Through qualitative interviews with women with IDD, this study intended to explore participants’ experiences of barriers to perinatal care in clinical settings, other unmet needs during pregnancy (outside of clinical settings), and how any unmet needs impacted their pregnancy experience. The findings reveal important aspects of participants’ pregnancy experiences, such as communication with providers, social and economic factors, and psychosocial factors.

Participants in our study consistently reported that provider communication was not adequate to address their needs, including explaining things in plain language and allowing time to answer questions or repeat information. Some participants felt their provider did not adequately communicate with them about their care options or include them in decision-making. Participants also perceived negative attitudes and judgement from providers. Communication plays a critical role in consent and respect of patients’ wishes (Back et al., 2019; Biglu et al., 2017), yet multiple studies have found that current clinician training does not adequately prepare providers for interacting with individuals with IDD (Holder et al., 2009; Shakespeare et al., 2009; Trollor et al., 2018). In particular, obstetric and gynecological providers have reported feeling unprepared to interact with individuals with disabilities, despite understanding that this population faces increased challenges and may require additional support (Amir et al., 2022; L. D. Smith et al., 2023; Taouk et al., 2018).

Participants in our study also reported feelings of stigma and bias within the context of their care, which is consistent with findings in other studies from the perspectives of women with IDD (Barnett et al., 2016; Höglund & Larsson, 2013; Malouf et al., 2017; Mayes et al., 2006; Potvin et al., 2019; Walsh-Gallagher et al., 2012). Ableism is discrimination against people with disabilities based on the belief that having a disability makes a person inferior (Eisenmenger, 2019). Ableism can manifest as negative attitudes and assumptions from providers, refusal to provide accommodations, poor treatment, or other forms of discrimination and has been documented by researchers (Iezzoni et al., 2021; Kaundinya & Schroth, 2022; Lagu et al., 2022; Mitra et al., 2016; L. Smith et al., 2024). Although ableism in public health and health care has historically received little policy attention (Lundberg & Chen, 2024), recent policy changes demonstrate that this issue is increasingly and rightfully being prioritized (Office for Civil Rights, U.S. Department of Health and Human Services, 2023). This study's findings underscore the importance of understanding and addressing ableism and how it manifests in perinatal care settings specifically. Training that includes increased exposure to people with disabilities has been found to improve clinician attitudes (Iezzoni & Long-Bellil, 2012; Shakespeare & Kleine, 2013; Symons et al., 2014). Clinician training has been found to increase competency to work with patients who have IDD, improve attitudes, and increase willingness to provide care (Boyd et al., 2008; Graham et al., 2009; Minihan et al., 2011; Shakespeare et al., 2009; Shakespeare & Kleine, 2013).

Our findings also show unmet needs outside of perinatal care. Many participants reported that they did not receive adequate supports during pregnancy, such as smoking cessation and transportation, and experienced housing and economic instability. For example, one participant reported only eating once daily during pregnancy because it was all she could afford. Although many women in our study did receive various supports, programs are likely not consistently available, especially in more rural areas (Fortney & Tassé, 2021). Although some participants had providers who provided support beyond traditional medical care, it is important to ensure adequate supports for women with IDD outside of medical care, given the increasing demands on clinician time. Policies and programs to address barriers and improve perinatal health of women with IDD should take into account factors identified in

this study and barriers at the various “levels” of influence (Khan et al., 2021) that impact experiences. For example, some states offer free at-home postpartum visits by a nurse to support new moms and their infants (City of New York, 2021; Massachusetts Department of Public Health, 2024). Expansion of coverage for postpartum services could also improve outcomes and experiences for people with IDD (Mitra, 2017). Future research is needed to evaluate existing programs and identify barriers to access for women with IDD, with consideration of those in more rural settings.

Despite the growing body of research showing disparities in pregnancy-related outcomes among women with IDD, policy and practice attention to improve perinatal care and support people with IDD still seem elusive. A study by Mitra and colleagues found that women with IDD had more than three times the risk of maternal mortality than women without IDD (Mitra et al., 2021). The disparities are even more staggering for Black women and Latinas with IDD (Akobirshoev et al., 2021). Thus, there is an urgent imperative to improve perinatal care, experiences, and outcomes for people with IDD. This study adds to an understudied area of research that examines care from the perspectives of women with IDD themselves, which are critical to development of policies, programs, services, and supports, especially given recent developments disproportionately threatening marginalized people’s reproductive rights (Powell, 2022).

Limitations

This study lacks racial and ethnic diversity as most participants identified as non-Hispanic, White. Because the screening process relied on self- and third-party-reports of disability and did not require a diagnosis, the researchers do not have a lot of specific information about each participant’s disability or co-existing diagnoses or disabilities, which might have yielded additional insight into findings or variations within our sample, or both. We recruited through community organizations and other agencies serving people with IDD. Women who are not connected to such resources may have been less likely to find out about the study and may have different experiences from women who participated. This study contains participants’ own perspectives on receiving perinatal care and, though consistent with other literature, have not been confirmed through observation or surveyed findings.

Additionally, parents with IDD were not included in the design or conceptualization of this study. Future work should consider including participatory action research methods to strengthen the applicability and inclusivity of research surrounding parents with IDD (Balcazar et al., 1998; Harrison et al., 2001). The use of Mitra et al.'s perinatal care framework in the design of the study and analysis could have influenced the findings, however this study nevertheless shows the importance of various factors in the framework and their influence in the context of perinatal care and pregnancy experiences. A standing limitation of qualitative interviews is that data may be subject to recall or social desirability bias.

Conclusion

This study centers the voices and experiences of women with IDD receiving perinatal care in the U.S. Findings demonstrate a need to improve perinatal care through clinician training, and to develop accessible programs and services to better support women with IDD during pregnancy and promote reproductive justice among people with disabilities.

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PREGNANCY EXPERIENCES OF WOMEN WITH IDD

Table 1*Participant Characteristics (n = 16)*

Characteristic	<i>n</i>
Race/ethnicity	
Non-Hispanic White	10
Other	4
Unspecified	2
Age	
20–24	5
25–29	4
30–34	6
Unspecified	1
Number of pregnancies	
1	4
2	2
3	3
>3	6
Unspecified	1
Marital status	
Married	4
Relationship	1
Single	3
Unknown	8

PREGNANCY EXPERIENCES OF WOMEN WITH IDD

Characteristic	<i>n</i>
Paternal involvement	
Yes	7
No	8
Unknown	1
Educational attainment	
No high school education	1
Some high school education	4
High school graduate or equivalent	7
Some college	2
College graduate	1
Unknown	1
Income level	
Below 50% FPL	2
50-100% FPL	7
100-150% FPL	
Above 150% FPL	1
Unknown	6
Receives benefits	
Y	14
N	1
Unknown	1

PREGNANCY EXPERIENCES OF WOMEN WITH IDD

Characteristic	<i>n</i>
Most recent pregnancy was planned	4
Most recent pregnancy deemed “high risk” by healthcare provider	2