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Attitudes, Assumptions, and Beliefs of Obstetric Care Clinicians Regarding Perinatal Care of Women With Intellectual and Developmental Disabilities

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Abstract

This study examines clinician attitudes, beliefs, and assumptions regarding perinatal care of women with intellectual and developmental disabilities (IDD) from the perspectives of both clinicians and women with IDD. We conducted semi-structured individual interviews with women ($n = 16$) and individual interviews and one focus group with clinicians ($n = 17$). Data were analyzed using a content analysis approach. Analysis revealed both supportive and restrictive categories. Supportive: (1) accommodating needs, (2) respecting autonomy, and (3) supporting motherhood. Restrictive: (1) unwillingness to accommodate, (2) assumptions about decision-making capacity, (3) questioning parenting abilities, and (4) biased contraception and sterilization practices. Clinician training to address attitudes, beliefs, and assumptions is needed to improve perinatal care for women with IDD.

Keywords: pregnancy, perinatal care, IDD, attitudes, disability

Introduction

The interconnected legacies of institutionalization, segregation, and eugenics have been well-documented and realized across oral histories and studies about the sexual health of people with intellectual disabilities (IDD) (Malacrida, 2006; Tilley et al., 2012). Past studies have shown ways that stigma and biased attitudes from healthcare providers reinforce stereotypes that people with IDD are incapable of consent and participation in their own care (Agaronnik et al., 2020; *Autonomy, Decision-Making Supports, and Guardianship*, 2016; Horner-Johnson & Bailey, 2013; Iezzoni & Mitra, 2017). Studies have also shown negative attitudes among healthcare providers, and formal and informal support providers, toward pregnant women with IDD about their pregnancy or desire to become a parent (Agaronnik et al., 2020; Höglund & Larsson, 2013; Llewellyn et al., 2008; Malouf et al., 2017; Mayes et al., 2014; Potvin et al., 2019).

Women with IDD face adverse experiences during their pregnancies, including perceived stigma, negative attitudes, and inadequate communication from providers, in addition to other psychosocial stressors (Barnett et al., 2016; Höglund & Larsson, 2013; Llewellyn et al., 2008; Malouf et al., 2017; Mayes et al., 2014; Potvin et al., 2019; Walsh-Gallagher et al., 2012). Furthermore, women with IDD are more likely to experience poverty and social exclusion (Khan et al., 2021; Parish et al., 2009) and are at increased risk for a number of adverse pregnancy-related outcomes, including preterm delivery, low birth weight babies, low Apgar scores, severe maternal morbidity, and maternal mortality (Brown et al., 2019; Mitra et al., 2021; Parish et al., 2015). The deleterious pregnancy-related health outcomes for women with IDD are clearly disparate compared to the general population and could stem from or be exacerbated by prejudicial attitudes from their support providers.

Disability justice and reproductive justice provide lenses to examine and understand disparities and experiences of people with disabilities. These lenses can also be used to dismantle barriers and develop approaches to address ableism within healthcare systems that may be impacting outcomes. The importance of improving sexual and reproductive healthcare for people with disabilities has been emphasized by the disability community (DiMatteo et al., 2022; Fletcher et al., 2023).

Existing studies indicate that women with IDD encounter prejudicial attitudes in various healthcare fields, yet there remains a significant gap in exploring clinician attitudes towards their perinatal health care. This study builds on previous work by specifically examining clinician attitudes in the context of perinatal care of women with IDD from dual perspectives of women with IDD and clinicians side-by-side. Understanding perspectives of both women with IDD and clinicians who provide care can yield valuable insight into barriers and disparities for people with disabilities seeking or receiving perinatal care. Specifically, this study aimed to examine clinician attitudes, beliefs, and assumptions regarding perinatal care of women with intellectual and developmental disabilities (IDD) from the perspectives of both women with IDD and clinicians. The hope is that this examination will foster more equitable perinatal experiences and outcomes for women with IDD while upholding their reproductive rights. This study used gendered language referring to “women” and therefore we use gendered language throughout this paper. However, we acknowledge the diversity of gender identities of people who give birth, including cisgender, transgender, queer, non-binary, and gender diverse individuals.

Methods

This investigation is part of a larger mixed-methods study examining pregnancy outcomes and experiences among women with IDD. The current qualitative study includes two groups of participants: women with IDD and obstetric care clinicians. We collected and coded data from the respective samples using separate processes and then analyzed across the two groups specifically for themes related to clinician attitudes, beliefs, and assumptions. The plan to analyze themes related to clinician attitudes, assumptions, and beliefs across the two datasets emerged after the two datasets were collected and analyzed separately, hence some differences in methodologies. This research was approved by the authors’ university’s Institutional Review Board and conforms to US Federal Policy for the Protection of Human Subjects.

Setting

Interviews with women with IDD were conducted between February 2016 and October 2017. The study was conducted in the United States with participants from anywhere in the country. In-person interviews with women with IDD were conducted within driving distance of the University conducting the study, or within driving distance of an interviewer located in North Carolina (the study's original two sites before remote methodology was added). In-person interviews were conducted in a location convenient to the participant, such as their home or a private room in a public space (e.g., library). Participants were given the option to have a support person present if they wanted; if the support person tried to respond to interview questions, the interviewer was instructed to ask the support person to please refrain and allow the woman with IDD to respond. Recruitment challenges led the investigators to expand the study to be nationwide, necessitating remote interviews over the phone. The in-person clinician focus group was conducted at the 2018 American College of Obstetricians and Gynecologists (ACOG) Annual Clinical & Scientific Meeting in Austin, Texas. Remote individual telephone interviews were conducted with clinicians across the country. The clinician interviews were conducted between June 2017 and June 2018. The study originally planned for remote interviews with clinicians across the country for participant convenience with scheduling. The in-person focus group method was added because of the opportunity to have clinicians together in one room at the ACOG conference, which enabled participants to build off of each other's ideas for richer discussion. Any potential participants who were not available at the time of the focus group were offered the chance to schedule a remote telephone interview instead.

Participants

Women With IDD

We conducted 16 semi-structured qualitative interviews with women with IDD. Eligibility criteria included women with self-identified or caregiver/support person-identified IDD, who gave birth to a child within the last 18 months, and who were able to provide verbal responses to interview questions.

Clinicians

We conducted individual phone interviews (*n* = 9) and one in-person focus group (*n* = 8) with obstetric care clinicians (i.e., obstetrician/gynecologist specialists, maternal fetal medicine subspecialists, perinatal nurses). Participants must have completed OB/GYN residency (OB/GYN participants), been currently practicing or practicing within one year in the US, and had self-reported experience providing perinatal care to women with IDD.

Data Collection

Qualitative moderator's guides were developed by study investigators based on their own findings from secondary data analysis, available literature, and Mitra's perinatal care framework (Mitra et al., 2015). The interview guide for women with IDD was pilot tested with two women with IDD and revised based on that pilot. A variety of recruitment strategies were employed. To recruit women with IDD, easy-to-read recruitment materials were distributed through various connections at organizations serving the disabled population, e.g., advocacy organizations, independent living centers, parenting programs. Interested women could contact study staff directly or a "consent-to-contact" process enabled organization staff members or a support person to get permission from the woman to contact study staff on her behalf. Study staff screened for eligibility over the phone. Participants gave informed consent or assent via a plain language informed consent document, which was read to them over the phone. Guardians provided subsequent informed consent, when applicable. Interviews were conducted either in person or over the phone by one of three study interviewers and audio-recorded and transcribed. Interviews lasted up to an hour. Interviewers were all trained qualitative researchers with prior experience conducting research with people with IDD. Interviewers had no relationships with participants prior to the study. Women were paid $50 to thank them for their time; there was concern that any higher amount may be considered coercive. Clinicians were recruited through connections with the disability community or a public profile indicating care for disabled women, and ACOG. Potential participants were invited to participate and screened for eligibility. Interviews and the focus group were facilitated by a practicing board-certified obstetrician-gynecologist who is an author on this paper. Interviews lasted about an hour and the focus group lasted 2 hours. Both were audio-recorded and transcribed. Participants received a $150 gift card as appreciation for their time; that amount was meant to compensate clinicians for time they may have lost from being able to see patients.

Analysis

Analysis of both samples used methods consistent with a content analysis approach (Hsieh & Shannon, 2005). Data from the two samples were coded separately but followed the same overall approach. Investigators first reviewed three transcripts and iteratively discussed and identified emergent themes. Some themes were derived from the data and some themes were identified beforehand. Utilizing an inductive coding model, identified themes were represented with codes and recorded in a codebook. The two samples were analyzed disparately at first; therefore, there were some minor differences in the coding process. A first round of coding was conducted by a single coder for interviews with women and by two coders for interviews with clinicians. All coding was reviewed by a second researcher for the interviews with women. For the interviews with clinicians, the two coders each reviewed the other's coding and discussed all areas of discrepancy to reach a consensus and then revised the codebook accordingly. The research team examined and compared coded data across both datasets for larger themes and relationships, specifically examining themes of clinician attitudes, assumptions, and beliefs. Final themes were determined through iterative review and discussion among the research team until consensus. Participants did not provide feedback on the findings. Analysis was managed using Dedoose web-based qualitative analysis application.

Positionality

All authors identify as women. Four of the authors identify as non-disabled; one identifies as disabled. The highest degree held by three of the five authors is doctoral level (one is a medical doctor), one author has a master's degree, and one has a bachelor's degree. Two identify as a person of color, and three identify as White.

Results

Participant Characteristics

Participating women with IDD were mostly non-Latinx, White with an average age of 26.8. A majority (*n* = 10) had had more than one pregnancy **(Table 1)**. Clinician participants were mostly non-Latinx, White, obstetrics/gynecology specialists with 14.5 mean years of experience (**Table 2**). A majority (*n* = 10) practiced in an academic hospital practice setting. Clinicians reported a range in the amount of experience they had working with women with IDD; five reported seeing 1–5 patients with IDD per month. Several reported a handful of patients over their entire experience practicing; one clinician recalled two particular patients with IDD. Several others worked in specialty clinics or clinics for Medicaid or uninsured individuals and therefore had a higher proportion of patients with IDD. One reported about 30 patients per month with IDD.

Findings from interviews with women with IDD and clinicians uncovered both supportive and restrictive attitudes, assumptions, and beliefs (**Table 3**). Supportive attitudes, assumptions, and beliefs included (1) accommodating women's needs, (2) respecting women's autonomy, and (3) supporting motherhood. Restrictive attitudes, assumptions, and beliefs included (1) unwillingness to accommodate women's needs, (2) assumptions about women's decision-making capacity, (3) questioning parenting abilities, and (4) biased contraception and sterilization practices. These findings are described below using example participant quotes. Additional example quotations can be found in **Table 4** and **Table 5**. Participant ID numbers are included with quotes.

Supportive Attitudes, Assumptions, and Beliefs

Accommodating Women's Needs

Several women emphasized the importance of accommodating the needs of women with IDD, highlighting the need for clinicians to take extra time to ensure patients fully understood pregnancy care. For example, one woman with IDD stated, "They seem very understanding and if I don't understand something, they explain it to me." (ID51) Likewise, another woman expressed appreciation for her clinician who took time to explain concepts in detail.

Many clinicians also described how they accommodated women with IDD, including taking additional time for explanations. One clinician, for example, discussed the importance of ensuring that their patients with IDD are fully aware of what will happen during labor and delivery:

> I think that I have always felt a responsibility to be almost like a translator, to make sure and gauge, "Is this person understanding? Have I got that person to … calm down enough to be okay in this moment, and to understand what's happening to them?" … what's happening to you right now is okay, and it's a normal part of this, and I know it doesn't feel good … medical folks, I believe, are so used to the jargon, and are so used to what they're saying to one another. (ID2)

Other clinicians said that they used accessible language when working with women with IDD, for example, by "avoid[ing] big medical words or anything and just keep[ing] it very simple." (ID7) Further, clinicians noted the importance of taking the necessary time to answer questions and reinforce conversations about pregnancy and labor. One participant said, "I spend time [asking], 'Do you understand what I'm saying? Does this make sense to you? Feed back to me what I'm explaining to you.' It takes a lot of time." (ID9)

Several clinicians explained that they accommodated the needs of women with IDD by allowing for longer appointments. One clinician mentioned, "We make some accommodations for the length of time we see them." (ID6) Likewise, a clinician commented that clinicians working with women with IDD should "know that you may need more time for this particular appointment. You may have to spend more time coordinating things with their caregivers and other family." (ID5) Notably, one clinician explained that while they can provide longer appointments for women with IDD, other clinicians might not have the same opportunities, thus scheduling short sessions with these women, which may not be adequate.

Respecting Women's Autonomy

One woman emphasized the importance of her providers honoring her autonomy. She said, "It should always be patient's choice unless the doctor really feels that they need a certain medication while they're giving birth." (ID52) Several women described experiences where they felt their autonomy was respected by their providers. One reported, "[My providers] were like, 'Okay we'll bring you for a c-section.' [I said] Just please give me …' She was like, 'I'll give you three more pushes.' I was like, 'Give me six more.' She was like, 'Okay.' … I got [my baby] out." (Camille) Women with IDD more often reported instances where their autonomy was not respected, mostly in the context of decision-making.

Interviews with clinicians also showed the importance of respecting the autonomy of women with IDD throughout their pregnancies. For example, one clinician remarked, "Be someone who teaches women [with IDD] about their options, about their bodies, about what is going on, and what is to come." (ID5) The same clinician stated that it is important to "know that these women do still have the right of choice. They may or may not want to continue the pregnancy. But if they do, then they still deserve to have great and normal prenatal care." (ID5)

Relatedly, some clinicians faced challenges when women's caregivers attempted to make decisions on their behalf, underscoring the need to recognize the women's autonomy, for example, when a caregiver advocated for a tubal ligation contrary to the women's desires. In these instances, some participants took on the role of advocating for their patient. Moreover, they noted the importance of recognizing their own biases to support their patient's autonomy. For example, a clinician noted that clinicians' assumptions of what is best for these patients may be at odds with the patients' own desires and needs.

Supporting Motherhood

Both women with IDD and clinicians offered examples of how clinicians can support women with IDD in their roles as mothers. For the women, supporting motherhood often meant clinicians not automatically referring them to the child welfare system. One woman expressed her appreciation for her clinician ensuring that other clinicians understood her capability to care for her child, preventing unnecessary referrals to child welfare system: "She made sure that when I left, I would not be thrown into a situation where [child welfare] would come and attack me because I didn't have anybody on my side." (ID 53) Likewise, another woman shared that she felt surprised and happy when she was not referred to child welfare. Even in instances where the hospital reported them to the child welfare system, some women expressed appreciation that they were allowed to interact with their newborns.

A few clinicians also recognized the importance of supporting women with IDD in their roles as mothers. For example, when asked whether they ever refer their patients to the child welfare system, a clinician stated, “I never make that determination as an obstetrician.” (ID9) That clinician further noted,

> I don’t think anyone has a right to tell someone—and even someone with a physical illness. Like people want to be parents, they want that experience. The hard part is do we think they understand what it means. But who am I to say what someone understands or should understand … (ID9)

Restrictive Attitudes, Assumptions, and Beliefs

Unwillingness to Accommodate Women’s Needs

The interviews with women revealed instances where some clinicians were unwilling to accommodate the needs of women with IDD. Several women felt that their disability-related needs were ignored which impacted the care that they and their children received. For example, one woman said that her clinicians did not provide her with needed information in an accessible manner throughout her pregnancy: “I am a talkative person and they do not really answer questions how I want to. I like things explained to me.” (ID54) Another woman explained that clinicians did not inform her that her newborn was experiencing medical complications: “No, they just kept telling me everything’s okay, don’t worry about it.” (ID55) In this instance, the woman’s family members were informed of the issues while she was not.

In another instance, one woman’s fear of needles was seen as “uncooperative,” leading to a report to the child welfare system. Another woman experienced frustration from clinicians due to her disability preventing her from assuming a specific position during labor and delivery.

Interestingly, some clinicians also described examples of other clinicians who were unwilling to meet the needs of women with IDD:

> I had an experience with an anesthesia team member who … was getting really annoyed and irritated, thinking that my patient … with intellectual disability was being, kind of, intentionally difficult … This particular anesthesiologist was, like, whispering under his breath, “I don’t have time for this,” swearing, and all those kind of stuff … (ID2)

Other clinicians similarly reported instances where certain clinicians were unwilling to provide care to women with IDD, based on presumptions about the women’s disability-related needs. For example, a clinician remarked, “A lot of general OB/GYNs are not comfortable following patients other than, basically, normal pregnant patients.” (ID4)

Assumptions About Women’s Decision-Making Capacity

While some women with IDD shared instances of clinicians respecting the autonomy of women with IDD, most interviews with women revealed clinicians making assumptions about their decision-making capacity. These assumptions were degrading and harmful to their care. For example, one woman said,

> [My providers] were whispering and stuff. I kind of felt like, you know, they kind of talked to [my partner and me] like we weren't intelligent. We're both very intelligent people. I have my learning disabilities and things here, but I comprehend very well things [*sic*]. (ID53)

One woman felt that her health “choices” were limited due to such presumptions. Another woman expressed frustration as her preferences concerning a home birthing plan were not taken into consideration. She feared child welfare involvement if she delivered in the hospital, which unfortunately occurred. Another woman reported being induced without her consent.

Some women with IDD mentioned being denied the opportunity to make choices about their newborns’ care due to clinician assumptions. For example, one woman shared that her clinician “hid” her newborn’s medical complications from her. Likewise, another stated that clinicians disregarded her and her partner’s specific wishes concerning medical treatment for their newborn because of their disabilities.

Clinicians' interviews revealed assumptions about the decision-making capacity of women with IDD. Some questioned whether the women understood pregnancy and perinatal care. For example, one clinician remarked, "They don't have the cognitive ability to understand what we're discussing." (FG7) Another clinician shared that "it's difficult to communicate with them because it's going to be different than a normal patient." (ID7) Others pondered whether their patients with IDD understood certain aspects of perinatal care, such as pelvic examinations and blood tests, in addition to their ability to comprehend basic care information that is not commonly addressed in perinatal care:

> [The obstetric care clinician takes on] a very parental and paternalistic role, I guess you'd say, when [they] start talking about selfcare and sleep hygiene and things that [one] normally [does not] have to go into tremendous detail about [with a patient who is] engaged in society and working. (ID8)

Many clinicians described instances where they questioned the capacity of women with IDD to consent to medical procedures. For example, one clinician explained that they often make decisions on behalf of their patients with IDD: "If I truly feel and it really seems like they would not be able to handle that at the level that they're functioning, I think that's our job." (FG1) Other clinicians shared instances when medical procedures such as cesarean deliveries, sterilizations, and cervical cytology screening (i.e., Pap smears) were performed (not necessarily by themselves) on women with IDD seemingly without the woman's consent.

Indeed, several clinicians discussed the role of others, including family members, spouses, and guardians, in making decisions on behalf of women with IDD. One explained that guardians sometimes decide whether to terminate a pregnancy or not. Another clinician said that when women with IDD are married, women "generally deferred to their husband." (FG4) Likewise, a clinician reflected on a woman with IDD they treated and the role of the husband in decision-making:

> [The patient with IDD] was very high risk, and seizures, things like that. And [her husband] wanted nothing to do with our recommendations, so in that situation, he's not

> the best person to be making her decisions, yet he is her husband and the person who probably can legally. You have to know who the person is that you should deal with in addition to the patient. (FG1)

Another clinician explained that in the absence of a strong social support system, the state often served as the decision-maker for women with IDD, sometimes to their detriment.

Many clinicians noted that they often involve other professionals, such as psychiatrists and social workers to assist in determining women's decision-making capacity. One clinician shared that even when involving psychologists, social workers, and caregivers in the care process, some patients are still unable to comprehend what is going on due to specifics of their disability. Another clinician noted, "If you have any questions about whether or not someone is intellectually disabled there should be an automatic psych involvement so that you're kind of protected." (ID3) The notion of wanting to legally protect oneself was echoed by several clinician participants.

Some clinicians' assumptions about the decision-making capacity of women with IDD informed their perceptions of these women as "non-compliant" or "difficult." For example, one clinician stated, "We have to have that team approach, because they are very difficult patients to treat." (FG6) Another noted the importance of being very patient when caring for women with IDD.

Questioning Parenting Abilities

Both women with IDD and clinicians noted how clinicians questioned the parenting abilities of women with IDD and referred them to child welfare services.

Many women constantly worried that their clinicians might report them to the child welfare system, and often their fears were realized. Strikingly, some women with IDD avoided perinatal care because of these concerns. For instance, one woman shared, "I didn't choose to go to the doctors until the day I gave birth because some doctors automatically assume to call [child welfare], and I didn't really want them involved in every step of the way." (ID56) Another woman commented that her clinician reported her to the child welfare system hours before giving birth. Other women were referred to the child welfare system because they were seen as "uncooperative."

Several clinicians expressed beliefs that women with IDD could not care for their children. For example, one clinician stated,

> They're not preoccupied about how they're going to provide for baby or how they're going to be able to financially support baby and in what type of social environment … Stuff like not having diapers there or not anticipating what the baby is going to be needing to eat. (ID7)

Another clinician shared other concerns, such as, "Where will the child reside? Will the child be in foster care? Will there be somebody else within the family to adopt the child or care for the child?" (ID8) Another clinician noted, "I think that's sometimes very difficult in those patients that are right at the border, that are maybe functioning at home alone. But possibly not able to take care of a baby." (FG2) Likewise, one provider noted that although women with IDD may desire to care for their baby, they might not be able to detect if an issue arises with the infant.

In response to assumptions about the parenting capabilities of women with IDD, many clinicians routinely referred them to social workers or the child welfare system. One clinician, for example, said, "I also want to make sure that they're evaluated from the point of view of the decision of whether they can take care of a baby, because you don't want to be the one to never figure that out." (FG7) Moreover, some clinicians explained that they refer their patients to social workers because they believe social workers can assist these families.

Biased Contraception and Sterilization Practices

This theme was not discussed by women with IDD. Some clinicians reported that they "try to start the contraception issues while someone is still pregnant so we have a plan for [labor and delivery] and immediate postpartum," but also acknowledged that, "like any population, talking about contraception is important." (ID1) That same participant stressed the importance of "being careful not to push it too hard. You know, we always do push our own values on who should have [certain methods of contraception]." (ID1)

Some interviews revealed possibly biased contraception and sterilization practices against women with IDD. For example, one clinician explained how they perceive that obstetric care clinicians often encourage women with IDD to use a long-acting reversible contraception (LARC) method after delivery:

> I think in LARC in particular there's so much push towards that in general which is great but it's not the right thing for everyone and people sort of default to that being the only right option in a patient with an intellectual disability. (ID1)

Others acknowledged the need for clinicians to make care decisions about the needs of women with IDD, including contraception use, particularly in situations when the women are "very low functioning" and may not be able to manage their pregnancy, delivery, and then taking care of the baby alone.

Discussion

This study offers important insights into obstetric clinicians' attitudes, assumptions, and beliefs when providing perinatal care to women with IDD by juxtaposing clinician perspectives with those of women with IDD. Considering the historical context of reproductive rights for people with IDD (Tilley et al., 2012), it is crucial to examine obstetric clinician attitudes through a reproductive justice lens (Alvares et al., 2011; DiMatteo et al., 2022; Fletcher et al., 2023), particularly as related to decision-making. Understanding the experiences of people with IDD, and the challenges that clinicians face in providing perinatal care, is of increasing importance in the current state of reproductive rights in the US (Powell, 2022).

Perinatal Care Decision-Making

This study's findings have some important implications related to decision-making in perinatal care. This study suggests that women with IDD may not always be included in decision-making during their care as seen in both sets of interviews. Findings show many instances where clinicians made assumptions about women's decision-making capacity. Some clinicians felt uncertain about the best way to provide care for women with IDD, particularly when caregivers opposed the woman's expressed wishes. Some clinician participants felt responsible for making decisions on behalf of their patient and followed caregivers' decisions on the woman's behalf without a clear understanding of the woman's legal guardianship status. This finding is consistent with other studies (Earle et al., 2012; Ledger et al., 2016; Powell et al., 2020) and is concerning, considering the disparities in contraceptive access for women with IDD and their increased likelihood of hysterectomy and other forms of sterilization at a younger age (Li et al., 2018; Wu et al., 2018). In this study, it was somewhat striking the way many of the participants discussed women with IDD's inability to make decisions for themselves while seemingly not acknowledging the broad range of abilities that encompasses IDD (Keywood & Flynn, 2003). Many people with IDD are capable of making decisions for themselves and even in cases of guardianship, the woman with IDD should still be centered and included in decision-making (*Autonomy, Decision-Making Supports, and Guardianship*, 2016; Horner-Johnson et al., 2022). Clinician training should address decision-making with people with IDD during pregnancy. In contrast, some women and clinicians both discussed instances where clinicians provided advocacy with child welfare services and caregivers (e.g., when a caregiver wants a tubal ligation and the woman with IDD does not), which is a somewhat novel finding.

Patient—Provider Communication

Women with IDD emphasized that they wanted their clinicians to take time to listen to them and slow down to explain things to them, but often did not feel like that was happening. Women in our study often felt that they did not understand their options, and the information provided was inaccessible. They valued clinicians who took time to explain things in ways women could understand and allowed for time to answer their questions.

Women discussed often feeling "judged" during their pregnancy. Although clinicians may be well-intentioned feeling concern for the infant, they sometimes express negative attitudes and make assumptions about parenting abilities of women with IDD. Some examples of such judgements can be seen in responses from clinician participants. However, some women in our study appreciated clinicians who did not judge them. To combat negative attitudes towards people with IDD, as found in this study and previous studies, (Agaronnik et al., 2020; Barnett et al., 2016; Greenwood et al., 2014; Höglund & Larsson, 2013; Khan et al., 2021; Llewellyn et al., 2008; Malouf et al., 2017; Mayes et al., 2014; Potvin et al., 2019; Walsh-Gallagher et al., 2012) clinician training is a crucial first step.

Need for Clinician Training and Accessible Resources for Patients

Disability health advocates and scholars have long pressed for including disability content and exposure to disabled people in medical training (Iezzoni & Long-Bellil, 2012; Shakespeare et al., 2009; Smeltzer et al., 2018). Clinicians have reported feeling ill-prepared and lacking confidence in caring for people with disabilities during pregnancy, including people with IDD (Agaronnik et al., 2020; Amir et al., 2022; Smith et al., 2023; Taouk et al., 2018). Some refuse to care for women with IDD and instead refer these patients to colleagues with experience caring for disabled people. Clinicians seek training, resources, and guidance (Amir et al., 2022; Smith et al., 2023); for example, including disability status, accommodations, and guardianship status in electronic medical records could assist clinicians in managing patients with IDD by reducing guesswork and assumptions (NHS Digital, 2020).

Women with IDD also have limited access to sexual and reproductive health education, which may contribute to their lack of knowledge about contraceptive options (Greenwood et al., 2014; Höglund & Larsson, 2013; Walsh-Gallagher et al., 2012, 2013). To address this, developing accessible pregnancy and sexual and reproductive health educational materials such as plain language resources is essential for empowering women with IDD to better participate in their own care. Accessible informational resources about pregnancy may also help in addressing some of the communication-related barriers reported by both women and clinicians by allowing woman to revisit information outside of visits.

Reimbursement for More Frequent or Longer Visits

Findings from this study indicate that perinatal care for women with IDD takes a longer amount of time for clinicians to provide optimal care. Explaining medical information in an accessible way, repeating information multiple times, and listening and answering questions all require clinicians to spend more than the typical allotted visit time. However, time pressures make it difficult for many clinicians to provide the extra time (Smith et al., 2023). To make perinatal care more inclusive for women with IDD, Medicaid policy changes could play an important role. Allowing clinicians to be reimbursed for additional time or visits would be an important step (Mitra, 2017; Ranji et al., 2020).

Limitations

Firstly, our study focused on clinicians with self-reported experience caring for pregnant people with IDD; therefore, less experienced clinicians might have additional or more pronounced attitudes, assumptions, and beliefs than identified here. Differences in data collection and analysis methodologies used both between and within each dataset may be a limitation of this study (e.g., in-person participants may have felt more rapport and spoken more freely), although it is likely outweighed by the benefit of examining perspectives of women with IDD and clinicians side-by-side. Additionally, both the clinicians and women with IDD were mostly White, potentially limiting the representation of experiences from individuals with diverse intersecting identities. As with any qualitative research, recall and social desirability biases are a possibility, particularly among clinicians who might have moderated their negative attitudes. In the responses from women with IDD, we could not verify clinical information and it was sometimes unclear what type of provider or other support person they referred to.

Conclusions

This study underscores the importance of providing clinician training and guidance for delivering appropriate perinatal care to people with IDD, for instance how to address communication barriers with women with IDD. Such training should be rooted in reproductive and disability justice perspectives, considering the historical context of eugenics and its impact on people with IDD (DiMatteo et al., 2022; Fletcher et al., 2023); accordingly, people with disabilities should be involved in design and development of training. Policy guidance for clinicians is needed to address decision-making, guardianship, and how to navigate discordance between women’s wishes and caregivers’ preferences. Notably, women with IDD highly valued clinicians who took the time to listen and explain things in an accessible manner and without judgement. Clinicians expressed a strong commitment to providing high-quality perinatal care, offering accommodations, and advocating for their patients. This study emphasizes the necessity of preparing all clinicians to deliver perinatal care to people with IDD.

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Table 1

Participant Characteristics of Women With IDD, n=16

Characteristic	*n*	%
Number of pregnancies		
1	5	31
2	3	19
3	3	19
>3	4	25
Unknown	1	6
Most recent pregnancy was planned	2	13

Most recent pregnancy deemed “high risk” by health care provider	7	44
Age (mean = 26.8; range = 20–34)		
20–24	5	31
25–29	4	25
30–34	6	38
Unknown	1	6
Race/ethnicity		
Non-Hispanic White	10	63
Non-Hispanic Black	3	19
Native American	1	6
Other	2	12

Table 2

Participant Characteristics of Obstetric Clinicians, n=17

Characteristic	*n*	%
Type of participation		
Individual phone interview	9	53
In-person focus group	8	47
Age (mean = 50.1; range = 31–87)		
31–40	4	24
41–50	6	35
51–60	4	24
60+	3	18
Race/ethnicity		
Non-Latinx, White	13	76

Latinx	1	6
Other	3	18
Years of post-residency experience (mean = 14.5; range = <1 yr–30+)		
5 years or less	4	24
6-10	3	18
11-15	1	6
16-20	4	24
21-25	0	-
26+	4	24
Unknown	1	6
Specialty		
Obstetrics/gynecology	13	76
Maternal-fetal medicine (sub-specialty)	3	18
Perinatal nurse	1	6
Practice setting		
Academic medical center	8	47
Community hospital or clinic	3	18
Private practice	6	35

Table 3

Themes, Codes, and Definitions

Theme	Definition	Code	Definition
Supportive attitudes,	Attitudes, assumptions, and beliefs regarding how	Accommodating women’s needs	Clinicians accommodating the needs of women with IDD during pregnancy

assumptions, and beliefs	clinicians support women with IDD during pregnancy		
		Respecting women’s autonomy	Clinicians’ support for women with IDD making decisions about their care
		Supporting motherhood	Clinicians’ support of women with IDD as mothers
Restrictive attitudes, assumptions, and beliefs	Negative attitudes, assumptions, and beliefs by clinicians about women with IDD during pregnancy	Unwillingness to accommodate women’s needs	Clinicians’ unwillingness to accommodate the needs of women with IDD
		Assumptions about women’s decision-making capacity	Clinicians’ assumptions that women with IDD cannot make decisions about their care
		Questioning parenting abilities	Clinicians’ beliefs that women with IDD cannot care for children
		Biased contraception and sterilization practices	Clinicians’ practices concerning contraception and sterilization of women with IDD

Table 4

Example Quotations of Supportive Attitudes, Assumptions, and Beliefs

Subtheme	Example quotation	
	Women with IDD	Clinicians
Accommodating women's needs	"He seemed positive about it, and he explained things to me in more detail. Explained like why he was doing the different things he was doing and stuff. I found that helpful. (Jenna)"	"Sometimes it is difficult to make sure that I am being understood. I always try—to any of my patients with intellectual disabilities or not—try to speak patient language and not doctor language. (ID5)"
	"She 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 … I take pictures of what I eat, and it tells me how far I am weekly. She did a lot for me. (Shea)"	"I think when you take the extra time to speak with the patient and kind of explain what may happen or what could happen, then that makes a huge difference. Again, these women will oftentimes have the same questions as women who do not have the disability mentally. 'How do I know what a contraction is?' 'How do I know if my water really is broken?' 'What does labor feel like?' It is the same conversation basically just reiterated a couple of times over. (ID5)"
Respecting women's autonomy	"[My provider] asked me permission [to speak with my family about my disability-related needs]... And we all talked together.	"[The caregiver] may want a C-section 'cause [the caregiver] want[s] you to tie their tubes. But the patient doesn't want their tubes tied, so it really puts us at a disadvantage. And so, you're trying to advocate for the patient, but the caregiver may have a different notion. (FG3)"

Subtheme	Example quotation	
	Women with IDD	Clinicians
	She was very good about it. (Camille)”	
Supporting motherhood	“I was surprised at how accepting my doctors and nurses were at first. Because for some people I know, they’ve had to deal with [child welfare] because the doctors would say they’re not capable being parents. And I was afraid of that happening to me and it ended up not happening at all. So, I’m really happy that that didn’t happen. (Jenna)”	“[Clinicians should be] very conscious of the fact that I think that a lot of us have kind of eugenic tendencies. And so, thinking that somebody wanted to be a mother, whether or not she be a mother, right? And that’s not really my place to say that. (ID9)”

Table 5

Example Quotations of Restrictive Attitudes, Assumptions, and Beliefs

Subtheme	Example quotation	
	Women with IDD	Clinicians
Unwillingness to accommodate	“They disrespected me, and they didn’t listen to me about like when I	“And I’ll be honest, I … think perinatologists are … comfortable taking care of fetuses that might have

Subtheme	Example quotation	
	Women with IDD	Clinicians
women's needs	was pregnant, I told them like I didn't feel any movements, they just said it was fine. (Kyra)"	impairments, but I don't think they're as used to patients that have impairment. (ID9)"
Assumptions about women's decision-making capacity	"My preferences, obviously didn't matter because if I had had it my way, she would have been born at home. (Reid)"	"I mean, there are cases where people are so significantly delayed that they kind of don't get it. (ID4)"
Questioning parenting abilities	"…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 [my daughter's] health and her safety first. (Reid)"	"I think one of the most difficult issues I find is a legal issue sometimes with who is the decision maker, who is going to take care of the baby afterwards, because the patient might really want to take care of that baby. But it's a question if she's able to or not, because I mean, I have unfortunately seen a bad outcome with a patient that was given care. And they might not recognize if something with the baby is wrong. (FG2)"
Biased contraception and	Not discussed by women with IDD	"Whether it be pregnancy, contraception, general care, surgery, whatever it is, so I think I really have to divide them up in that way, because I think when they are very

Subtheme	Example quotation	
	Women with IDD	Clinicians
sterilization practices		low functioning, I do think that we should be making the decisions about contraception for their own benefit, I think. Because I don’t think they would be able to either handle going through a pregnancy, or the delivery, and then what's going to happen to the baby if they have no family, etc. (FG1)”