

# Intellectual and Developmental Disabilities

## Formal and informal supports for women with intellectual and developmental disabilities during pregnancy

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### **Formal and Informal Supports for Women with Intellectual and Developmental Disabilities during Pregnancy**

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### Abstract

This paper explores the role of formal and informal supports for women with intellectual and developmental disabilities (IDD) throughout their pregnancy, childbirth, and postpartum experiences. Data from qualitative interviews with women with IDD (n=16) were analyzed. Results showed that formal supports aided in planning, transportation, advocacy, and providing emotional support throughout pregnancy. Informal supports helped with errands, comfort, and emotional encouragement. The community surrounding these women facilitated communication with providers, self-empowerment regarding health choices, and increased preparedness for parenthood. Findings indicate the importance of encouraging and sustaining both formal and informal supports during pregnancy, childbirth, and postpartum to improve pregnancy and parenting experiences for women with IDD.

### **Introduction**

Recent research indicates parents with disabilities experience significantly poorer health and more chronic conditions compared to parents without disabilities (Li, Parish, Mitra, & Nicholson, 2017). Additionally, individuals with intellectual disabilities are more likely to be socially isolated and at risk of poor psychological well-being (Darbyshire & Stenfert Kroese, 2012). Individuals with intellectual and developmental disabilities (IDD) face health care inequities in areas of access, knowledge, communication, and quality (Ward, Nichols, & Freedman, 2010). Women with IDD often report feeling the healthcare and social welfare systems do not meet their needs (Magaña, Parish, & Cassiman, 2008). In a review of social workers' perceptions of parents with IDD, Lewis, Stenfert Kroese, and O'Brien (2015) highlighted a lack of support services for these parents, leading to communication obstacles between providers and parents and failures to comprehend resource availability and use.

Research has increasingly found women with IDD are vulnerable to numerous pregnancy-related disparities. They experience higher rates of antenatal and postpartum hospitalization, greater risks for pregnancy complications, increased odds for a range of adverse pregnancy outcomes (Clements, Mitra, & Zhang, 2018; Mitra, 2017; Mitra, Akobirshoev, Valentine, Clements, & Moore-Simas, 2019; Mitra, Akobirshoev, Rosenthal, & Moore-Simas, 2018; Mitra, Akobirshoev, Clements, Parish, & Zhang, 2018; Mitra, Parish, Clements, Cui, Diop, 2015; Parish, Mitra, Son, Bonardi, Swoboda, & Igdalsky, 2015), and face greater psychiatric challenges than the general population (Brown, Lunskey, Wilton, Cobigo, & Vigod, 2016). Thus, pregnant women with IDD are typically considered 'high-risk' for poor maternal and child outcomes (Potvin, Brown, & Cobigo, 2016). Identifying strategies to better support women with IDD during pregnancy is an important step in addressing these disparities.

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The positive effects of support on overall health and well-being are well documented. Social support is related to lower rates of morbidity and mortality (Uchino, 2006), increased coping competence and life satisfaction (Siedlecki, Salthouse, Oishi, & Jeswani, 2014), increased feelings of self-efficacy and happiness (Feeney & Collins, 2014), and increased positive psychological capital (Li et al., 2014).

It is particularly beneficial to maximize the positive effects of support during pregnancy, childbirth, and the postpartum period because prenatal stress can affect both children's birth outcomes and maternal mental health (Van den Bergh et al., 2017; Glover, 2014). Several studies have documented the beneficial impacts of both formal and informal supports specifically for women during pregnancy and parenting. For example, staff support during childbirth had a greater influence on women's psychological well-being than actual birth events (Ford & Ayers, 2009). In one study of women in their second trimesters, those who reported low levels of support showed greater stress and depressive symptoms than those with more support (Glazier, Elgar, Goel, & Holzapfel; 2004). Other studies have similarly found women with an increased number of supportive people around them have greater protection against postpartum depression (Morikawa et al., 2015; Leahy-Warren, McCarthy, & Corcoran, 2011). Social work interventions during childbirth have been noted to reduce stress in pregnant women, generally (Sable & Wilkinson, 1999). Pregnant women who utilize support services often report feeling an increased sense of preparedness, as well as motivation to accept further support such as home visiting program referrals (Price, Coles, & Wingold, 2017). Further, women report increased satisfaction with their childbirth experiences when a companion of their choice accompanies them to appointments and the childbirth itself (Bruggemann, Parpinelli, Osis, Cecatti, & Carvalhinho Neto, 2007).

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A few studies have investigated the role of formal and informal supports in well-being and health outcomes of women with IDD. A recent study found that parents with IDD especially value the support they receive and that early support has the potential to reduce stress for parents, boost their self-confidence, and enhance their parenting success (Ward & Tarleton, 2007). Another study found evidence of a positive relationship between satisfaction with social support and positive maternal reactions among parents with intellectual disability (Darbyshire & Stenfert Kroese, 2012). Furthermore, women with IDD reported the most effective and beneficial kinds of social support during pregnancy were those that were accessible and respectful of their autonomy (Potvin et al., 2016). In addition, social workers can enhance service coordination and support referrals by increasing service providers' awareness of health disparities affecting vulnerable populations including women with IDD (Gage, 2012). Women with disabilities are more likely to report stressful life events during pregnancy (Mitra et al., 2015) and can especially benefit from social work services. Unfortunately, research on the impact of formal supports for women with IDD during pregnancy and postpartum is sparse.

Given the myriad vulnerabilities experienced by women with IDD and the documented benefits of support both overall and around pregnancy, women with IDD are potentially uniquely positioned to benefit from additional support during pregnancy and postpartum. Social work engagement in high-risk reproductive issues is limited (Blyth, 2008). Recent research has determined support systems that advocate on behalf of people with IDD do so by educating and empowering people with IDD to become better informed health care consumers (Ward et al., 2010). Though there is noted enthusiasm by professionals to develop strategies for overcoming access barriers and increasing support for parents with IDD (Ward & Tarleton, 2007), there is a paucity of research on what types of supports parents with IDD find beneficial during pregnancy.

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This paper begins to address that gap in the research by exploring the role of formal (e.g., social workers and professional programs) and informal (e.g., friends, family, neighbors, partners) supports for women with intellectual and developmental disabilities (IDD) throughout pregnancy, childbirth, and postpartum experiences.

### **Methods**

#### **Study Design**

As part of a larger, mixed-methods investigation of pregnancy outcomes of women with IDD, we conducted semi-structured qualitative interviews with 16 women with IDD who had recently given birth. The research protocol was approved by the authors' institutional review board.

#### **Instrument Development**

The recruitment flyer, informed consent, and interview guide, were developed by the research team, all of whom have extensive experience conducting research with people with IDD. Materials were designed for people with limited or no literacy. Specifically, materials were designed with plain language, simple sentence structure, and illustrations to support comprehension. The recruitment flyer was accompanied by a web link to an online audio/video presentation about the study. Additionally, the consent process included study staff reading the informed consent to the participant. The interview and informed consent processes were pilot tested with a woman with IDD.

The interview guide was modeled on one used for a prior study of pregnancy experiences of women with physical disabilities (Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith, 2016). To adapt the interview guide for women with IDD, we incorporated key concepts in the published literature on pregnancy and women with IDD. A panel of three qualitative researchers with



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expertise working with women with IDD reviewed the draft guide. The panel's suggestions were incorporated into a second draft. Following the procedures recommended by Bowen (2008), we cognitively tested the second draft with one woman with IDD. In this "think-aloud" procedure, the aim is to determine how the respondent understands and answers the questions (Bowen, 2008). This procedure yielded a final version of the interview guide. The final semi-structured interview guide included a total of 28 questions, plus additional probes. The guide started by asking some background about the participant, such as how many children she has and with whom she is currently living. The rest of the interview guide focused on the woman's most recent pregnancy. Questions asked about conception, prenatal care and experiences with providers, labor and delivery, recommendations for other women with IDD who are or want to be pregnant, and recommendations for providers.

### **Recruitment**

Using convenience sampling, we recruited women who either self-identified as having an intellectual or developmental disability (intellectual disability, cognitive impairment, a learning disability, or being 'slow') or were identified as such by a caregiver or support person. To participate women must have been at least 18 years old, had given birth within the last 18 months, and been able to respond to interview questions in English or Spanish. Recruitment involved study staff distributing informational flyers through healthcare facilities, disability and other community-based organizations across the United States, and via social media. Women could either contact study staff directly, or could give "consent to contact" to a caregiver or support person to contact study staff on her behalf to facilitate scheduling and screening for eligibility.

### **Ethics**

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The researchers followed established recommendations for recruiting and obtaining consent from people with IDD (Swaine, Parish, Luken, & Atkins, 2011; Swaine, Parish, Luken, Son, & Dickens, 2014). A research team member contacted women who expressed interest in the study to determine their eligibility to participate and asked whether the woman had a legal guardian. Sometimes guardianship information was confirmed by a staff person or support person who knew the woman. If the woman was deemed eligible to participate, the study staff member read through the informed consent with participants, solicited and answered questions, and obtained verbal consent or assent to participate. If the woman had a guardian, then the guardian was subsequently contacted to provide consent. The informed consent used easy-to-understand language, simple sentence structure, and illustrations to support comprehension. The researchers then scheduled an in-person or telephone interview (depending on distance from the university where this study was conducted). Immediately prior to the interview, the interviewer read the informed consent to the woman for the second time and again gave the opportunity to ask any questions and withdraw their consent. This approach is consistent with prior research as a conservative approach to ensure voluntary consent (Swaine et al., 2011). If any participant was determined by the interviewer to not understand confidentiality or informed consent based on the assessment questions or any other indications, that person was not interviewed, even if they provided consent/assent. The study also had a reporting protocol for potential abuse disclosures during the interviews (Sammet Moring, Parish, Mitra, & Alterio, 2019).

### **Procedure**

Research team members conducted one-hour semi-structured interviews either in-person or over the phone using an interview guide. All interviewers had experience conducting research with people with IDD. They were trained to closely monitor participants for any signs of fatigue

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or discomfort and to periodically offer breaks. Interviewers were trained to follow the interview guide, which included probes to help guide participants as needed. Interviewers also were trained to re-phrase questions if participants were having trouble understanding questions. All interviews were conducted in a private setting, such as a private room at a library, or the participant's home. The participant was allowed to have a support person present for the interview if they desired. For interviews conducted over the phone, participants were asked to confirm that they were in a private setting, and if there was another person with them, the interviewer confirmed that the woman desired for that person to be present during the interview. All interviews were conducted in English, though a Spanish option was available. Interviews were audio-recorded and then transcribed by a professional transcription service.

### **Data Analysis**

Following a thematic analysis approach (Braun & Clarke 2012), study staff read the transcripts, and independently generated overall themes and met to discuss detail. Based on existing literature as well as concepts newly emerging from the data, the research team established larger categories and relationships between them. A codebook was developed with uniform definitions and agreement across the team. This initial codebook identified and defined 17 main themes and 65 sub-themes. Each of the sub-themes related back to a single main theme. Two research team members independently coded a transcript and compared their coding. This process of coding-revision included both substantive additions and eliminations. The codebook was refined and revised accordingly. Each interview was coded by the study's two coders. We used Dedoose, a qualitative analysis application, to code and analyze the data (Dedoose, 2017).

## **Results**

### **Participants' Demographic Characteristics**

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The final sample includes data from 16 interviews. The mean age of participants was 27 years old ranging from 20-34 (see Table 1). Ten women identified as non-Hispanic White. Five women had one pregnancy. Seven of the sixteen women reported that their pregnancies were identified as “high-risk” by healthcare providers. All participants reported that their most recent births occurred in hospital settings. Nearly all of the women (94%) mentioned receiving some type of informal support (e.g., family, friends, and neighbors) during pregnancy. More than half (63%) of the participants reported that their child’s father was involved in their pregnancy, although involvement varied in scope. For instance, some fathers attended healthcare appointments during the pregnancy and some were still in contact with the mother during the time of the interview. Fourteen women reported receiving one or more types of formal supports services (e.g., social worker, parenting program, community services) during pregnancy. Fifteen women reported having or receiving at least one type of informal support.

<< INSERT TABLE 1 ABOUT HERE >>

### **Formal Supports**

Participants identified four different formal supports they received during pregnancy: in-home or residential care, mental health counseling, parenting programs, and social work services. Formal supports were especially helpful for women who needed help getting to and from medical appointments. Speaking about her social worker, one respondent noted “She is the only person who can give us transportation [to prenatal appointments].” Another woman noted appreciatively, “She either comes here and picks me and my daughter up or takes us – if one of us has an appointment, she will take us to the appointment.” Another noted that she has a program that pays for her bus pass so she can move around her city more independently. One

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woman talked about a community program she works with: “if we need rides. . . just call or let them know in advance and they’ll bring us to our appointments.”

Many women noted the importance of formal supports with regard to planning during pregnancy. “She helps me with my goals. Every year, the beginning of July I meet with her and we go over my plan, and – to see if there’s any changes. She’s here to help me if I need anything...,” one woman reflected about her social worker. Another recalled that her social worker located a gynecologist for her. Many women described learning about healthy habits – including exercise and healthy eating – during pregnancy. One woman described her social worker who:

...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.

Planning often came in conjunction with home visits from formal supports, including social workers or public health nurses. One interviewee said:

They help out, they have visits once a week. They come and meet with us and discuss housing and ways they can help us... She comes every Tuesday at 11:00 and we weigh [my baby], we get her height and we get her head measurement to see how she’s growing...

Another participant recalled:

[S]he was really nice too and she was able to give me some advice about parenting and we watched videos on pregnancy, and then it showed in the video what I should expect throughout my pregnancy with the baby, because she’s my first born... And she would

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tell me what to do to take care of myself. And she would tell me what was okay for me to eat and drink and what wasn't – and so she was very helpful.

One woman recalled a social worker who worked with her both during and after her pregnancy.

[S]he comes here and she spends about an hour and we talk. She asked me questions about [my baby], she weighs [my baby], or she'll ask me about doctor appointments. And if I ask her something about the baby, like clipping his nails or something, she'll go and get me the research or tell me about it...

Several women reported an underlying fear of having their infants removed by child protective services, but many of the respondents reported their social workers were especially helpful in preparing them as parents so they would be able to continue caring for their children. “[T]hey made sure that I was capable of caring for him and everything. And, they made sure I had basically everything that I needed,” said one woman. Another poignantly recalled that her social worker “made sure that when I left [the hospital], I would not be thrown into a situation where DCF would come and attack me because I didn't have anybody on my side.”

Respondents widely and generally reported their social workers played a vital role by both offering moral support, and increasing the mother's confidence when they were fearful of medical procedures or unknown aspects of pregnancy or delivery.

### **Informal supports**

Fifteen of the 16 respondents spoke at least once about the assistance they received from informal or unpaid supports. These included support from family, friends, community members, and partners during or after their pregnancies. Just as for formal supports, informal support for

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transportation to and from appointments was especially valued. One woman was involved in her church;

[S]o I called a member of the church ... and I asked for help from them. And she said, 'Oh, yeah, we'll be glad to take you.' ... I was able to have the member of the church with me. She was pretty helpful and there for me each time I got the pain.

Sometimes informal supports were not helpful, even if the women understood the person's intentions were positive: "Sometimes [my aunt] was judgmental. She'd [say to my medical provider], 'I found two Mountain Dew cans in her room from last night.' Things like that. But my aunt's a nurse and she always means well, but sometimes I would get annoyed."

Informal supports proved valuable in many ways for each of the women we spoke with, if only for the benefit of not being alone. One woman recalled going into the delivery room by herself and commented, "It was just me. I was actually quite scared."

Another important feature that arose from these interviews was the value of peer supports, both from peers in the IDD community and from the community at large. Peer supports were helpful because they often provided pregnancy information. For example, one woman described a peer: "She had two children and she has cerebral palsy. But she was able to have two children... so she's been giving me good information." Other women also reported their peer supports were a comfort: "It was okay but it was better if I had somebody with me." Nine women (56% of the sample) had friends join them for many prenatal health appointments and some of the women had friends present with them during childbirth. "I had two of my best friends in the hospital with me," one recalled. Another described her helpful friends: "[T]hey won't judge me because they know how difficult it is for me because I don't have anyone." One

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woman lived with her best friend. “I live with a roommate. She’s actually one of my best friends; we went to high school together,” she noted in her interview.

Notably, many women relied on informal supports, including family and peers, for everyday activities and chores, which were sometimes unrelated to pregnancy: “...my dad took me grocery shopping one time to help me food-wise,” recalled one woman. Another respondent recalled she relied on her mother-in-law for mental health support: “His mother did help me to not be stressed out. She talked to me and tried to help me calm down.” The woman who went to appointments with a member of her church also reported that same woman’s daughter-in-law provided childcare for her other children while they went to the hospital.

[H]er daughter-in-law picked up [my] other three kids because no one was home at the time. It was just me and the kids... so she took the three kids to the house and the member of the church took me to the hospital.

Notably, more than half (63%) of the women in the sample mentioned receiving support from their partner. Women noted a wide range of involvement, and many noted that their partners were helpful both during pregnancy and the postpartum period. Some women indicated that their partners provided practical assistance. For example, one woman explained: “I was throwing up and my husband was so concerned about me. [He said,] ‘Try to eat anything, even a little bit.’” Some women indicated their partners’ main support was financial. One respondent’s explanation was typical of the women interviewed whose partners provided this type of support: “[H]e was involved because he ended up getting stuff for the babies. And also, he ended up spending his money to get the cravings for me,” while another respondent noted, “I didn’t need a lot of money but he would give me . . . money every few weeks when he got paid, so I would have certain things I wanted to get for me and the baby...”



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Some women reported that their partners focused on encouraging the women to exercise during pregnancy – “Yeah, he would [say], ‘Go out. Go walk that way,’” recalled one interviewee. Finally, a small number of women reflected that their partners provided exceptional support, noting it was beyond their expectations. One participant characterized this support as follows: “Anything I needed or I said I wanted, he would go get it,” said one woman. Another interviewee recalled:

My boyfriend talked to me and when I was going through my contractions, he said try to think of something or sing something or. . . distract [yourself from the] pain. So I sang a song and my boyfriend sang it with me.

Another woman noted, while neither she nor her boyfriend had a car, they still traveled to appointments together. “He walked with me, because we didn’t have a car at the time, so we were walking everywhere.”

Some of the women had highly negative experiences with their partners, including abuse. One woman described how her live-in boyfriend left her for another woman after he found out she was pregnant, although they continued to live together:

He was not altogether with me on this whole pregnancy this time. Even though we were living in the same house as his mother, his mother was upset about him treating me the way he is while I’m pregnant because stress is not good for a pregnant mother, could cause early labor.

This participant further described how the environment got so toxic in the home that Social Services became involved in the situation. “...They’re more involved because of the incident he started,” she remarked. Another woman also spoke about how her baby’s father involved Social Services during the pregnancy:

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He didn't believe [I was pregnant] at first. And then after he realized it was true, he started threatening me about taking the baby after she was born. He was going to take me to court and get full custody of her. And I dealt with that throughout my whole pregnancy... 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.

### **Discussion**

Though women with IDD often face many challenges and social risks, like low income, limited education, communication difficulties, comorbid psychiatric conditions, and complications during pregnancies, the role of formal and informal supports during pregnancy for these women has not been thoroughly examined (Parish et al., 2015; Brown et al., 2016). This paper investigated perspectives of women with IDD about the formal and informal supports they received during pregnancy and the postpartum period.

### **Limitations**

Before discussing the implications of our findings, we first consider the study limitations. Though our sample size is larger than the few existing qualitative studies about the pregnancy experiences of women with IDD, our sample of 16 women is modest; therefore, our findings may not include the full range of experiences of women with IDD. Additionally, most of the women in our study identified as White, non-Hispanic and are therefore not representative of the general population of people with IDD which is much more ethnically and racially diverse (Hatton, 2002). Second, like all interview studies, we relied on the recall of our participants. It is possible that women incorrectly recalled or erroneously reported their pregnancy and postpartum

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experiences. While this is plausible, in other research, women with IDD were no less accurate reporters about an event's occurrence than non-disabled women. However, women with IDD were not accurate about reporting specific event timing (Son, Parish, Swaine, & Luken, 2013). Other researchers have found acquiescence is a potential problem when interviewing people with intellectual disability (Finlay & Lyons, 2002). To address this potential threat to the validity of the data, we adhered to guidance from the literature and ensured questions were not leading or had binary (right/wrong; yes/no) responses; all questions required respondents to provide a narrative answer (D'Eath et al., 2005; Jen-Yi, Krishnasamy, & Der Thanq, 2015). These tactics likely mitigated against acquiescence bias. A related issue is social desirability bias. Few participants spoke of negative or deleterious consequences from the formal or informal supports they employed during pregnancy or afterward. It is possible that some women felt uncomfortable discussing negative experiences, or were even fearful of participating due to concerns about heightened surveillance or engagement with child welfare services. Further research could fruitfully explore this issue in greater depth.

One final limitation is that much of our recruiting was done through disability-related organizations and healthcare centers. As such, participants may have had greater resources and been more connected to healthcare and community services than mothers with IDD who are not directly connected to disability or health service organizations. This recruitment process may have led to inclusion of women with relatively high receipt of support from social workers, and does not reflect experiences of those with less support. Despite these limitations, this study is one of few that have examined the use and value of supports during pregnancy from the perspectives of US women with IDD.

### **Implications**

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Prior research has noted that women with IDD often have low income and lack accessible and reliable transportation. These factors mean that transportation to medical appointments can be a particularly challenging barrier to obtaining timely, consistent health care (Parish et al., 2015; Stock, Davies, Hoelzel, & Mullen, 2013; Abbott & McConkey, 2006; Verdonschot, DeWitte, Reichrath, Buntinx, & Curfs, 2008). Transportation to and from prenatal and postnatal appointments is particularly important because women with IDD are less likely to receive adequate prenatal care than other women (Mitra et al., 2015; Horner-Johnson, Biel, Caughey, & Darney, 2019). Our study highlights the role of formal supports in making transportation to healthcare appointments easier and more accessible for women with IDD.

Individuals with IDD sometimes face challenges in executive functioning and planning ahead, which can make adherence to guidelines and recommendations during pregnancy (e.g., staying healthy, birthing plans, parenting plans) especially difficult (Hauser-Cram, Woodman, & Heyman, 2014). The findings of this study show that formal supports were particularly helpful for women with IDD in terms of pregnancy and postpartum planning. Study participants talked about how community supports helped them interact with doctors, follow a healthy diet and exercise plans, and prepare them for parenting by answering questions or following parenting programs with them. The role of helping these parents plan and prepare for parenthood is especially important, as parents with IDD are more likely to have their parenting abilities questioned and, as a whole, are overrepresented within the child welfare system in the United States (Lightfoot & Slayter, 2014; National Council on Disability, 2012). Additionally, the integration of social work and health care can catalyze connections to additional community services and support systems for people with IDD.

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Similar to our findings for the role of formal supports, informal supports also played essential roles for transportation and pregnancy, delivery, and postpartum planning. When many women were asked about the help that they received during pregnancy, they often answered in terms of transportation to medical appointments and, notably, remarked on the value of the emotional support of going with someone as well.

Family supports were highlighted in the interviews we conducted. More than two-thirds of the participants mentioned family members helping out during their pregnancies – whether in everyday help or pregnancy-specific help. Transportation issues aside, many of the participants relied on family members for housing, financial support, and/or parenting help and childcare. This is consistent with findings of previous research that adults with IDD in the United States are most likely to be cared for by family members, often their parents (Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). Contrary to other literature in this area (Potvin et al., 2016; Bigby, 2008) we found that all of the women we interviewed did have significant social supports aside from family members who played key roles in supporting them practically and emotionally during and after their pregnancies. Many women spoke about support they received from parents and siblings that not only prepared them for pregnancy but also helped them in developing parenting skills and provided childcare and financial support. Previous research has found that women with disabilities do not always receive familial, and especially partner support (Parish, Magaña, & Cassiman, 2008). Most of the women we interviewed (15 out of 16) reported receiving crucial support from their families and partners. Two respondents reported abuse by their partners. Previous research has found that women with disabilities raising a child are much more likely to experience abuse from their partners than women without disabilities (Parish et al., 2008; Brownridge, 2006). Women with intellectual disability are at higher risk of abuse in

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general (Wacker, Macy, Barger, & Parish, 2009). Further research is needed on specific resources and services to support women with IDD experiencing abuse around the time of pregnancy.

Recent research has begun to recognize the importance of peer and social support for individuals with IDD in terms of ameliorating mental health and depressive symptoms (Lunsky & Benson, 2001). The gratitude these respondents expressed for support from friends, family, and community members suggests these individuals may play a significant role in assisting mothers with IDD to have successful pregnancies.

### **Conclusion**

To our knowledge, this is the first study to qualitatively examine both the formal and informal supports during pregnancy from the perspective of women with IDD. Our findings highlight the importance of support during pregnancy, especially amongst women with IDD. Through qualitative interviews with mothers with IDD, we found that formal supports aided in planning throughout pregnancy, transportation to clinical care, advocating for the woman, and providing emotional support before, during, and after childbirth. Informal supports also helped with logistical aspects such as transportation, errand running, and overall comfort and emotional encouragement. An important finding of this study was the reported partner support amongst this sample of women, both during and post-pregnancy. This study indicates women with IDD need both formal and informal supports during pregnancy, childbirth, and the postpartum period to improve their pregnancy and parenting experiences.

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Table 1: Description of the Sample (n=16)

<b>Characteristic</b>	<b>n</b>	<b>%</b>
Number of pregnancies		
1	5	31
2	3	19
3	3	19
>3	4	25
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
Infant's father was involved during pregnancy	10	63
Any formal supports received during pregnancy	14	88
Any informal (unpaid) supports received during pregnancy	15	94

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