JoDD
Journal on Developmental Disabilities
Volume 25 Number 1, 2020
On-Line First

Preparing for Motherhood: Women with Intellectual Disabilities on Informational Support Received During Pregnancy and Knowledge about Childbearing

Author Information

Lynne A. Potvin[1]
Rebecca D. Lindenbach [1]
Hilary K. Brown [2]
Virginie Cobigo[1]

[1]School of Psychology, University of Ottawa, Ottawa ON
[2]Interdisciplinary Centre for Health and Society, University of Toronto, Scarborough ON

Correspondence:

virginie.cobigo@uottawa.ca

Keywords

intellectual disability
developmental disability
perinatal support
pregnancy
childbirth

Abstract

Information about pregnancy and childbirth is frequently inaccessible to women with intellectual and developmental disabilities (IDD). Our objectives were therefore to describe pregnancy and childbirth-related knowledge among women with IDD, perinatal informational support received, and the barriers and facilitators to obtaining this support. Using secondary data from a broader qualitative study on social support received by women with IDD during pregnancy and childbirth, we developed two case studies specific to informational support received during this period. Content analysis was used to analyze interview data. Both women with IDD possessed general perinatal knowledge. Factors influencing receipt of informational support included information format (e.g., written versus verbal instruction; group vs. one-on-one learning), level of autonomy, and caregiver involvement (formal and informal). Findings are consistent with previous research demonstrating that perinatal informational support is not always accessible to women with IDD. Accessible perinatal informational support may contribute to improved pregnancy outcomes and therefore should be a social and clinical priority.

Introduction

There is a growing need for accessible perinatal informational support for women with intellectual and developmental disabilities (IDD). In contrast with historically low childbearing rates in this population due to involuntary institutionalization and sterilization, more women with IDD are now accessing pregnancy-related services (Homeyard, Montgomery, Chinn, & Patelarou, 2016; Royal College of Midwives, 2000). Data from Ontario, Canada, demonstrate a general fertility rate of 20.3 livebirths per 1000 women with IDD, in contrast with 43.4 per 1000 in women without IDD (Brown, Lunsky, Wilton, Cobigo, & Vigod, 2016). Age-specific fertility rates are similar in 18 to 24-year-olds with and without IDD (Brown et al., 2016), and women with IDD are nearly twice as likely as those without IDD to give birth to another child within a year of first delivery (Brown, Ray, Liu, Lunsky, & Vigod, 2018). Women with IDD experience high rates of pregnancy complications compared to women without IDD; they are at higher risk for preeclampsia (Brown, Cobigo, Lunsky, & Vigod, 2016; McConnell, Mayes, & Llewellyn, 2008a), venous thromboembolism (Brown et al., 2016), caesarean section (Höglund, Lindgren, & Larsson, 2012), and preterm delivery (Brown et al., 2016; Höglund et al., 2012; McConnell, 2003; Mitra, Parish, Clements, Cui, & Diop, 2015). Moreover, newborns of women with IDD are more likely to be small for gestational age (Brown et al., 2016) and to have low birth weight (McConnell et al., 2008a; Mitra et al., 2015), to have low APGAR scores (Mitra et al., 2015), and to experience neonatal morbidity and mortality (Brown et al., 2016). Factors that contribute to these morbidity and mortality risks include lifestyle behaviours such as smoking (Höglund et al., 2012; Parish, Mitra, Son, Bonardi, Swoboda, & Igdalsky, 2015), concurrent mental illness (Brown et al., 2016; McConnell, Mayes, & Llewellyn, 2008b), and the broader social context in which these pregnancies occur (e.g., poverty, social isolation, stigma and prejudice) (Llewellyn & Hindmarsh, 2015; Llewellyn & McConnell, 2002; Lunsky, Klein-Geltink, Yates, & Institute for Clinical Evaluative Sciences in Ontario, 2014; McConnell, Dalziel, Llewellyn, Laidlaw, & Hindmarsh, 2008; Percy, Machalek, Brown, Pasquali, & Fung, 2017; Potvin, Barnett, Brown, & Cobigo, 2019).

In general, research has demonstrated that social support, including informational support, is invaluable for women with IDD preparing for motherhood (Mayes, Llewellyn, & McConnell, 2008). Perinatal informational support is integral to making informed decisions (Dugas, Shorten, Dubé, Wassef, Bujold, & Chaillet 2012; Guay, Aunos, & Collin-Vézina, 2017) and promoting healthy lifestyle behaviours during and after pregnancy (e.g., smoking cessation, breastfeeding) (Orr, 2004). In this context, perinatal informational support refers to strategies that promote health knowledge related to the perinatal period (Brown, 1986; Willis & Shinar, 2000). Research has demonstrated that preconception exposures (Dean et al., 2013) impact fertility, fetal development, and maternal and infant health outcomes (James, 2004; Percy et al., 2017). Therefore, timely informational support is critical to optimize healthy pregnancies and early childhood development and well-being. This includes information on the benefits of proper nutrition and vitamin supplementation (e.g., the role of folic acid in preventing congenital disorders), stress management, the impact of medication and substance use, early recognition of signs of pregnancy, and the importance of timely and continuous perinatal health care (Cragen, 2014; James, 2004; National Institute for Health and Care Excellence, 2008; Shonkoff, Garner, Committee on Psychosocial Aspects of Child and Family Health, & Committee on Early Childhood, Adoption, and Dependent Care, 2012; Wilson, 2015).

Women with IDD generally possess limited knowledge related to reproductive health. For example, Höglund & Larsson (2013) reported that many women with IDD possessed little to no knowledge on the topics of fertility, conception, pregnancy, and childbirth. Malouf, McLeish, Ryan, Gray, and Redshaw (2017) described an instance where a woman with IDD signed a consent form for a caesarean birth without adequately understanding the procedure and its rationale. Therefore, there remains a dearth of accessible perinatal informational support for women with IDD (James, 2004; Gaudion, Godfrey, & Homeyard, 2013; Höglund & Larsson, 2013; McConnell et al., 2008a; Porter, Kidd, Murray, Uytman, Spink, & Anderson, 2012; Redshaw, Malouf, Gao, & Gray, 2013; Walsh-Gallagher, Sinclair, & McConkey, 2012), despite the finding that such support increases general health-related knowledge in this population (Lunsky, Straiko, & Armstrong, 2003). Research has shown that appropriate informational support increases feelings of self-efficacy and confidence in making informed choices during and after pregnancy among women with IDD (McGarry, Stenfert Kroese, & Cox, 2016). For example, women with IDD have reported that understanding the benefits of breastfeeding influenced their decision to breastfeed their infant (Guay et al., 2017; Malouf et al., 2017). This is significant because women with IDD are less likely than their peers without IDD to breastfeed (Goldacre, Gray, & Goldacre, 2015; Guay et al., 2017). Most perinatal services, however, were developed for the general obstetric population (Walsh-Gallagher et al., 2012), resulting in a lack of appropriate pregnancy-related information for women with IDD (Burgen, 2010; Conder, Mirfin-Veitch, Sanders, & Munford, 2011; Höglund & Larsson, 2013; O'Connor, 2011). Furthermore, pregnancy among women with IDD occurs within a broader social context in which women with IDD frequently confront negative attention and attitudes based on prejudicial beliefs related to their capacity to parent (Llewellyn & Hindmarsh, 2015; Potvin et al., 2019). Consequently, expectant mothers with IDD are frequently socially isolated (Llewellyn & McConnell, 2002; McConnell et al., 2008).

However, the availability of perinatal informational support is insufficient; its nature is also valuable. According to Tucker and Johnson (1989), support that is delivered in a way that promotes autonomy leads to enhanced feelings of maternal well-being and competence, such as recognizing one's value and abilities related to parenting. Competence-promoting support leads to greater autonomy as it assumes that parents with IDD can learn functional skills and become increasingly independent. Conversely, support can be delivered in a way that inhibits beliefs related to competence. Competence-inhibiting support can diminish mothers' sense of well-being and parenting performance as it is based on the assumption that persons with IDD are incapable of parenting; this type of support is primarily focused on meeting children's needs rather than constructively supporting mothers as they learn parenting skills (Tucker & Johnson, 1989).

The provision of optimal perinatal informational support for women with IDD is challenging because they have varying intellectual and adaptive functioning abilities. For example, some may have diverse support needs related to everyday social and practical skills (American Association on Intellectual and Developmental Disabilities, 2013). In the context of pregnancy, this may translate to different abilities to comprehend complex or abstract information. In fact, some women with IDD have reported that pregnancy is an overwhelming period that is difficult to understand (Höglund & Larsson, 2013). This is not unique to women with IDD, however; women without IDD have also reported wanting support to navigate complex pregnancy-related information (Teeeffelen, Nieuwenhuijze, & Korstjens, 2011).

This study's objectives were therefore to describe pregnancy and childbirth-related knowledge among two Canadian women with IDD, the perinatal informational support they received during their pregnancies, and barriers and facilitators to obtaining this support.

Methods

Ethics approval for this study was granted by the University of Ottawa Office of Research Ethics and Integrity. This study used data previously collected for a broader qualitative study on social support experienced by women with IDD during pregnancy and childbirth (Potvin, Brown, & Cobigo, 2016). In the current study, we produced two case studies specific to perinatal informational support.

Participant Selection

This research is based on secondary use of data collected for a project on support for women with IDD during pregnancy and childbirth. Eligible participants were women with IDD aged 18 years or older who had given birth within the past five years and who could verbally engage in an interview. The women were invited to participate through the developmental services agency (i.e. offering services specific to persons with IDD) from which they received support, and then called the first author to schedule an in-person interview. In the original study, four participants were recruited by purposive sampling at local agencies supporting persons with IDD. Two cases (n=2) were selected for the secondary analyses presented in the current study because of the richness of the data on informational support that emerged from the interviews.

Data Collection

Semi-structured interviews were conducted by the first author: a psychology student and birth doula. The interview included socio-demographic questions, a social circles task to illustrate social networks (Antonucci & Akiyama, 1987), and the Social Support Self-Report (SSSR) (Lunsky & Benson 1997; 2001), which was adapted to illicit information specific to social support during pregnancy and childbirth. This tool is validated to measure social support among adults with IDD (Lunsky & Benson, 1997). Both women chose to bring their caseworkers to their interview. Interviews were audio recorded and transcribed. The women were assigned pseudonyms.

Data Analysis

Using mixed content analysis (i.e. inductive and deductive), we analyzed data related to perinatal knowledge, informational support received during pregnancy and childbirth, and barriers and facilitators to obtaining this support; this method is helpful for drawing valid and reliable conclusions from qualitative data (Weber, 1990). First, we uploaded interview transcripts into NVivo 10. Adhering to qualitative research guidelines (Elo & Kyngas, 2008; Holloway & Wheeler, 2010), we read transcripts multiple times prior to coding to increase familiarity with the data. We then developed preliminary codes and created operational definitions for each code to ensure coding consistency (Miles, Huberman, & Saldaña, 2014); these codes served as a starting point for analysis and were expected to evolve. We further analysed codes containing multiple constructs and divided them into sub-codes; we merged codes that were not easily differentiated (Elo & Kyngas, 2008). The second author, an undergraduate student in psychology, coded all the transcripts; the two senior researchers, who have extensive research experience in the field of IDD, audited the coding process to confirm the representativeness of the coded data. Lastly, we created matrices to organize the data relevant to the research objectives (Groenland, 2014; Miles et al., 2014).

Findings

Catherine (Pseudonym)

Catherine was in her late twenties at the time of the interview. She resided in a rural town with her partner and their 2 young children.

Knowledge related to childbearing

Although both pregnancies were planned, Catherine did not recognize the signs of her first pregnancy; her physician informed her she was pregnant. Suspecting her second pregnancy, Catherine took a home pregnancy test, which was negative. She understood that these tests can sometimes be unreliable, therefore, she consulted her physician who confirmed the pregnancy. Moreover, Catherine was aware of some changes related to pregnancy.

> *"When you're pregnant everything [hormones] is higher than it's supposed to be...So, like, the simplest little thing could make you cry or, like, the simplest little thing can make you mad."*

Perinatal knowledge increased after her first pregnancy. For example, Catherine had learned that labour was related to cervical dilation and about labour induction.

> *"[...] like you can't carry a baby for longer than the time unless it's like ten days or something...but past that if you don't have the baby they have to make it come on [...] I know that you don't need to be at the hospital until you're however many dilated or whatever [...]"*

Catherine also understood why both her children were delivered by caesarean section: her first child had a nuchal cord, and for her second child her "bone or whatever is too small, so he was too big."

Furthermore, Catherine understood basic newborn care:

> *"There's this way that you hold the baby, it's called the football hold and stuff, and you get to wash the baby's head first, like you always start from clean to dirty...[new] moms don't know that kind of stuff."*

Perinatal informational support received

The main person Catherine contacted for perinatal information was her obstetrician. Other important sources were Catherine's caseworker and prenatal classes. A home-visiting nurse also modeled parenting skills (e.g., how to prepare baby food).

Catherine reported receiving much support from a relative and her neighbour, both of whom had children.

> *"I learned a lot from [relative]...she had a little daughter [...], so I was learning a lot from her when I had [first child] 'cause I was bathing her daughter, like I bathed her daughter, I fed her daughter, I did everything [...]."*

Catherine explained, however, that she did not rely on her mother for support due to her mother's mental health problems.

Barriers and facilitators to informational support

Although Catherine preferred verbal instruction, she mostly received written information.

> *"I liked it better if [physicians] talked to me and explained stuff 'cause I found that easier… like they always gave me pamphlets and stuff, but I tried to tell them that I like it*

> *better if they explained it…"*

Unsolicited involvement of caregivers was sometimes an issue. For example, a relative imposed support and Catherine found this invasive.

Conversely, Catherine sought after the support of others. For example, Catherine requested her caseworker's presence during prenatal appointments and referrals to other services.

> *"[The caseworker is] the one…that told me about the health unit, told me about the parenting courses, told me about all the stuff that I never knew but I needed. I would have never knew, or found out about it until she told me…."*

Proximity of support persons and services also facilitated informational support.

> *"You go to the health unit, they have everything from the parenting people to the prenatal people…you name it, they have it. You just talk to one secretary […]."*

Catherine also emphasized the importance of autonomy and choice; she clearly asserted desired support (e.g., preferring verbal information and certain support persons).

Rose (Pseudonym)

Rose was in her early twenties at the time of the interview and had three young children; together they lived with her current partner in a small town. Rose also had several miscarriages.

Knowledge related to childbearing

Rose's first two children were unplanned; however, her later pregnancies were intentional. Despite nausea and weight gain, she did not suspect her first two pregnancies until others helped her acquire and take a pregnancy test.

> *"I didn't take it right away. I didn't understand, didn't know how to go about it."*

Rose, however, understood a positive test meant that there was a "baby in [her] belly."

Moreover, she recognized pain and excessive spotting as warning signs of miscarriage.

> *"When we went for that ultrasound I knew just, I knew already deep down that it [baby] was gone."*

Rose knew the dangers of substance use during pregnancy; therefore, she abstained from all contraindicated substances during her last pregnancy. Rose also recognized that rupture of the membranes (i.e. waters breaking), consistent pain, and inductions led to childbirth. Moreover, she understood that epidural and breathing techniques were pain management strategies for childbirth.

> *"I agreed to enroll in the labour classes, labour and breathing, because I didn't do well with [labour for her first two children]."*

She did not however, understand the gestation period: she reported delivering one of her infants at 10 months, 1 week, and 2 days.

During the postpartum period, Rose understood the risks of smoking while breastfeeding: "I breastfeed, so I don't smoke at all." However, she expressed a desire to acquire more parenting skills.

Perinatal informational support received

Rose attended prenatal and CPR classes during her first pregnancy and received much support from her physician for all pregnancies. However, Rose most heavily relied on the Internet for information.

> *"I just had questions about [nutrition to ask the physician]. Other than that, I had to search everything else up online […] I was big for Internet."*

Rose received ample support from her mother**.** Relatives also provided nutrition-related information by helping her prepare healthy meals.

Barriers and facilitators to informational support

Group prenatal classes were seen as unaccommodating; Rose preferred one-on-one learning.

> *"[Prenatal class instructors] were talking to people as a group… I'm better to understand one-on-one."*

Furthermore, unsolicited support from caregivers was sometimes perceived as unhelpful.

> *"I had a dietician, I didn't go see her again… she was trying to force me to go to classes for [abuse Rose had experienced]…and that's none of her business."*

Rose also reported a lack of available information.

> *"It was taught good [CPR class], but there was more they could have helped with. But she didn't have, I think, the DVD and stuff to help us… there was more she was supposed to do with us."*

In response to insufficient information, Rose often referred to the Internet for information. Moreover, Rose reported not receiving desired coaching on breathing techniques during childbirth. Transportation was also discussed as a reason why Rose missed prenatal appointments.

In addition to external barriers, Rose's personal characteristics sometimes interfered with receiving support.

> *"I'm very stubborn, I don't like to talk to people…I guess, I need support, but I'm very closed in at the same time."*

The availability of a nurse to explain information provided during prenatal classes, however, facilitated comprehension.

> *"But the stuff I brought back [from prenatal classes] the nurse was able to explain it to me."*

Moreover, Rose appreciated her physician's accommodating approach.

> *"[The doctor] had said 'Oh, you have trouble keeping appointments' and stuff. So then by the second [appointment], he was pleased that she was booking appointments. Like, he really took her where she was at…and he built from there, which was nice." [Caseworker]*

Receiving written information was also helpful.

> *"[Books and pamphlets are] what gave me a lot of my information…anytime I would see a pregnancy book…or anything about birthing…then I would read them."*

Furthermore, family members reminded Rose to attend appointments, and her caseworker also sometimes accompanied her to appointments.

Discussion

Perinatal Knowledge

Both women in this study demonstrated childbearing-related knowledge, such as how to acquire and use a pregnancy test, the importance of scheduling a medical appointment once pregnancy was suspected, understanding some pregnancy-related complications, understanding the dangers of substance use during pregnancy, recognizing signs of miscarriage and labour, knowledge of some pain management techniques used during childbirth, and newborn care such as how to hold and bathe an infant. This knowledge appeared to increase with subsequent pregnancies. However, both women had difficulties identifying signs of pregnancy and one did not understand the length of gestation. Previous research has demonstrated that women with IDD often struggle to attain such knowledge (Burgen, 2010; Conder et al., 2011; James, 2004; Gaudion et al., 2013; Höglund & Larsson, 2013; Homeyard et al., 2016; Malouf et al., 2017; McConnell et al., 2008a; O'Connor, 2011; Porter et al., 2012; Redshaw et al., 2013; Walsh-Gallagher et al., 2012).

Sources of Perinatal Informational Support

Both women in this study relied on formal sources of informational support (i.e. family physicians, obstetricians, nurses, case workers), with one woman relying more heavily on formal sources of support, potentially because of the lack of support from her family and the availability of her caseworker who referred her to several services during pregnancy. Research has demonstrated that professional support can enhance maternal well-being in women with IDD through competence-promoting support characterized by continuous care, respect for individual strengths and needs, and provision of opportunities to engage in decision-making processes (Höglund & Larsson, 2014; Malouf et al., 2017; Tarleton & Ward, 2007). Women with IDD, however, often receive antenatal information from social service and healthcare providers who continue to hold negative beliefs and who display prejudicial attitudes toward their pregnancies and capacity to parent (Höglund, Lindgren, & Larsson, 2013; Potvin et al., 2019; Strnadová, Bernoldová, Adamčíková, & Klusáček, 2017). Such support is competence-inhibiting and may limit opportunities to receive appropriate support which scaffolds on existing capacities.

One woman in our study indicated her mother as a primary source of informational support. Previous research has shown that, in general, women with IDD rely more heavily on their families for perinatal support (Wilson, McKenzie, Quayle, & Murray, 2013). Mothers are frequently identified as key support persons for women with IDD during pregnancy (Burgen, 2010; Conder et al., 2011; Wilson et al., 2013). Findings from a study examining three generations of mothers with IDD revealed that female relatives in particular were key support persons, providing emotional and practical support and advocacy (Traustadóttir & Sigurjónsdóttir, 2008). It has been argued that the benefits of informal support are often overlooked; for example, such support can provide opportunities for modelling and practicing newly learned skills in an everyday familial context (Llewellyn, 1997; Mayes, Llewellyn, & McConnell, 2006). Moreover, informal support may impact child removal rates (Malouf et al., 2017; Traustadóttir & Sigurjónsdóttir, 2008) which are more elevated among mothers with IDD (Booth & Booth, 1994; Brown, Potvin, Lunsky, & Vigod, 2018; McConnell, Llewellyn, & Ferronato, 2002). Yet, research has also demonstrated that family members also often hold negative views toward pregnancy in their family member with IDD, which could limit competence-promoting support, maternal well-being, and the perceived quality of support (Höglund & Larsson, 2013; Mayes et al., 2006; Potvin et al., 2019).

Findings of this study show that the nature of support is as important as its mere presence (Tucker & Johnson, 1989). For example, unsolicited support was an issue for both the women in this study. Many women with IDD value decision-making opportunities related to their pregnancies (Mayes et al., 2006). Moreover, prejudicial attitudes of caregivers may inhibit women with IDD from disclosing their pregnancies and needs, hence limiting opportunities for support (Höglund & Larsson, 2013). Nonetheless, consistent with our study's findings, social support has been shown to increase appointment attendance (Burgen, 2010), providing opportunities to receive invaluable perinatal informational support. Healthcare providers should therefore consider connecting pregnant patients with IDD to a consistent support person (e.g., caseworker, family member, birth doula) or advocate (Tarleton, Ward, & Howarth, 2006) who is knowledgeable and respectful of their needs and capacities.

Information format was also shown to influence the perceived quality of perinatal informational support in this study: one woman preferred verbal information, the other benefited from written information (i.e. pamphlets and books). Information presentation, including use of medical jargon and consultation length has been shown to limit content accessibility (Walsh-Gallagher et al., 2012; O'Connor, 2011). Avoiding complex and abstract language, allowing extra time for information processing and understanding, and distributing information written in simple language, with illustrations, have been commonly recommended to facilitate communication with patients with IDD across medical settings (Guidelines & Audit Implementation Network [GAIN], 2010; McConnell et al., 2008a). Moreover, adapting general health curricula designed for persons with IDD (Lunsky et al., 2003; Taggard & Cousins, 2014) to the context of pregnancy may increase pregnancy-related informational support for women with IDD.

This study found that when lacking information, one woman referred to the Internet. This parallels findings that adolescents with IDD tended to rely more on media sources for sexual health information than their peers without IDD (Ailey, Marks, Crisp, & Hahn, 2003). This is concerning since much information online is unregulated. The provision of more accessible information by trained professionals (i.e., health care and social services) could reduce reliance on unreliable sources.

Limitations

As with all case studies, our results cannot be transferred to all women with IDD. Firstly, the case studies represented two Anglophone mothers and may therefore not reflect the experiences of mothers with IDD from linguistic minority groups. For example, in Ontario, French-speaking residents are a minority, and the availability of French-language health services is scarce (Boileau, 2009). Both women in this study lived independently, had custody of their children, and received support from the same service agency. Findings may not reflect the experiences of those who receive services from other agencies and who have more complex support needs. Our findings may also not reflect the experiences of women who were grieving the loss of a baby or who had lost custody of their child. Furthermore, data were collected as part of a study on social support during pregnancy and childbirth more broadly; thus, findings likely lacked details specific to informational support.

Conclusion

The women in this study had varying informational support needs; however, perinatal informational support appeared to be especially influenced by information format, the women's level of autonomy, and the nature of caregiver involvement. Such knowledge is relevant, as informational support accessibility has been shown to promote healthy behaviours during and after pregnancy (Orr, 2004; Lunsky et al., 2003; Taggard & Cousins, 2014), and may thus affect the health of pregnant women with IDD and of their newborns. This study offers insight about the perinatal knowledge and experiences of perinatal informational support of two women with IDD, adding to the limited body of existing research on the topic in Canada. Findings are consistent with research conducted in other countries and highlight the need for accessible perinatal informational support that is competence-promoting and respectful of the individual needs of women with IDD. Further research and the development of capacity building models are required to improve the quality of perinatal informational support for this population.

Key Messages

People with disabilities: Getting good information about pregnancy and childbirth is important for your health and the health of your baby.

Professionals: Women with intellectual and developmental disabilities are at increased risk for adverse maternal and neonatal outcomes. Informational support is beneficial to target some factors that contribute to this risk, such as lifestyle behaviours. The provision of accessible informational support for this population should be an essential component of pregnancy and postpartum care.

Policymakers: Policies to promote the development and dissemination of accessible perinatal information for women with intellectual and developmental disabilities may contribute to reducing risks associated with adverse maternal and neonatal outcomes.

Acknowledgments

We are grateful to the volunteer research assistant – Préscillia Dupont – who contributed to the transcription of the interviews.

References

Ailey, S. H., Marks, B. A., Crisp, C., & Hahn, J. E. (2003). Promoting sexuality across the life span for individuals with intellectual and developmental disabilities. *Nursing Clinics of North America, 38*(2), 229-252.

American Association on Intellectual and Developmental Disabilities. (2013). *Definition of intellectual disability*. Retrieved from http://aaidd.org/intellectual-disability/definition#.WH0_vYWcFrQ

Antonucci, T. C. & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology, 42*(5), 519-527.

Boileau, F. (2009). *Special report on French language health services planning in Ontario* (p.28). Ontario, Canada: Office of the French Language Services Commissioner. Retrieved from http://csfontario.ca/wp-content/uploads/2009/05/FLSC_report_french_health_planning_2009.pdf

Booth, T., & Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham, England: Open University Press.

Brown, A. M. (1986). Social support during pregnancy: A unidimensional or multidimensional construct? *Nursing Research, 35*(1), 4-9.

Brown, H. K., Cobigo, V., Lunsky, Y., & Vigod, S. (2016). Maternal and offspring outcomes in women with intellectual and developmental disabilities: A population-based cohort study. *An International Journal of Obstetrics and Gynaecology, 124*(5), 757-765. https://dx.doi.org/ 10.1111/1471-0528.14120

Brown, H. K., Lunsky, Y., Wilton, A. S., Cobigo, V., & Vigod, S. N. (2016). Pregnancy in women with intellectual and developmental disabilities. *Journal of Obstetrics and Gynaecology Canada, 38*(1), 9-16.

Brown, H. K., Potvin, L. A., Lunsky, Y., & Vigod, S. N. (2018). Maternal intellectual or developmental disability and newborn discharge to protective services. *Pediatrics, 142*(6), e20181416. doi: https://doi.org/10.1542/peds.2018-1416

Brown, H. K., Ray, J. G., Liu, N., Lunsky, Y., & Vigod, S. N. (2018). Rapid repeat pregnancy among women with intellectual and developmental disabilities: A population-based cohort study. *CMAJ : Canadian Medical Association Journal = Journal de l'Association Medicale Canadienne*, *190*(32), E949–E956. https://doi.org/10.1503/cmaj.170932

Burgen, B. (2010). Women with cognitive impairment and unplanned or unwanted pregnancy: A 2-year audit of women contacting the pregnancy advisory service. *Australian Social Work, 63*(1), 18-34.

Conder, J., Mirfin-Veitch, B., Sanders, J., & Munford, R. (2011). Planned pregnancy, planned parenting: Enabling choice for adults with a learning disability. *British Journal of Learning Disabilities, 39*(2), 105-112.

Cragen, J. D. (2014). Medication use during pregnancy. *BMJ, 349*, g5252. doi: 10.1136/bmj.g5252

Dean, S., Rudan, I., Althabe, F., Webb Girard, A., Howson, C., Langer, A., … Bhutta, Z. A. . (2013). Setting research priorities for preconception care in low-and middle-income countries: Aiming to reduce maternal and child mortality and morbidity. *PLoS Med, 10*, e1001508. doi:10.1371/journal.pmed.1001508

Dugas, M., Shorten, A., Dubé, E., Wassef, M., Bujold, E., & Chaillet, N. (2012). Decision aid tools to support women's decision making in pregnancy and birth: A systematic review and meta-analysis. *Social Science & Medicine*, *74*(12), 1968–1978. https://doi.org/10.1016/j.socscimed.2012.01.041

Elo, S., & Kyngas, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107–115.

Gaudion, A., Godfrey, C., & Homeyard, C. (2013). Mothers with a learning disability: Access, information provision and ongoing engagement in antenatal care. *The Polyanna Project.* Retrieved from http://www.thepolyannaproject.org.uk/wp-content/uploads/polyanna_project-mothers_with_a_learning_disability.pdf

Goldacre, A. D., Gray, R., & Goldacre, M. J. (2015). Childbirth in women with intellectual disability: Characteristics of their pregnancies and outcomes in an archived epidemiological dataset. *Journal of Intellectual Disability Research, 59*(7), 653-663.

Groenland, E. A. G. (2014). Employing the Matrix Method as a tool for the analysis of qualitative research data in the business domain. Retrieved from: http://ssrn.com/abstract=2495330

Guay, A., Aunos, M., & Collin-Vézina, D. (2017). Mothering with an intellectual disability: A phenomenological exploration of making infant-feeding decisions. *Journal of Applied Research in Intellectual Disabilities*, *30*(3), 511–520. https://doi.org/10.1111/jar.12298

Guidelines & Audit Implementation Network (GAIN). (2010). Guidelines on caring for people with a learning disability in general hospital settings. Retrieved from: https://acppld.csp.org.uk/system/files/caring_for_people_genhosp.pdf

Höglund, B., & Larsson, M. (2014). Professional and social support enhances maternal well-being in women with intellectual disability – A Swedish interview study. *Midwifery, 30*(11), 1118–1123. https://doi.org/10.1016/j.midw.2014.03.018

Höglund, B., & Larsson, M. (2013). Struggling for motherhood with an intellectual disability- A qualitative study of women's experiences in Sweden. *Midwifery, 29*(6), 698-704. https://doi.org/https://doi.org/10.1016/j.midw.2012.06.014

Höglund, B., Lindgren, P., & Larsson, M. (2013). Midwives' knowledge of, attitudes towards and experiences of caring for women with intellectual disability during pregnancy and childbirth: A cross-sectional study in Sweden. *Midwifery*, *29*(8), 950–955. https://doi.org/https://doi.org/10.1016/j.midw.2012.12.002

Höglund, B, Lindgren P, Larsson M. (2012). Pregnancy and birth outcomes of women with intellectual disability in Sweden: A national register study. *Acta Obstet Gynecol Scand*, 91: doi:10.1111/j.1600-0412.2012.01509.x.

Holloway, I., & Wheeler, S. (2010). *Qualitative research in nursing and health care* (3rd ed.). Oxford: Wiley-Blackwell Publishing.

Homeyard, C., Montgomery, E., Chinn, D., & Patelarou, E. (2016). Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review. *Midwifery*, *32*, 45–57. https://doi.org/10.1016/j.midw.2015.10.002

James, H. (2004). Promoting effective working with parents with learning disabilities. *Child Abuse Review, 13*(1)*,* 31-41. https://doi.org/10.1002/car.823

Llewellyn, G. (1997). Parents with intellectual disability learning to parent: The role of experience and informal learning. *International Journal of Disability, Development and Education, 44*(3), 243-261. doi: 10.1080/0156655970440306

Llewellyn, G., & Hindmarsh, G. (2015). Parents with intellectual disability in a population context. *Current Developmental Disorders Reports*, *2*(2), 119–126. https://doi.org/10.1007/s40474-015-0042-x

Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their social networks. *Journal of Intellectual Disability Research, 46*(1), 17-34. https://doi.org/10.1046/j.1365-2788.2002.00347.x

Lunsky, Y. & Benson, B. A. (2001). Association between perceived social support and strain, and positive and negative outcomes for adults with mild intellectual disability. *Journal of Intellectual Disability Research, 45*(2), 106-114.

Lunsky, Y. & Benson, B. A. (1997). Reliability of ratings of consumers with mental retardation and their staff on multiple measures of social support. *American Journal of Mental Retardation, 102*(3), 280-284.

Lunsky, Y., Klein-Geltink, J. E., Yates, E. A., & Institute for Clinical Evaluative Sciences in Ontario. (2014). *Atlas on the primary care of adults with developmental disabilities in Ontario*. Retrieved from http://www.deslibris.ca/ID/240814

Lunsky, Y., Straiko, A. & Armstrong, S. (2003). Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 16*(4), 247-253.

Malouf, R., McLeish, J., Ryan, S., Gray, R., & Redshaw, M. (2017). "We both just wanted to be normal parents": A qualitative study of the experience of maternity care for women with learning disability. *BMJ Open*, *7*(3). https://doi.org/10.1136/bmjopen-2016-015526

Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: Mothers with intellectual disabilities creating their social support network. *Journal of Applied Research in Intellectual Disabilities, 21*(4), 341-350.

Mayes, R., Llewellyn, G., & McConnell, D. (2006). Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandanavian Journal of Disability Research*, *8*(2–3), 120–131. https://doi.org/https://doi.org/10.1080/15017410600774178

McConnell D. (2003) Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual and Developmental Disability, 28*, 122–134.

McConnell, D., Dalziel, A., Llewellyn, G., Laidlaw, K., & Hindmarsh, G. (2008). Strengthening the social relationships of mothers with learning difficulties. *British Journal of Learning Disabilities*, *37*(1), 66–75. https://doi.org/10.1111/j.1468-3156.2008.00526.x

McConnell D., Llewellyn G. & Ferronato L. (2002) Disability and decision making in Australian Care Proceedings. *International Journal of Law, Policy and the Family, 16*, 270–299.

McConnell, D., Mayes, R., & Llewellyn, G. (2008a). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research, 52*(6), 529-535. http://dx.doi.org/10.1111/j.1365-2788.2008.01061.x

McConnell, D., Mayes, R., & Llewellyn, G. (2008b). Pre- partum distress in women with intellectual disabilities. *Journal of Intellectual Disability, 33*(2), 177-183. http://dx.doi.org/10.1080/13668250802007903

McGarry, A., Stenfert Kroese, B., & Cox, R. (2016). How do women with an intellectual disability experience the support of a doula during their pregnancy, childbirth and after the birth of their child? *Journal of Applied Research in Intellectual Disabilities, 29*(1), 21-33. doi: 10.1111/jar.12155

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook (*3rd ed.). Los Angeles, CA: SAGE publishing.

Mitra, M., Parish, S. L., Clements, K. M., Cui, X., & Diop, H. (2015). Pregnancy outcomes among women with intellectual and developmental disabilities. *American Journal of Preventive Medicine, 48*(3), 300-308. http://dx.doi.org/10.1016/j.amepre.2014.09.032

National Institute for Health and Care Excellence (2008). Maternal and child nutrition. Retrieved from https://www.nice.org.uk/guidance/ph11

O'Connor, J. (2011). *Literature review on provision of appropriate and accessible support to people with an intellectual disability who are experiencing crisis pregnancy.* Dublin, Ireland: Crisis Pregnancy Agency.

Orr, S. (2004). Social support and pregnancy outcome: A review of the literature. *Clinical Obstetrics and Gynecology*, *47*(4), 842–855.

Parish, S. L., Mitra, M., Son, E., Bonardi, A., Swoboda, P. T., & Igdalsky, L. (2015). Pregnancy outcomes among U.S. women with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *120*(5), 433. https://doi.org/10.1352/1944-7558-120.5.433

Percy, M., Machalek, K., Brown, I., Pasquali, P.E., & Fung, W. A. (2017). The first 1000 days of fetal and infant development. In M. L. Wehmeyer, I. Brown, M. Percy, W. A. Fung, & K. A. Shogren (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (2nd ed., pp. 475-494). Brookes Publishing. Retrieved from https://ebookcentral.proquest.com

Porter, E., Kidd, G., Murray, N., Uytman, C., Spink, A., & Anderson, B. (2012). Developing the pregnancy support pack for people who have a learning disability. *British Journal of Learning Disabilities*, *40*(4), 310–317. https://doi.org/https://doi.org/10.1111/j.1468-3156.2011.00713.x

Potvin, L. A., Barnett, B. M., Brown, H. K., & Cobigo, V. (2019). "I didn't need people's negative thoughts": Women with intellectual and developmental disabilities reporting attitudes toward their pregnancy. *The Canadian Journal of Nursing Research, 51*(3), 154-167. doi: 10.1177/0844562118819924

Potvin, L. A., Brown, H. K., & Cobigo, V. (2016). Social support received by women with intellectual and developmental disabilities during pregnancy and childbirth: An exploratory qualitative study. *Midwifery, 37,* 57-64. doi: 10.1016/j.midw.2016.04.005

Redshaw, M., Malouf, R., Gao, H., & Gray, R. (2013). Women with disability: The experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy & Childbirth, 13*, 174. Retrieved from http://www.biomedcentral.com/1471-2393/13/174

Royal College of Midwives. (2000). *Position paper 11a. Maternity care for women with disabilities.* London: Royal College of Midwives.

Shonkoff, J. P., Garner, A. S., The Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care & Section on Developmental and Behavioral Pediatrics. (2012). The lifelong effects of early childhood adversity and toxic stress. *Pediatrics, 129*(1), e232-e246. Retrieved from http://pediatrics.aappublications.org/content/129/1/e232

Strnadová, I., Bernoldová, J., Adamčíková, Z., & Klusáček, J. (2017). Good enough support? Exploring the attitudes, knowledge and experiences of practitioners in social services and child welfare working with mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *30*(3), 563–572. https://doi.org/10.1111/jar.12307

Taggard, L., & Cousins, W. (2014). *Health promotion for people with intellectual and developmental disabilities.* Berkshire, England: McGraw-Hill Education, Open University Press.

Tarleton, B., & Ward, L. (2007). “Parenting with support”: The views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *4*(3), 194–202. https://doi.org/10.1111/j.1741-1130.2007.00118.x

Tarleton, B., Ward, L., & Howarth, J. (2006). *A review of issues and positive practice in supporting parents with learning difficulties and their children*. The Baring Foundation. University of Bristol, Bristol. Retrieved from http://baringfoundation.org.uk/wp-content/uploads/2014/10/Findingrightsupport.pdf

Teeeffelen, A. S., Nieuwenhuijze, M., & Korstjens, I. (2011). Women want proactive psychosocial support from midwives during transition to motherhood: A qualitative study. *Midwifery, 27*(1), e122-e127.

Traustadóttir, R., & Sigurjónsdóttir, H. B. (2008). The “mother” behind the mother: Three generations of mothers with intellectual disabilities and their family support networks. *Journal of Applied Research in Intellectual Disabilities*, *21*(4), 331–340. https://doi.org/10.1111/j.1468-3148.2008.00450.x

Tucker, M., & Johnson, O. (1989). Competence promoting vs. competence inhibiting social support for mentally retarded mothers. *Human Organization*, *48*(2), 95. https://doi.org/10.17730/humo.48.2.d64q452755008t54

Walsh-Gallagher, D., Sinclair, M., & McConkey, R. (2012). The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. *Midwifery, 28*(2), 156-162.

Weber, R. (1990). Introduction. *Basic Content Analysis* (pp.10-16). Thousand Oaks: SAGE Publications Inc.

Willis, T. A. & Shinar, O. (2000). Measuring perceived and received social support. In, Cohen, S., Underwood, L. G., & Gottlieb, B.H. (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp.86-135). New York: Oxford University Press.

Wilson, R. D., Genetics Committee, & Special Contributors. (2015). Pre-conception folic acid and multivitamin supplementation for the primary and secondary prevention of neural tube defects and other folic acid-sensitive congenital anomalies. *Journal of Obstetricians & Gynaecologists of Canada, 37*(6), 534-552.

Wilson S., McKenzie K., Quayle E., & Murray G. (2013). The postnatal support needs of mothers with an intellectual disability. *Midwifery*, 29(6), 592-8.