

# **Experiences of Women With Physical Disabilities During the Perinatal Period: A Review of the Literature and Recommendations to Improve Care**

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*Although pregnancy and childbirth have significant identity and health implications for all women, perinatal research has focused primarily on nondisabled women. In this article, I provide a review of literature regarding the perinatal care experiences of women with physical disabilities. I found that many women with physical disabilities encounter attitudinal, informational, physical, and financial barriers during the perinatal period that contribute to poor care experiences and may subsequently affect health outcomes. In an effort to improve perinatal care experiences and outcomes, I offer recommendations to address the barriers identified in the literature, including increased disability content in medical school curricula.*

Women with physical disabilities are marginalized in many areas of their lives, including access to appropriate health care. According to a number

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of major health authorities, including the American College of Obstetricians and Gynecologists (“the College”; 2005), this is particularly true in the area of sexual and reproductive health. In this article, I summarize the literature concerning the perinatal care experiences of women with physical disabilities. Chiefly, I outline the various barriers that women with physical disabilities commonly report encountering during the perinatal period and in turn provide recommendations to address these barriers. Eliminating barriers to perinatal care for this patient population is needed in order to improve care experiences and may consequently improve maternal or infant outcomes. Advances in medical technology, changing attitudes toward disabled people (which may be somewhat related to the increase in disability rights legislation), and a growing disabled population further demonstrate the need for improvements in the provision of perinatal care for women with physical disabilities.

According to the *World Report on Disability*, most of the world’s disabled population lives in developing countries (World Health Organization [WHO] & The World Bank [WB], 2011). Moreover, of the more than one billion people in the world living with some form of disability, more women than men live with a disability (WHO & WB, 2011). In Canada, 14.3% of Canadians report living with a disability, 54% of whom are women and girls (Statistics Canada, 2008). Women of reproductive age (ages 15 to 44) represent 10.5% of Canada’s disabled population (Statistics Canada, 2008). Figures in the United States are slightly higher; according to the National Institute of Child Health and Human Development (2010, para. 1), “more than 1 million women of childbearing age report that they need assistance with activities of daily living because of a disabling condition.” The most common types of disabilities reported by Canadians age 15 and over are pain related (86.7%), mobility (85.5%), and agility (82.4%) disabilities (Statistics Canada, 2010). Figures in the United States are similar (Brault, 2008; Schiller, Lucas, Ward, & Peregory, 2012).

Compared with nondisabled women and disabled men, women with disabilities in general experience lower educational attainments, fewer economic opportunities, and higher rates of poverty (Iezzoni, Yu, Wint, Smeltzer, & Ecker, 2013; Masuda, BC Centre for Excellence for Women’s Health, & DisAbled Women’s Network [DAWN] Canada, 1999; Parnes et al., 2009; Piotrowski & Snell, 2007; Steinmetz, 2006; WHO & WB, 2011). Further, research indicates that women with disabilities are less likely to marry (Asch & Fine, 1997; Begley et al., 2009; Lee, 2007; Traustadottir, 1990), more likely to be divorced or separated (Begley et al., 2009; Iezzoni et al., 2013; Traustadottir, 1990), more likely to live alone (Silverberg & Odette, 2011; Steinmetz, 2006), and more likely to experience sexual and physical abuse, often at the hands of their caregivers (Begum, 1992; Bremer, Cockburn, & Ruth, 2010; Brownridge, 2006; Parnes et al., 2009; Piotrowski & Snell, 2007; Smeltzer & Sharts-Hopko, 2005; Traustadottir, 1990). Disabled women’s physical and

mental health concerns often go unmet. This is particularly true with regard to their sexual and reproductive health (Asch & Fine, 1997; Bremer, Cockburn, & Ruth, 2010; Collins, 1999; Kallianes & Rubenfeld, 1997; Piotrowski & Snell, 2007; Smeltzer, 2007). For instance, women with physical disabilities report low rates of breast and cervical cancer screening (American College of Obstetricians & Gynecologists, 2005; Angus et al., 2012; Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Parnes et al., 2009; Smeltzer, 2007; Sudduth & Linton, 2011), and there are little data concerning physically disabled women's sexuality (Basson, 1998; Mona et al., 2009; Mona, Gardos, & Brown, 1994; Nosek et al., 1994; Nosek, Howland, Rintala, Young, & Chanpong, 2001; O'Toole, 1996; Shuttleworth & Mona, 2002; Silverberg & Odette, 2011; Yoshida, Li, & Odette, 1999). Although pregnancy and childbirth have significant identity and health implications for all women, research to date has focused almost exclusively on nondisabled or able-bodied women. Indeed, nondisabled women dominate the discourse and ideologies of femininity, body image, pregnancy, childbirth, and motherhood. For example, rarely when one imagines a mother do they picture a woman in a wheelchair (Kuttai, 2010).

In this article, I provide an overview of the literature concerning the perinatal care experiences of women with physical disabilities. This includes women with both congenital and acquired mobility-limiting conditions, such as spinal cord injury, cerebral palsy, multiple sclerosis, and rheumatoid arthritis. This review is limited to women with physical disabilities for a number of reasons, most notably the reality that there is scant data on the perinatal care experiences and outcomes of women with developmental or cognitive disabilities. In this review, I outline a number of barriers that women with physical disabilities commonly report encountering during the perinatal period. In an effort to improve perinatal care experiences and ultimately maternal and infant outcomes, I conclude this review with recommendations to address the barriers identified herein.

## METHODS

The studies I reviewed for this article were gathered between April 2010 and May 2012 from a number of databases, including PubMed and Google Scholar. A few additional articles were reviewed at the time of revision. I also reviewed publications and resources developed by the College (American College of Obstetricians & Gynecologists, 2005; American College of Obstetricians & Gynecologists, Cox, Signore, & Quint, 2012), as well as relevant social science and interdisciplinary journals, such as *Disability & Society* and *Sexuality & Disability*. Grey literature, including reports by disability advocacy organizations, such as DAWN Canada, as well as narrative accounts (Kiloran, 1994; Kuttai, 2010), a sort of "what to expect when you are expecting"

guidebook for women with physical disabilities (Rogers, 2006), and conference proceedings (Mona, 2011; Thierry, 2011) were also reviewed. Most studies included in this review are North American, Australian, and European in origin. Only English language studies and those published after 1990 were reviewed. Key words and phrases used to identify relevant studies included “pregnancy among women with physical disabilities,” “women with physical disabilities,” “physically disabled women,” “pregnancy,” “childbirth,” “birth,” “perinatal,” “perinatal experience,” “spinal cord injury,” and other types of physical disabilities, as well as combinations of these key words and phrases. Those studies that particularly addressed perinatal care experiences were reviewed in detail, whereas those that emphasized maternal or infant outcomes were not, although these studies did provide some insight regarding care experiences. The studies relied on most heavily for this review focused on the perinatal care experiences of women with physical disabilities broadly. The disabilities most commonly noted in the literature and often grouped together under “women with physical disabilities” include spinal cord injury, spina bifida, cerebral palsy, multiple sclerosis, rheumatoid arthritis, and muscular dystrophy. The social model of disability (Barnes & Mercer, 2004; Oliver, 2009) and feminist disability theory (Garland-Thomson, 2002; Thomas, 1999; Wendell, 1989, 1996) served as guiding theoretical frameworks for this review.

## FINDINGS

Echoing Signore and colleagues’ recent summary of the literature (Signore, Spong, Krotoski, Shinowara, & Blackwell, 2011), I found that most women with physical disabilities experience normal fertility and are capable of becoming pregnant and of vaginal delivery. Generally, “common symptoms of pregnancy may be more severe than among women without disabilities; in addition, pregnancy may alter the course of the disability, temporarily or even permanently” (Smeltzer & Sharts-Hopko, 2005, p. 14). Perinatal outcomes among women with physical disabilities vary depending on the type and severity of their disability (for more information, see American College of Obstetricians & Gynecologists, 2002; Arata, Grover, Dunne, & Bryan, 2000; Morton et al., 2013; Nosek et al., 2001; Rogers, 1993; Rogers, 2006; Signore et al., 2011; Smeltzer & Sharts-Hopko, 2005; Smeltzer, 2007). As mentioned, the focus of this review is perinatal care experiences, not maternal or infant outcomes, though in many cases these may be related. Further, outcomes likely vary based on a number of factors, including where (country, city, etc.) women with physical disabilities receive care and the specific barriers to care that they may encounter.

The literature indicates that most women with physical disabilities encounter barriers during the perinatal period, contributing to less than

satisfactory perinatal care experiences. For instance, a systematic review commissioned by the National Disability Authority in Dublin, Ireland, found that the prenatal education and perinatal care needs of women with physical disabilities are not being met (Begley et al., 2009; also see Blackford, Richardson, & Grieve, 2000; Signore et al., 2011). This is in stark contrast to the results of the Maternity Experiences Survey (MES), a cross-sectional, population-based survey of 6,421 Canadian women who have recently given birth, in which the majority of the respondents (presumably nondisabled women because the MES failed to include disability as a sociodemographic item) reported very high satisfaction with perinatal care services (Public Health Agency of Canada, 2009).

### Attitudinal Barriers

As a group, women with disabilities are often viewed as asexual; unlikely to be lovers, wives, and mothers; and thus incapable of taking care of others (Basson, 1998; Grue & Lærum, 2002; Kallianes & Rubinfeld, 1997; Lipson & Rogers, 2000; Smeltzer & Sharts-Hopko, 2005; Traustadottir & Harris, 1997). These ideas about women with disabilities are pervasive in society, even among health care providers (Asch & Fine, 1997; Begley et al., 2009; Kallianes & Rubinfeld, 1997; Lam et al., 2010). As such, providers rarely discuss sexual and reproductive health issues like contraception and pregnancy with their disabled patients (Kallianes & Rubinfeld, 1997; Nosek et al., 2001). Equally, it is not uncommon for women with physical disabilities to experience negative reactions to their pregnancies from family members and health care providers (Kallianes & Rubinfeld, 1997; Kuttai, 2010; Lipson & Rogers, 2000). For example, of the 69 respondents who reported a pregnancy in Cooper's (2006) retrospective survey of the health of 1,095 English-speaking Canadian women with physical disabilities, 24.2% reported negative reactions to their pregnancy. Likewise, 36% of the disabled women in an Australian study reported receiving negative reactions to their pregnancy from others, compared with 9% of the nondisabled respondents (Westbrook & Chinnery, 1995).

Negative attitudes among health care providers affect the quality of care that women with physical disabilities receive (Lam et al., 2010). Further, some women with physical disabilities have been denied care altogether; nearly a third (31%) of the 475 women with physical disabilities who participated in Nosek and colleagues' national (U.S.) study reported that they had been "refused care by a physician because of their disability" (Nosek et al., 2001, p. 9). Similarly, Asch and Fine (1997) found that some gynecologists have discouraged women with disabilities from having children altogether. For instance, one participant in their study recalled her gynecologist opining her to: "Get your tubes tied. You couldn't take care of a child yourself" (p. 248).

Similar sentiments have been found in other studies (Begley et al., 2009; Berkeley Planning Associates, Toms Barker, & Maralani, 1997; Piotrowski & Snell, 2007; Rogers, 2006; Smeltzer & Sharts-Hopko, 2005). Related to this, Nosek and colleagues (2001) found that women with physical disabilities were more likely to have had a hysterectomy than their nondisabled peers (22% versus 12%). These data support the College's (2005) assertion that, "the more insidious barriers to health care for women with disabilities involve the ignorance, social prejudice, and pervasive negative attitudes about life with disabilities" (p. 39).

### Informational Barriers

Many women with physical disabilities report receiving or finding little information about how their disability might affect their pregnancy/labor and vice versa (Begley et al., 2009; Blackford, Richardson, & Grieve, 2000; DAWN Canada, 2007; Kuttai, 2010; Lipson & Rogers, 2000; Prilleltensky, 2003; Rogers, 2006). The literature also suggests that many health care providers lack knowledge about the interaction of pregnancy, labor/birth, and disability (Begley et al., 2009; Collins, 1999; Cooper, 2006; Kuttai, 2010; Lipson & Rogers, 2000; Nosek et al., 2001; O'Toole, 2002; Prilleltensky, 2003; Rogers, 2006; Rotheram & RNC Midwifery Society, 2007; Smeltzer, 2007). Prilleltensky (2003), a mother with muscular dystrophy, writes that this is somewhat ironic given that, "the medical system has a long history of managing illness and disability" (p. 29).

Related to this, many of the participants in the reviewed studies noted that there was little communication between their perinatal care providers and those who provided them with disability-specific care (e.g., rehabilitation therapists), and, as a result, their care was very fragmented, as if their pregnancy and disability did not exist within the same body (Begley et al., 2009; Kuttai, 2010).

Based in Berkeley, California, Through the Looking Glass (TLG) is one of the most well-known resources for families with disabilities in the United States. In the mid-1990s TLG commissioned a national survey on parents with disabilities. From their convenience sample of nearly 1,200 parents with disabilities, TLG found the following:

44% of all respondents mentioned at least once on the survey that pregnancy and birthing was an issue that was affected by their disability. Of the 979 respondents who answered the question that specifically asked about this type of barrier, over one-third (36%) report that the providers' lack of disability expertise caused problems during prenatal and birthing services. (Berkeley Planning Associates, Toms Barker, & Maralani, 1997, p. 4-2)

A retrospective, mixed-methods study of 245 Canadian women with disabilities conducted by DAWN Canada, a national organization run by women with disabilities, included 88 mothers with disabilities, nearly half (47%) of whom became mothers while they had a disability. One third of these mothers reported that “lack of social/medical workers who understood [their] situation” was a barrier to raising their children (DAWN Canada, 2007, p. 7).

When providers are uneducated (or have negative attitudes about women with disabilities), care may be inadequate (Gibson & Mykitiuk, 2012) and lead to situations that can cause harm (Lam et al., 2010). For instance, treating all women with physical disabilities as “high risk” and thus in need of increased medical intervention (e.g., assuming that a woman with a spinal cord injury must have a cesarean section) might not always be appropriate and expose them unnecessarily to know risks associated with cesarean sections (Cooper, 2006; Kuttai, 2010; Nosek et al., 2001). Indeed, the recovery time for cesarean delivery is often longer for women with physical disabilities (Smeltzer, 2007). Simply put, in their guide for health care providers on the care of women with physical disabilities, Smeltzer and Sharts-Hopko (2005) contend that, “the need for a cesarean delivery should be based on each woman’s overall health status, the progress of labor, and the well-being of her fetus, rather than on the fact that she has a disability” (p. 16; also see Smeltzer, 2007).

In sum, many obstetricians and gynecologists (and other health care providers) lack the appropriate information and thus training to adequately care for women with physical disabilities during the perinatal period and the overemphasis or ignorance of disability may be problematic (Prilleltensky, 2003).

## Physical Barriers

In addition to attitudinal and informational barriers, many women with physical disabilities report encountering physical accessibility barriers during the perinatal period (Begley et al., 2009; Berkeley Planning Associates et al., 1997; Kuttai, 2010). Many women with physical disabilities report the absence of ramps, physically inaccessible delivery rooms, narrow doorways, and inaccessible ultrasound and examination tables and delivery beds (i.e., nonadjustable) and washrooms (particularly toilets and showers) as barriers to perinatal care (Kuttai, 2010; Rogers, 1993; Smeltzer, 2007; Smeltzer & Sharts-Hopko, 2005).

Mothers with physical disabilities report a lack of accessible parking spaces and equipment (e.g., cribs) to adequately care for their children and participate in their lives (Jackson, 2002; Lipson & Rogers, 2000; Smeltzer, 2007). Of the 88 mothers with disabilities who participated in

DAWN Canada's (2007) aforementioned study, over one third reported that transportation was a barrier to raising their children.

### Financial Barriers

Because women with disabilities often have fewer financial resources than their nondisabled peers have (Iezzoni et al., 2013; Steinmetz, 2006), the financial weight of pregnancy, birth, and childrearing may be particularly high for this population. Additional expenses for women with physical disabilities may include informational resources, equipment (e.g., wheelchairs and cribs), human resources (e.g., personal attendant services), and accessible transportation (e.g., Wheel-Trans). Such costs may be inflated for those who do not have health insurance, those who live in remote and rural areas, and those who parent alone (American College of Obstetricians & Gynecologists, 2005). Over half (54.5%) of the 88 mothers with disabilities who participated in DAWN Canada's (2007) study indicated that they were or have been single parents. Moreover, limited resources may mean that disabled women delay seeking care or receive second-rate care (Bremer, Cockburn, & Ruth, 2010). Indeed, in addition to attitudinal and informational barriers, inadequate financial supports together with social supports explain why some women with physical disabilities may not envision becoming mothers in the first place (Bristo, 1993; Collins, 1999; Prilleltensky, 2003).

### Systematic Barriers

The barriers experienced by women with physical disabilities during the perinatal period are not just the result of individual service providers' actions (or inactions). The roots of these barriers lie within larger systems and institutions:

When we think about the quality of care given to new and expectant mothers we tend to think small—looking at client characteristics, professional-client relationships, or clinical contexts. It is easy to forget that what happens in a maternity care clinic is a product of work done in legislative assemblies and ministries of health. State policies influence everything from the interactions between caregivers and clients to the clinical outcomes. (Wrede, Benoit, & Sandall, 1999, p. 28)

In sum, the literature reveals that women with physical disabilities encounter numerous barriers during the perinatal period that can hinder the care they receive and likely have an impact on how they adapt to motherhood. Likewise, the above-mentioned barriers may consequently affect maternal or infant outcomes.

## DISCUSSION

The barriers that women with physical disabilities encounter during the perinatal period need to be addressed in order to improve their perinatal care experiences and outcomes. Arguably, the most significant barriers to positive perinatal care experiences for women with physical disabilities are negative attitudes and lack of knowledge among health care providers. Addressing these barriers could begin in the classroom.

### Education and Training

Increased disability content in medical and nursing school and residency program curricula is essential. This training can challenge stereotypes about women with disabilities:

Doctors and other health professionals who encounter disabled people in their professional practice should be aware not only of the causes, consequences, and treatment of disabling health conditions, but also of the incorrect assumptions about disability that result from stigmatised views about people with disabilities that are common within society. (Shakespeare, Iezzoni, & Groce, 2009, p. 1815)

This training should also include discussions of different approaches to disability (i.e., not just the medical model) and the lived realities of women with disabilities. Indeed, in their qualitative study of medical students' interactions with physically disabled patients, Iezzoni and colleagues (2005) found the following:

The students strongly urged medical educators not to separate teaching about the pathophysiology of disease from its implications for patients' daily activities. Instead, bringing patients into classrooms both to demonstrate physiological aspects of conditions and to talk about the impact of their conditions on their lives provides compelling and memorable lessons. (p. 25)

This study and others emphasize that, "it is important for [health] professionals to understand not just disease, but also the experience of living with disability" (Shakespeare, Iezzoni, & Groce, 2009, p. 1816).

Disability-specific education and training initiatives could be developed collaboratively; clinicians and researchers could collaborate with scholars in disability studies and related areas of study, as well as with individual women with physical disabilities to learn about their lived realities and the definitions and approaches to disability most relevant to this patient population. As Iezzoni and colleagues (2005) have noted, having women with physical

disabilities speak about their own perinatal care experiences may be a particularly impactful part of the curriculum. Relatedly, results from Satchidanand and colleagues' (2012) systematic review indicate "that previous experience (e.g., casual and professional experience) with persons with physical disabilities, previous training in treating patients with physical disabilities, and the female sex were associated with better attitudes among healthcare students and professionals" (p. 541).

In addition to educating trainees, it may be advantageous to have disability-specific training available to health professionals already practicing in the area of perinatal health (i.e., a continuing medical or nursing education credit course (e.g., Begley et al., 2009; Rogers, 2006; Rotheram & RNC Midwifery Society, 2007; Sudduth & Linton, 2011).

To make said training practical, it may be worthwhile to develop interactive workshops, where practitioners get the chance to role play various provider–patient interactions. Indeed, health researchers are increasingly turning to theatrical performances as an innovative and accessible approach to disseminate research findings. Research-based productions have been developed for the purpose of disseminating research findings to health practitioners and students on the topics of schizophrenia (Mienczakowski, 1992), breast cancer (Gray et al., 2000), traumatic brain injury (Colantonio et al., 2008; Kontos et al., 2012), and Alzheimer's disease (Kontos & Naglie, 2006), among others.

Based on theories of adult education, performance of findings may serve to concretize the research, and the resulting audience engagement with research material may offer greater potential for transforming social understanding than do text-based strategies (Gray et al., 2000). Research-based theater encourages service providers to reflect on the care they provide, increase their understanding of patient care issues, and enhance communication skills (Kontos & Poland, 2009; Mienczakowski, 1995). Interactive training for students and practitioners in the area of reproductive health may therefore be a particularly effective training method, as various studies (as mentioned) have suggested that there is a lack of knowledge among health care providers concerning the perinatal care needs and desires of women with physical disabilities.

### Service Provision

A number of disability-specific perinatal care resources for health care providers, particularly nurses and midwives, have been published (e.g., Blackford, Richardson, & Grieve, 2000; Carty, 1998; Carty, Conine, & Hall, 1990; Carty, Conine, Holbrook, & Riddle, 1993; Rotheram & RNC Midwifery Society, 2007; Smeltzer & Sharts-Hopko, 2005; Sudduth & Linton, 2011). Unfortunately, the research reviewed for this article suggests that the

recommendations made in these resources have not been widely implemented. As such, they are summarized below.

First, service provision needs to move beyond the medical model of disability, which locates disability within individuals and subsequently pathologizes and stigmatizes individual with disabilities, to a model of holistic or multidimensional health (Rogers, 2006). This recommended model is in line with the social model of disability, which reasons that disability is the product of systemic barriers, negative attitudes, and exclusion by society; in other words, disability is socially constructed (Barnes & Mercer, 2004; Hughes, 2002; Rotheram and RNC Midwifery Society, 2007; Shakespeare, Iezzoni, & Groce, 2009). A holistic approach recognizes that, while disability often plays a major role in the lives of individuals with disabilities, so do other social determinants of health such as socioeconomic status and race. In short, disability should not be taken as the defining factor in how to care for women with physical disabilities during the perinatal period (Rogers, 2006).

Providers could adjust their practices to meet the unique needs of women with physical disabilities. For instance, perinatal appointments could be made at times when accessible transportation is available or efforts could be made to bring care to women's homes (Carty, 1998). Recognizing that some women with physical disabilities have a history of poor interactions with health care providers and thus may avoid traditional care setting as a result, home care may be essential for some to get the care they need; home care "usually provides a non-threatening environment and 'safe place' for disabled women" (Rotheram & RNC Midwifery Society, 2007, p. 13). Further, in line with a holistic approach, Shakespeare and colleagues (2009) found that, "visiting patients in their own homes enables [medical] students to understand disabled people in context, and appreciate what their capabilities are" (p. 1816; also see Rotheram & RNC Midwifery Society, 2007).

Health care settings and equipment must be physically accessible for women with physical disabilities (Begley et al., 2009; Carty, 1998). When women with physical disabilities come to traditional health care settings, accessible parking spaces, ramps, wide doorways and hallways, and lowered reception desks should be available for them (Begley et al., 2009; Carty, 1998; Smeltzer & Sharts-Hopko, 2005). Adjustable ultrasound, examination and delivery tables/beds, and accessible washrooms should be available for them.

Because of their physical accessibility needs and the potential impact of their disability on their pregnancy or vice versa, many women with physical disabilities will require more time for perinatal visits than nondisabled patients will as well as more frequent visits (Smeltzer & Sharts-Hopko, 2005). Some may even require extended periods of hospitalization (Kuttai, 2010; Rogers, 2006).

Further, women with physical disabilities are entitled to feel psychologically comfortable in clinical settings (Carty, 1998). For example, women

with physical disabilities can be asked in a respectful manner, “What can we do to make your visit here easier?” and always spoken to directly: “Health professionals need to understand that they should communicate directly with disabled people themselves about health matters, not only through carers, relatives, or other proxies” (Shakespeare et al., 2009, p. 1816; also see Carty, 1998; Rotheram & RNC Midwifery Society, 2007). Women with physical disabilities are the experts of their bodies (Begley et al., 2009; Killoran, 1994; Kuttai, 2010; Shakespeare et al., 2009) and have the right to make decisions about their perinatal care. Moreover, because many women with physical disabilities have had poor care experiences in the past, it may be especially important that they are able to have their partner or other social support person/s in the examination, ultrasound, and labor and delivery rooms when requested (Rogers, 2006). Additionally, because women with disabilities are at high risk of sexual and other forms of abuse, having an open dialogue about sexual health and conception are important. There may be cases where pregnancy was not wanted by the patient. Providers should be trained to screen for abuse with this patient population or refer them to appropriate providers to do so (Piotrowski & Snell, 2007; Sudduth & Linton, 2011).

Collaboration among different types of service providers, such as obstetricians, gynecologists, nurses, and occupational and physical therapists, as well as with individual women with physical disabilities and their social supports is essential for positive perinatal care experiences (Rogers, 2006). This is particularly important as studies reveal that most obstetricians who specialize in high-risk pregnancies have limited disability-specific training (Kuttai, 2010; Rogers, 2006). Because many women with disabilities have a history of being pathologized and silenced, it is particularly important that they have a say in their care (Rotheram & RNC Midwifery Society, 2007). As such, many have recommended that a multidisciplinary team of providers consult with the patient (and her partner or other support person/s) to develop a written (and signed) birth plan (Carty, 1998; Rogers, 2006; Rotheram & RNC Midwifery Society, 2007; Smeltzer & Sharts-Hopko, 2005). Related to this, it is recommended that a plan be set up to ensure that accessible rooms and equipment are available at the time of labor (Carty, 1998); this may include a training exercise on the part of hospital staff and an opportunity for women with physical disabilities to try equipment out before labor/birth (Rotheram & RNC Midwifery Society, 2007). In short, communication and coordination among these various parties is vital to avoid unnecessary treatment, to reduce harm, and to reduce postpartum recovery time (Bristo, 1993; Kuttai, 2010; Lipson & Rogers, 2000).

Finally, women with physical disabilities should be provided with informational resources and local supports that are appropriate to them (Begley et al., 2009; Blackford, Richardson, & Grieve, 2000; Carty, 1998; Rotheram &

RNC Midwifery Society, 2007). If providers are unaware of appropriate local resources and supports, they can work together with relevant stakeholders to develop them and ensure they are available in clinical settings and disseminated to women with physical disabilities more broadly. Health care providers and other relevant parties should do a better job of disseminating perinatal care information to women with physical disabilities.

In addition to the studies and reports cited in this review, community-based organizations, such as TLG, The Parenting Network (Centre for Independent Living Toronto, Canada), and Disability, Pregnancy & Parenthood International (London, United Kingdom), offer appropriate resources for both health care providers and patients. Service providers may also wish to consult Carty and Conine's (1995) report on the accessible childbearing and parenting program that they developed for women with disabilities at British Columbia Women's Hospital & Health Centre and the resources available on the College's website (American College of Obstetricians & Gynecologists et al., 2012). Although it has been written as a resource for women with physical disabilities, Rogers' (2006) guide is also a useful resource for health care providers.

## Policy and Legislation

A number of the service provision recommendations mentioned above, however, cannot be implemented without changes at the policy level. For instance, while home care would be ideal for some women with physical disabilities, the reality is that, in most jurisdictions, care is not funded in a way that permits home care. The same can be said about the increased frequency and length of perinatal visits that some women with physical disabilities may require. Nevertheless, many of the barriers to perinatal care that women with physical disabilities still encounter should no longer exist given the various pieces of legislation in place that prohibit discrimination on the basis of disability status. For instance, most Western nations have national human rights codes and legislation (e.g., Americans with Disabilities Act, Canadian Human Rights Act) that prohibit discrimination based on disability status, and many have ratified the UN Convention on the Rights of Persons with Disabilities (e.g., Australia, Canada, Germany, France, New Zealand, United Kingdom):

State Parties shall: (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes. (Article 25, Office of the United Nations High Commissioner for Human Rights, 2008)

## LIMITATIONS

Some methodological limitations must be considered in the interpretation of this data. This is not a systematic review and thus some studies, particularly those concerned with perinatal outcomes for specific disabled populations, may not be included in this review. Furthermore, only English language studies and reports were included in this review. Most of the reviewed studies include samples of only women with physical disabilities; thus, some women with disabilities (e.g., women with intellectual or cognitive disabilities and hearing impaired and deaf women) and their experiences may not be reflected in this review. Nevertheless, some of the recommendations provided herein may be appropriate for women with various types of disabilities.

In conducting this review, a number of significant research gaps were identified, and thus the data should be viewed with caution, particularly with regard to generalizability or representativeness. For instance, the majority of peer-reviewed articles reviewed for this article share results of retrospective, single-site, qualitative studies with small samples, often recruited through convenience sampling (e.g., Grue & Lærum, 2002; Lipson & Rogers, 2000; Prilleltensky, 2003). Moreover, all of the larger, survey-based studies included in this review relied on convenience sampling. Very few prospective and population-based studies were identified. Similarly, we do not know a great deal about the diversity of the physically disabled population, as most studies have homogeneous samples of primarily White, presumably heterosexual, urban dwelling women with physical disabilities. Likewise, few studies of the perinatal care experiences or outcomes of women with physical disabilities in developing nations were identified. Furthermore, there have been few population-based studies conducted to determine how many women with physical disabilities intend to, have become pregnant, or have given birth; the incidence and prevalence of pregnancy and childbirth among women with physical disabilities is largely unknown (Signore et al., 2011). Of note, however, is a recently published population-based study conducted by Iezzoni and colleagues (2013) concerning the prevalence of pregnancy among U.S. women with and without chronic physical disabilities (CPD). Using the National Health Interview Survey data from 2006 to 2011, they identified 6,043 women with CPD (or 12.7% of their total sample) of child-bearing age (18–49 years). Consistent with earlier data (Steinmetz, 2006), they found that most women with CPD were more likely to be African American, have low educational attainment, and less likely to be employed. Not surprisingly, women with CPD were more likely to be older. Interestingly, “after accounting for sociodemographic characteristics related to pregnancy,” Iezzoni and colleagues (2013) found that “women with CPD become pregnancy at similar rates as to other women” (p. 562). Although this data is promising, there are many challenges to collecting data concerning pregnancy and childbirth among physically disabled women, for a number of

reasons, including the various ways in which disability is measured (Iezzoni et al., 2013; Signore et al., 2011). Finally, more research is needed concerning health care providers' knowledge of and attitudes toward women with physical disabilities during the perinatal period and, in turn, the relationship between knowledge, attitudes, access to care, quality of care, and outcomes. Thus, in addition to the recommendations made above, in order to address the barriers to perinatal care that women with physical disabilities encounter, a number of significant research gaps need to be addressed.

## CONCLUSION

Many women with physical disabilities report encountering barriers to accessing equitable and culturally appropriate perinatal care. These barriers, particularly attitudinal barriers and a lack of knowledge about disability among health care providers, may lead to poor perinatal care experiences and subsequently poor outcomes for both mothers and their infants. Further research is needed to determine essential factors contributing to these barriers and other research and service provision gaps concerning the perinatal care of women with physical disabilities. Related to this, more research is needed to determine why many of the recommendations to improve perinatal care for this population have yet to be taken up in practice. Data included in this review support initiatives designed to improve knowledge about the lives and perinatal care needs of women with physical disabilities among obstetricians and gynecologists and other health and social service providers.

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