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# Adaptive parenting strategies used by mothers with physical disabilities caring for infants and toddlers

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## Abstract

There is a paucity of information concerning adaptive parenting strategies utilised by mothers with physical disabilities, particularly during early motherhood. The purpose of this study is to describe the adaptive strategies used by mothers with physical disabilities during early motherhood. This qualitative study included semi-structured telephone interviews between January and March 2014 with US mothers with a range of physical disabilities who had a baby within the past 10 years ( $N = 25$ ). Interviews were audio-recorded, professionally transcribed, and coded using content analysis. Analysis revealed five broad themes indicating important adaptive parenting strategies for mothers with physical disabilities caring for infants and toddlers: They are as follows: (a) acquiring or modifying baby-care equipment, (b) adapting the home environment, (c) accessing information and supports, (d) developing communication strategies to facilitate safety, and (e) receiving assistance from others. This study indicates that mothers with physical disabilities employ a variety of adaptive strategies during early motherhood. The findings from the study suggest the need for more availability of supports and equipment for mothers with physical disabilities as well as information for prospective mothers with disabilities. In addition, health-care and social work professionals must receive training about adaptive parenting strategies.

## KEYWORDS

adaptive, motherhood, parenting, parents with disabilities, strategies

## 1 | INTRODUCTION

Motherhood is an important aspect of the life course for women with physical disabilities, just as it is for non-disabled women (Shandra, Hogan, & Short, 2014). In fact, after accounting for differences in age distributions, women with physical disabilities are pregnant at rates comparable to women without disabilities (Horner-Johnson, Darney, Kulkarni-Rajasekhara, Quigley, & Caughey, 2016; Iezzoni,

Yu, Wint, Smeltzer, & Ecker, 2013). In response, an emerging body of research concerning mothers with disabilities has focused on their experiences during pregnancy and the early postpartum period (Clements, Mitra, & Zhang, 2018; Long-Bellil, Mitra, Iezzoni, Smeltzer, & Smith, 2017; Mitra, Akobirshoev, et al., 2017; Mitra, Smith, et al., 2017; Powell et al., 2017; Smeltzer, Mitra, Iezzoni, Long-Bellil, & Smith, 2016; Smeltzer, Mitra, Long-Bellil, Iezzoni, & Smith, 2018; Tarasoff, 2015). Far fewer studies, however, have

examined the early motherhood experiences of mothers with physical disabilities. To effectively support women with physical disabilities in caring for their infants and toddlers, a better understanding of how healthcare and social work professionals can best support mothers throughout early motherhood, especially as it relates to adaptive parenting strategies, is urgently needed.

Many women with physical disabilities experience unmet needs and barriers to perinatal care during pregnancy and childbirth (Long-Bellil et al., 2017; Tarasoff, 2015; Smeltzer et al., 2016). Women with physical disabilities encounter inaccessible providers' offices and healthcare facilities, clinicians with limited understanding of how to provide prenatal care to women with disabilities, and a paucity of information related to pregnancy and disability (Iezzoni, Wint, Smeltzer, & Ecker, 2015a, 2017; Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith, 2016; Mitra, Akobirshoev, et al., 2017; Mitra, Smith, et al., 2017; Smeltzer et al., 2016). They also face stigma and negative attitudes concerning their pregnancy from healthcare providers, family members, and strangers (Frederick, 2017; Iezzoni, Wint, Smeltzer, & Ecker, 2015b; Powell et al., 2017). Improved prenatal and postpartum care for women with physical disabilities is necessary and must include better supports throughout the postpartum period and beyond.

Additionally, healthcare and social work professionals often lack understanding of how to support mothers with disabilities in their care-giving role (Wint, Smith, & Iezzoni, 2016). Indeed, despite the importance of adaptive parenting strategies for mothers with disabilities, clinicians often are ill-equipped to support mothers with postpartum planning and many women receive very different care and instruction, or no instruction at all, depending on clinician knowledge (Lipson & Rogers, 2000). Likewise, mothers with disabilities report a paucity of breastfeeding supports, including lactation consultants who understand their needs and strategies for adapting their breastfeeding techniques to accommodate their disabilities (Guay, Aunos, & Collin-Vézina, 2017; Powell et al., 2018). Although a small number of studies have shown that occupational therapists are sometimes helpful in advising new mothers with disabilities about adaptive strategies, it is imperative that all healthcare and social work professionals increase their knowledge in this area (Payne & McPherson, 2010; Wint et al., 2016).

As people with disabilities increasingly choose to become parents (National Council on Disability, 2012), it is crucial to understand how mothers with physical disabilities utilise adaptive parenting strategies. It is equally important to elucidate barriers related to adaptive parenting strategies, particularly vis-à-vis adaptive parenting equipment. This qualitative study aims to describe adaptive parenting strategies used by US mothers with physical disabilities caring for infants and toddlers.

## 2 | METHODS

### 2.1 | Study design

Data for this study were collected in the context of a larger mixed-methods study that examined the health needs and experiences

### What is known about this topic

- Women with and without physical disabilities have comparable rates of pregnancy.
- There is little empirical research on how to support women with physical disabilities during early motherhood.
- Healthcare and social work professionals lack training about parents with disabilities.

### What this paper adds

- Women with physical disabilities utilise a range of adaptive parenting strategies to care for their infants and toddlers.
- There is a need for more availability of parenting supports and equipment for women with physical disabilities as well as information on adaptive parenting strategies and baby-care equipment.
- Healthcare and social work professionals must be prepared to support women with physical disabilities during early motherhood.

before, during, and after pregnancy for women with physical disabilities in the United States. To answer this article's aims, the qualitative component of our study was analysed. The results of analysis presented in this article are limited to the adaptive strategies women with physical disabilities utilise during early motherhood.

### 2.2 | Sampling and recruitment

To participate in our study, women must (a) have had a physical disability or health condition that affected her ability to walk or to use her arms or hands at the time of her pregnancy; (b) have delivered a child within the last 10 years in the United States; (c) be of age 55 or younger at the time of the interview; and (4) speak English fluently. The sample included participants from across the United States.

Participants were recruited through a variety of techniques. Using convenience sampling (Hsieh & Shannon, 2005), recruitment materials were distributed via email lists, websites, social media of disability organisations and self-advocates, and disability-related blogs. In addition, we used snowball sampling whereby participants referred other mothers to participate in the study (Patton, 2002).

Thirty-one women contacted the study coordinator and expressed interest in participating in the study. Subsequently, two women were determined to be ineligible, two women were unable to be reached for screening, and two women were interviewed but later excluded because their interviews did not confirm physical disability. The final analytic sample included 25 mothers with physical disabilities.

## 2.3 | Data collection

While recognising the numerous complexities of power and positionality associated with research about marginalised communities (Merriam et al., 2001; Tang, 2007), we aimed to present an authentic and insightful understanding of our participants. To that end, our research team was comprised of both “insiders and outsiders.” Both interviewers have lived experience as women with disabilities. Although disclosing one's disability was not an explicit component of the interview guide, the interviewers' in-depth understanding of shared disability identity and experience with participants allowed for greater familiarity with the topics (Gair, 2012). Moreover, having “outsiders” involved in the study design and data analysis allowed for meaningful questions and “curiosity with the unfamiliar” (Merriam et al., 2001, p. 411).

Participants were provided an informed consent document prior to the scheduled interview. Before the telephone interview began, verbal consent was obtained, as approved by the institutional review boards.

Semi-structured interviews were conducted in English by telephone over a 3-month period between January and March 2014. Interviews were conducted by one of two trained interviewers and lasted approximately 2 hrs. Interviews followed an interview guide, which was developed by the study's co-investigators based on Mitra, Long-Bellil, Smeltzer, and Iezzoni's (2015) perinatal health framework for women with physical disabilities and a comprehensive literature review. Prior to data collection beginning, the interview guide was piloted with three women with physical disabilities to ensure that the questions were clear and understandable (Kvale, 2007; Pontin, 2000). No changes were made to the interview guide as no issues arose during the piloting.

Each interview was audio-recorded and professionally transcribed. A member of the research team reviewed transcripts to ensure accuracy and remove any identifying information. All participants received a \$50 gift card to thank them for their time. Interviews continued until saturation was achieved and no additional themes emerged.

## 2.4 | Data analysis

Analysis of the interview transcripts was iterative and inductive, and followed traditional qualitative content analysis methodology (Creswell, 2013; Patton, 2002; Hsieh & Shannon, 2005). Line-by-line, in-depth analysis of the data was completed and codes were developed iteratively. Kurasaki's (2000) method of coding was used to ensure reliability and consistency. Specifically, interview transcripts were reviewed by study co-investigators and preliminary codes were identified. Thereafter, a codebook was developed and updated continuously as new codes emerged from the data. Similar codes were grouped together to develop themes based on the study's research questions. Next, under the supervision of the principal investigator, a research associate completed all coding. The research associate and principal investigator met repeatedly throughout the process to discuss and refine codes. The final codebook was approved by each co-investigator. Atlas.ti version 7 software was used for data analysis.

## 2.5 | Ethical consideration

The institutional review boards of the authors' institutions approved this study. Participants provided verbal consent before starting their interview.

## 3 | FINDINGS

### 3.1 | Participant characteristics

Table 1 presents the participants' characteristics. The average age was 32 years old, most were non-Hispanic White, married, and had college or graduate degrees. More than half reported that their most

**TABLE 1** Demographic characteristics of sample (at the time of interview) (N = 25)

| Characteristics                 | n  |
|---------------------------------|----|
| Age (in years)                  |    |
| 21–25                           | 4  |
| 26–30                           | 8  |
| 31–35                           | 9  |
| 36+                             | 4  |
| Race/Ethnicity                  |    |
| Non-Hispanic White              | 19 |
| Other                           | 6  |
| Marital status                  |    |
| Married                         | 19 |
| Not married                     | 6  |
| Highest educational attainment  |    |
| High school                     | 2  |
| Some college                    | 7  |
| 4-year college degree           | 11 |
| Graduate degree                 | 5  |
| Assistive technology use        |    |
| Used mobility aid               | 18 |
| Did not use mobility aid        | 7  |
| Planned pregnancy               |    |
| Planned                         | 15 |
| Unplanned                       | 10 |
| Number of children              |    |
| 1                               | 14 |
| 1+                              | 11 |
| Youngest child's age (in years) |    |
| Under 1                         | 6  |
| 1–3                             | 4  |
| 3–5                             | 4  |
| 5–10                            | 11 |
| Disability status of child      |    |
| Had disability                  | 7  |
| Did not have disability         | 18 |

recent pregnancy was planned. Fourteen participants had one child at the time of the interview, and two participants were pregnant. The age of participants' youngest child's age ranged from <1 to 10 years old. Seven participants had at least one child with a disability. The participants had a range of physical disabilities, including dwarfism, muscular dystrophy, osteogenesis imperfecta, cerebral palsy, amputation, spinal cord injury, stroke, spina bifida, and multiple sclerosis. Eighteen participants used mobility devices.

### 3.2 | Adaptive parenting strategies

Participants reported five broad themes relating to adaptive parenting strategies for mothers with physical disabilities caring for infants and toddlers: They are as follows: (a) acquiring or modifying baby-care equipment, (b) adapting the home environment, (c) accessing information and supports, (d) developing communication strategies to facilitate safety, and (e) receiving assistance from others (see Table 2). These findings are described below using case examples and participant quotes.

#### 3.2.1 | Acquiring or modifying baby-care equipment

Nearly all of the participants acquired or modified baby-care equipment in order to care for their infants and toddlers. For example, some participants acquired cribs designed specifically for parents with disabilities whereas others attained traditional cribs and made modifications or had cribs specially built for them. Several

participants reported using cribs with rails that dropped or opened outward, had a one-handed drop side, opened outward, or had sliding doors or a gate that folded down. These cribs were particularly helpful for participants who used wheelchairs because they could roll underneath the crib and reach their infants. These adaptations allowed them to lift their infant in and out of the crib. One participant explained that her family modified a crib so that the "front of the crib has two doors that swing open like fridge doors," further stating "that's something that I wouldn't be able to do, to lift her over the side of the crib." Notably, some of the participants who used cribs with drop sides mentioned that these types of cribs have been discontinued and are challenging to find.

Meanwhile, some participants elected to use other types of baby-care equipment, such as bassinets and co-sleepers, instead of cribs because they were more accessible. One participant used a bassinet that worked for her because her arms were short and she could not reach into a traditional crib. Another participant explained that she put the bassinet on a table so she could reach her infant without having to bend down. Some participants used co-sleepers that were placed on the floor and others attached co-sleepers to their beds, so they could reach their infants without getting out of bed. A few participants also used a "Pack n' Play" because it was lower and more accessible than a crib.

Many participants utilised certain baby-care equipment to safely bath their infants. Some participants bathed their infants in infant bathtubs, which they placed on the floor or a table, so they could easily reach their infants. One participant explained,

**TABLE 2** Adaptive parenting strategies for mothers with physical disabilities caring for infants and toddlers

| Parenting strategy                                            | Definition                                                                                                                                                 | Sample quote                                                                                                                                                                                                                                                                                                                                                                                              |
|---------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Acquiring or modifying baby-care equipment                 | Baby-care equipment acquired or modified to assist mothers with caring for infants and toddlers, such as cribs, infant bathtubs, baby carriers, and slings | "I had a good friend of mine that made a sling, but she made it big enough that it went around the back of my chair, so the weight of it was on my chair but she was still secured up against me."                                                                                                                                                                                                        |
| 2. Adapting home environment and modifying mobility equipment | Adaptations made to homes, such as placement of furniture, that enable mothers to care for their infants and toddlers                                      | "We just learned to adapt the house so that I could minimize walking and things were set up different than a lot of my friends who had babies, how they had their house set up, but we made it very functional for us."                                                                                                                                                                                   |
| 3. Accessing information and supports                         | Experiences of mothers accessing information and supports relating to motherhood with a disability                                                         | "You know, towards the end when I wasn't working anymore, I would just sit at home and Google everything I could possibly think of. And I ended up, just through, you know, research on the Internet, finding what I could."                                                                                                                                                                              |
| 4. Developing communication strategies to facilitate safety   | Strategies used by mothers to compensate for physical limitations and ensure their infants and toddlers were safe                                          | "I mean we have very good communication between the two of us and she knows when I say 'no' or something, that I mean it...It's all in the way I think you raise a child, and the tone of my voice and I'm very clear in my expectations with her, and I've been that way since she was an infant, you know, and she started crawling around. She knew where she was allowed to go and where she wasn't." |
| 5. Receiving assistance from others                           | Physical assistance provided by others, such as spouses and family members, which enable mothers to care for their infants and toddlers                    | "I could not do all of that myself, so I always had someone helping me, but I always – I've always done whatever I can do, as much as I can do myself for her."                                                                                                                                                                                                                                           |

Bending over a bathtub at that point in time, I didn't feel like I had enough trunk strength to be able to do that for a long period of time, to lift them in and out of the tub while I was recovering and all of that.

Other participants used elevated bath seats in the bathtub, so they did not have to reach all the way into the bathtub.

Moreover, to safely hold or "carry" their infant, both inside and outside the home, participants used a variety of adaptive parenting strategies. For example, some participants utilised strollers to transport their infant because "it's easier to push them around than to just carry." Some participants adapted strollers to make them more accessible. For instance, one participant she places her feet on the back of the stroller to "keep connected to it and keep momentum" while she pushes her wheelchair. Another participant adapted her stroller, "we put in extra padding so I could reach in and get the baby out easier." Others used a car seat to transport their child, both inside and outside the home.

Many participants utilised slings or baby carriers, rather than carrying their infants in their arms. The participants reported using a variety of types of slings, including across-sling, Baby Bjorn, and Snuggli. Some participants attached baby carriers to their wheelchairs. One participant had a sling specially made, so it could fit around her and her wheelchair. Another participant explained that using a baby carrier allows her to "hold the baby more often." Moreover, one participant explained, "we used a ... backpack-type like baby carriers. And I would hang that on the front of me, and it would hook onto my wheelchair." Another participant explained how she carries her son: "He'll sit on the back of my chair, or he'll get on the front of my chair, 'Mommy will carry me.' You know? 'My mommy will carry me.' And you know, I do!" Some participants, however, were unable to find baby carriers or slings that they could use. Some mentioned having short torsos, others described difficulties finding one that worked with their wheelchairs.

In addition, some participants used pillows to hold their infant. One participant explained that she was able to hold her infant by putting the Boppy around her waist when she was in her wheelchair. Other participants used pillows, including the Boppy, to position the infant for breastfeeding. One participant reported using pillows while seated to position herself to care for her infant.

Although many of the participants say they benefited tremendously from adapted baby-care equipment, some of the participants reported frustration over the lack of availability of equipment. Other participants found the high cost of the equipment to be prohibitive. One participant tried several types of baby carriers but never found one that met her needs. Eventually she stopped searching, in part, "because they're expensive." Another participant said she had the "good fortune of being educated" and having a "good career," which allowed her to afford several different types of equipment. Another participant remarked, "But the only real modification that I've needed was the crib. And it's something that is not readily available unless you want to pay a pretty penny for it."

### 3.2.2 | Adapting the home environment

Several of the participants discussed the importance of their home being fully accessible to their needs and how that directly related to their parenting capabilities. For some participants, this meant ensuring baby-care equipment and supplies were "strategically placed around the house." A few participants mentioned having "landing pads" or "landing stations," which involved "spots in every room" where they could lay their infants down. Having these allowed them to safely rest if carrying became difficult. One participant explained, "I just always made sure that there were wipes and diapers in every room." Another participant reported, "I put everything where I needed to reach them." One participant explained,

... when he (husband) left for work in the morning would set us all up in the living room...he would have their swing and their bouncer and everything in the living room. And just kind of camped out in one room for the whole day, you know.

Participants also adapted their home environment, so that they could independently change diapers and dress their infants and toddlers. Some participants put changing pads on the floor or couch rather than use a changing table because it was more accessible. Other participants used desks or kitchen tables because changing tables were too high. One participant reported putting a changing pad on top of a book shelf. Another "flipped an Ikea bookcase on the side to use as a changing table and storage", so it was low enough for her to reach. Similarly, one participant had the legs of a changing table cut down to lower the height of the table.

For other participants, adapting their home environment meant ensuring that their home was structurally accessible. A few participants mentioned the importance of living in a one-story home, with all rooms were on the same level. Others described having accessible kitchens with lower cabinetry and sinks. According to one participant, "Everything was accessible. We've always catered to me."

### 3.2.3 | Accessing information and supports

Many of the participants emphasised the importance of ongoing access to advice and information, particularly from other parents with disabilities. Several of the participants used the Internet, especially Facebook groups, to connect with their peers. One participant explained,

And since then I've been in contact with a lot of other moms with [same disability] like what I have, and so they have been a tremendous help as far as kind of giving me some tips and tricks and ideas. And we kind of brainstorm together a lot of times.

Another participant said these online communities allow parents with disabilities "to talk to each other about what it was like and how did you

adapt things ... The way I adapted things and the way I did things may help somebody else doing it in a way that's easier for them." Similarly, one participant explained, "I feel a little bit more safe in there and that has more kind of open discussions about pregnancy and parenting issues with [same disability]." Moreover, another participant started a website for mothers with the same disability, so that she would be able to connect with her peers.

Other participants described the importance of being members of disability organisations. For example, a few participants mentioned the importance of Little People of America, and one participant remarked, "It helps to be part of the community, you know? We are very involved with our community ... so we share a lot of friends, and we hear a lot of war stories." Another participant stated,

I think having support from people who have similar disabilities and have been through raising children in a different way helps. I have lots of friends, so if I ever have a challenge, I could turn to them and say, 'What do you suggest?'

Notwithstanding peer supports, many of the participants were frustrated by the lack of available information on parenting with a disability. One participant remarked, "I think that the biggest frustration for me was the lack of information on how to care for my babies once they were there... I couldn't find resources on, you know, available things to help disabled parents raise babies." Another participant said she "searched desperately" for information, to no avail. One participant explained that she read a lot of parenting books "but none of them really pertained to raising a child and having a disability." Another remarked, "...It just drove me crazy that I could not find a single person to talk to who had been there and done that."

Other participants were frustrated by the paucity of supports available for parents with disabilities. For example, one participant tried groups for mothers but never felt welcome because of her disability, remarking "disabled moms we're often isolated." Another participant wished there were more resources, explaining she wished she "found more people online who were like, hey, you know. I've done this before. Here's what I did." Similarly, one participant explained "we need a network of women who have had babies that can say to these mothers, you know, it's OK, everything's fine." Another stated, "I definitely could have gone for some sort of help for the postpartum because that was really, really hard. It would have been really nice to have connected with another mom with a disability so I didn't feel like the only one."

Participants reported varying experiences related to accessing supports, such as occupational therapy. One participant met with an occupational therapist prior to giving birth to practice parenting tasks, such as diapering and bathing, with a baby doll. Another participant stated that she was "pretty prepared for everything." However, one participant tried seeing an occupational therapist but said it "wasn't helpful" explaining,

The occupational therapy part was a little bit more frustrating because I felt like what I wanted to do was,

you know, to learn again those strategies to help with carrying my kids or to help with, you know, figuring out different ways to deal with them. And ... they had no idea what to suggest. They called the local rehabilitation hospital, and they had no idea what to suggest.

Another participant considered working with an occupational therapist but stated "they admitted that like they really had never dealt with anything like that before in terms of the parent being the one having the disability."

### 3.2.4 | Developing communication strategies to facilitate safety

To compensate for their physical limitations and ensure their infants and toddlers were always safe, some of the participants described communication strategies they used. One participant remarked, "all I had was really my voice. And so, we kind of accommodated to where she did start to learn my voice." Another participant discussed discipline and using "conditioning" and "positive reinforcement" to offset her physical limitations.

Developing communication strategies to ensure safety was especially important for participants when they were in the community with their infants and toddlers. One participant explained,

I taught her very young that you hold a hand. Even now, we still reinforce a lot of safety things... Like when you're crossing the street with someone, you never play. It's not playtime. Street-crossing time is time to focus. And we always say things like, "We're crossing - we've checked here, we've checked here. Now it's safe. What do you think?" That kind of thing. Just a lot of education and reinforcement.

Similarly, one participant, recalling experiences with her daughter, stated,

The few times she's not where I can see her, you know, and I tell her, I said, 'hey, that's not OK, I always need you to be where I can see you,' she corrects it, and that's just ever really been a problem with her.

Likewise, one participant explained that in order to keep her son safe as a toddler in the community, such as at the store, she would "keep him engaged." By continuously interacting with him and keeping him busy, he did not "get the idea of running off."

### 3.2.5 | Receiving assistance from others

For some of the participants, receiving physical assistance from others was an important parenting strategy. Some of the participants received help with parenting tasks from their extended families while others depended on the other parent. A few of the participants

received personal assistant services that helped them. There was variance in what participants needed assistance with. Many reported receiving physical assistance with household chores, such as cooking, laundry, and cleaning. Other participants needed physical help to enable them to care for their infants and toddlers. One participant had her husband place their daughter in her arms on a table, so she could give the infant a bottle. Another participant could feed her infant but needed help with burping. Other participants explained that at night the other parent would get out of bed and help their infant if a feeding was needed. Some participants needed physical assistance during bath time with lifting their babies in and out of the tub. One participant reported, "I already had it in my mindset that there was a lot of things I wasn't going to be able to do on my own and...I try to figure out, you know, simple ways that'll kind of help me do stuff with her." Several of the participants explained the importance of dividing up parenting responsibilities based on their abilities. One participant explained,

But it's been a learning process, and we figured it out as we go. I mean, for example, I can't change a diaper. So, my husband will do the diapers, where I'll feed her, because I'm able to do that. So, it's like we have our own jobs of, you know... I do as much as I can, and then he'll fill in where I'm unable to.

In addition, some participants received help with caring for their infants and toddlers from personal assistant services while others were unable to access this type of support. One participant explained that she "pays out of pocket" for someone to assist her but that she will not be able to afford to do so long term. A few participants receive publically funded personal assistant services but are not allowed to use the services to assist with parenting tasks. One participant remarked,

I'd like to be able to make enough money where I can just cut them out completely and just be on my own, and I'd make my own rules and you know, if I want them to do this, they can do that, you know?

Another participant, echoing that sentiment, explained,

The PCA programme is not meant for childcare. And so, the whole time, if you're getting a PCA to help with any childcare whatsoever you feel guilty, you feel like you're doing something wrong. You feel like you might get arrested by the state and thrown to jail. You don't know what's going to happen. It's terrifying.

## 4 | DISCUSSION

This study provides information important to understanding strategies mothers with physical disabilities use to care for their infants

and toddlers. Findings indicate that mothers with physical disabilities utilise a range of adaptive parenting strategies to assist with childrearing, including purchasing or modifying baby-care equipment, adapting their home environment, receiving ongoing advice and information from peers, developing communication strategies to facilitate safety, and receiving assistance and support from others. Nevertheless, mothers with physical disabilities also experience a lack of available information and supports as well as accessible baby-care equipment. These findings have important implications for healthcare and social work practice and policy.

Findings from our study, consistent with prior research (Wint et al., 2016), demonstrate the importance of adaptive baby-care equipment and home modifications for mothers with disabilities. However, some participants in the present study were priced out from purchasing needed equipment because of its high costs. This is particularly notable because while most of the participants in this study had college education and higher income, most mothers with physical disabilities in the United States live in poverty (Horner-Johnson et al., 2016; Parish, Magaña, & Cassiman, 2008). Moreover, some participants had difficulty finding appropriate equipment, which is consistent with past studies that have revealed a dearth of adaptive baby-care equipment (National Council on Disability, 2012; Kaiser, Reid, & Boschen, 2012; Shpigelman, 2015). Although some mothers with disabilities may encounter challenges related to caring for infants and toddlers, most difficulties can be ameliorated with access to appropriate equipment and adaptations (Tuleja & DeMoss, 1999). Indeed, research indicates that the combination of adaptive parenting techniques and adaptive baby-care equipment produces the most successful outcomes for parents with disabilities (Kaiser et al., 2012; Tuleja & DeMoss, 1999). Hence, the availability of adaptive baby-care equipment must be increased and information about these resources must be widely disseminated to mothers with disabilities. Financial resources must also be available for these families to purchase equipment and make adaptations to their home environment. Healthcare and social work professionals must also acquire information on the types of equipment and modifications available, so they can best support mothers with physical disabilities as they care for infants and toddlers.

This study also reinforces the need for the development and implementation of peer support services for mothers with physical disabilities (Andrews & Ayers, 2016; National Council on Disability, 2012; Shpigelman, 2015). Several of the participants described their informal networks for support and the importance of having a network of other parents with similar disabilities to obtain information, ideas, and resources whereas others indicated that they would have benefited from peer supports, particularly during early motherhood. Accordingly, resources should be devoted to developing and implementing peer supports. Healthcare and social work professionals should also encourage mothers with disabilities that they work with to seek out opportunities to network with other parents, especially through social media. Likewise, disability organisations, such as independent living centres which offer peer supports to people with disabilities, could expand services to support parents with disabilities, if

their funding streams were increased and they received appropriate training. Fortunately, new resources for peer support have recently been developed, including the Disabled Parenting Project (<http://www.disabledparenting.com>), an online community for parents and prospective parents with disabilities, which is part of the National Research Center for Parents with Disabilities (<http://www.centerforparentswithdisabilities.org>).

Additionally, although the participants in this study did not specifically discuss the stigma they encountered as mothers with disabilities, findings from prior studies suggest the importance of accessing peer supports to assist with coping with these challenging experiences (Iezzoni et al., 2015b; National Council on Disability; Powell et al., 2017; Shpigelman, 2015). As such, peers supports, resources, and information about their legal rights should be readily available to mothers with disabilities to assist with addressing any discrimination they encounter (National Council on Disability, 2012; Shpigelman, 2015). Further, future research should investigate strategies used by mothers with disabilities to combat stigma and discrimination.

Moreover, publically funded personal assistant services should be expanded to allow for help with childrearing tasks (Jacob, Kirshbaum, & Preston, 2017; Lipson & Rogers, 2000; Prilleltensky, 2003; Shpigelman, 2015). Although receiving personal assistance would greatly assist some mothers with disabilities, most publicly funded personal assistant services programmes do not include assisting with parenting tasks because childrearing is not considered an instrumental activity of daily living (Mitra et al., 2016; National Council on Disability, 2012). Moreover, some mothers with physical disabilities are unable to pay out of pocket for personal assistant service to help with parenting, leaving them with inadequate supports. Notably, in 2017, the Disability Integration Act (S. 910, H.R. 2472) was introduced in the United States Congress. If passed, this legislation would allow personal assistant services to help with childrearing. Expanding such services would undoubtedly improve outcomes for both children and mothers.

Healthcare and social work professionals are in a unique and important position to support mothers with disabilities in their caregiving role as they develop adaptive parenting strategies, especially throughout early motherhood. Nonetheless, healthcare and social work professions, including those who work with women with physical disabilities during the time of their pregnancy, often lack knowledge of adaptive parenting strategies and how to support mothers with disabilities and their families and may have preconceived ideas about adaptive parenting strategies (Lipson & Rogers, 2000; Mitra, Akobirshoev, et al., 2017; Mitra, Smith, et al., 2017; Wint et al., 2016; Payne & McPherson, 2010; Tuleja & DeMoss, 1999). However, with the appropriate training, healthcare and social work professionals can assist mothers with identifying adaptive parenting equipment, modifying their home environment, and developing effective strategies to assist mothers with childcare (Wint et al., 2016). Therefore, it is imperative that healthcare and social work professionals receive ongoing training related to adaptive parenting strategies and up-to-date information about adaptive parenting equipment. Perinatal healthcare clinicians should be prepared to provide referrals to

occupational therapists, in-home supports, and other services, as needed or requested by the mothers. Further research is needed to elucidate specific strategies that healthcare and social work professionals should recommend to mothers with physical disabilities.

Although this study offers important insight into the early motherhood of women with physical disabilities and their use of adaptive parenting strategies, there are limitations which should be acknowledged. First, because the majority of the participants had a college education, were non-Hispanic White, and spoke English, the sample lacks diversity and may not reflect the experiences of all mothers with physical disabilities. Second, because the study was voluntary, mothers who chose to participate may have had experiences that are not representative of others mothers. Third, because recruitment was primarily done through social media, mothers with physical disabilities who lack Internet access may have been excluded from the study. Fourth, because the study included mothers who had given birth as far back as 10 years, recall bias is possible, especially for mothers who gave birth many years before the interview. Therefore, future research should aim to explore the use of adaptive parenting strategies by mothers with physical disabilities from diverse backgrounds. Finally, although we attempted to present a balanced report of the participants' experiences, it is possible that their accounts were distorted by the researchers' perceptions as well perceived imbalances of power between researcher and participant. To counter potential power imbalances or biases, we used "insider and outsider" researchers. Notably, however, our use of "insiders" as members of the research team is consistent with calls for disability research to be conducted by researchers with disabilities (Shakespeare, 2006).

## 5 | CONCLUSION

Despite the study's limitations, we believe that it provides important information about the adaptive parenting strategies used by mothers with physical disabilities throughout early motherhood, including purchasing or modifying baby-care equipment, adapting their home environment, receiving ongoing advice and information from peers, developing communication strategies to facilitate safety, and receiving assistance and support from others. At the same time, our study also found that mothers with physical disabilities experience a paucity of available information and supports as well as accessible baby-care equipment.

This study has important implications for healthcare and social work policy and practice. First, it is essential that healthcare and social work professionals must devote greater attention to supporting mothers with physical disabilities. To that end, healthcare and social work professionals should be provided the training and information needed to support mothers with physical disabilities caring for infants and toddlers. Second, mothers with physical disabilities need greater availability of supports and equipment as well as information on adaptive parenting strategies, baby-care equipment, legal rights. Third, additional research is needed to investigate the use of adaptive strategies by mothers with physical

disabilities from diverse backgrounds and across all stages of motherhood as well as strategies employed to address stigma and discrimination.

## FINANCIAL DISCLOSURE

Authors have no financial interests to disclose.

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