

Becoming Mothers: Experiences of Mothers with Physical Disabilities in Ontario

Key Findings and
Recommendations
from a Qualitative
Study

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Background

While women with physical disabilities are becoming pregnant at roughly the same rate as non-disabled women (Iezzoni et al., 2013; Horner-Johnson et al., 2016), we still do not have a great deal of information about how they experience pregnancy, labour/delivery, and early motherhood, including breastfeeding. This is especially true in Ontario and Canada more broadly. Unfortunately, research indicates that many women with physical disabilities experience significant perinatal health disparities. Notably, women with physical disabilities report interactions with perinatal care providers who have limited understanding of disability and they experience high rates of caesarean delivery and preterm birth (Signore et al., 2011; Mitra et al., 2015; Tarasoff, 2017).

A qualitative dissertation study was conducted to learn more about how women with physical disabilities in Ontario experience the perinatal period and early motherhood. From November 2014 to November 2015, thirteen women with physical disabilities who had given birth in the last five years were interviewed.

This report shares key findings from that study, including findings regarding perinatal care experiences and outcomes, as well as provides recommendations to better support pregnant and parenting women with physical disabilities.

This report is intended to be read by women with physical disabilities who wish to become mothers, their partners and other support persons, community organizations serving people with disabilities, perinatal health and social service providers, and researchers interested in the perinatal and motherhood experiences of women with physical disabilities.



Participants

Disability-Related Characteristics

Thirteen women with a range of physical disabilities participated in the study, including four born with cerebral palsy and three who acquired a spinal cord injury.

Arthritic condition	
Juvenile idiopathic (rheumatoid) arthritis	1
Ankylosing spondylitis	1
Type not specified	1
Cerebral palsy	4
Congenital amputation (sybrachydactyly)	1
Congenital blindness (leber congenital amaurosis)	1
Congenital bone growth disorder (spondyloepiphyseal dysplasia)	1
Degenerative disc disease	1
Fibromyalgia	1
Muscular dystrophy	1
Osteoporosis	1
Scoliosis	
Neuromuscular scoliosis	1
Congenital scoliosis	1
Spinal cord injury	
Lumbar Spinal Cord Injury, L1-L5 (partial paralysis)	1
Cervical Spinal Cord Injury, C4-C6 (quadriplegia)	2

Many participants reported living with more than one disability or health condition, as well as reported experiencing secondary or associated conditions, such as fatigue and chronic pain.

Pain always present	7
Pain comes and goes	3
No pain	3

Most use an assistive device on a regular or daily basis, including a cane, power wheelchair, scooter, crutches, and other devices and tools for mobility and to assist with daily activities (e.g., tasks that require hand dexterity). Just over half of participants indicated that they require assistance from others to complete daily activities.

Socio-Demographic Characteristics

- Average age 36.5 (range 26 to 44)
- Predominately white, heterosexual, married or in a common law relationship
- All reside in large urban centres
- Few live in subsidized housing (n=2)
- Most have a household income of \$60,000 or greater (n=8)
- Most have a university degree (n=11)
- At the time of the study, most reported that their main daily activity or responsibility was caring for their family, though several were also working

Perinatal Care and Outcomes

Data below apply to most recent birth experienced by the participants in this study.

Prenatal Training

- Nine participants reported that they attended some sort of prenatal training class or course, with two of these participants indicated that this training was a “crash course” in hospital
- Many of those who did attend a prenatal class, however, reported that the class was not particularly relevant or helpful to them as a woman with a disability; in all cases, participants noted that they believed that they were the only woman with a disability in the class

Care Providers

- 11 participants had an obstetrician as their main perinatal care provider
- 3 participants had a doula during pregnancy and/or present with them during labour and delivery

Type of Birth

- 5 had vaginal births
- 8 had caesarean deliveries; 3 were unplanned/emergency

Outcomes

- In all three cases of unplanned caesarean delivery, the participant and/or her infant had a poor outcome (e.g., low Apgar score, mother in intensive care, mother with major blood loss)
- One participant had twins
- Three participants reported having a preterm birth (<37 weeks gestational age) (one of these three includes a set of twins)
- Five participants reported experiencing what they considered to be postpartum depression and/or anxiety
- Five participants shared that their newborns spent time in the neonatal intensive care unit (NICU), including two because of medication withdrawal (i.e., withdrawal from medication that participants had consumed to manage their disability-related symptoms; 2-4 week stays) and one due to maternal complications, wherein the participant herself spent eight days in the ICU

Perinatal Care Experiences

While most participants generally enjoyed being pregnant and not all had poor care experiences, most did identify barriers to perinatal care or experiences that made their perinatal care experience unsatisfactory. Notably, many participants felt that their perinatal care providers did not have a thorough understanding of their disability, or seemed to overlook their disability and disability-related needs to focus solely on their pregnancy.

"I kept trying to say to people I have a disability and I need some help and I need someone to pay attention to that. And I really wasn't getting a lot of uptake so in one way, it was kind of the opposite. People would say to me 'oh well, you know, like look at you, you'll do fine. You get along fine. You're great. You'll just figure it out, I'm sure.' Well, I don't think I can figure this out on my own; I would like some help."

Several participants described experiencing inaccessibility in perinatal care settings. Participants reported difficulty accessing basic facilities like washrooms and equipment like examination tables, and some also noted that spaces like the neonatal intensive care unit (NICU) were physically inaccessible for them.

"There were no accessible beds and so my partner always had to lift me up onto the bed. And it just seemed really ridiculous to me because out of any place, this should be where there should some specialized equipment. Every time you go in, you have to provide a pee sample and the washroom wasn't accessible. It didn't make sense to me. I felt like disability wasn't an expected part of this high risk clinic, even though high risk was usually associated with medical conditions."

Accessing appropriate information about

pregnancy and disability, even online, was difficult for participants. Many reported that although their care providers seemed eager and willing to learn, they seemed to lack knowledge and prior experience caring for women with physical disabilities.

"I had a hard time finding information.... Even online, I dug around the internet and there just wasn't a lot of information. What studies I did find were vague and said stuff what I already knew. I found the high risk [pregnancy] unit affiliated with hospital X when I started saying I would like to try having a kid. We had a consult with them and they basically said come back when you were pregnant so that was the extent of the information I was able to find. That was very frustrating. There were a lot of unknowns. I was told that the pain could be the same, could get worse, or could get better with pregnancy."

Participants encountered negative attitudes from some health care providers, including administrative staff, ultrasound technicians, and nurses about their fitness for motherhood. A lack of communication among perinatal and disability-related health care providers was also noted by participants.

The barriers that participants described encountering in perinatal care settings ultimately suggests that perinatal care settings are not set up with women with physical disabilities in mind. Moreover, ironically, while research indicates that women with physical disabilities may be more likely to have preterm birth and low birth weight babies, findings from this study suggest that the NICU is designed only as a place for "sick" babies, not "sick" or disabled parents.

For more information about participants' perinatal care experiences, see Tarasoff (2017).

Breastfeeding

Just over half of participants reported that they had breastfed or were breastfeeding their most recently birthed child (for a few days up to over 2 years in duration), whereas three indicated that they had tried/attempted to breastfeed. Three participants chose not to breastfeed their most recently birthed child. Reasons for not breastfeeding included personal choice and disability-related challenges. Moreover, maternal and infant complications, including infants spending time in the hospital due to medication withdrawal, made initiating breastfeeding challenging for some participants. Relatedly, some participants' need to go back on their medication shortly after birth to manage disability-related symptoms informed their breastfeeding decisions.

"Yeah, I did [breastfeed] for a time, not very long, a couple of weeks because I had to go back on my medications. Because within the typical prognosis of what they say with people with inflammatory arthritis is that within 4 to 6 weeks your body will actually flare. I was starting to notice that within about a week so I tried to nurse her a little bit. Then I moved her over to formula."

Many felt that they did not receive adequate disability-specific breastfeeding support.

"I was surprised that I didn't have any special attention around breastfeeding [in the hospital]. And I think that I actually should have had more of an intensive support."

Four participants shared that they had hired a postpartum doula and/or lactation consultant.

Bonding and health benefits were two of many reasons why breastfeeding was important to participants. Further, because many were physically unable to engage in some parenting activities, such as bathing their child and changing diapers, breastfeeding seemed to be particularly important for some participants.

"It was the most important thing for me [to breastfeed] because and maybe it's because—I don't know if it was connected to a disability or not—but I was determined to do whatever was the best thing for him. So it was clearly the best thing for him, based on what I read. So he was gonna be breastfed for as long as I could do it and still manage it. That's why. That's why I want to make it work."

Children and Childcare

Number of Children	
1	7
2	4
3	1
4*	1

*includes step-children

- Three participants had a child under the age of three months
- Nine participants (including one of those with a child younger than three months old) had a child or children ranging in age from ten months to three years
- All children live with at home with the participants; no participants reported ever losing custody of their child or children
- Two participants indicated that they had planned to have more children and three reported that they were not sure about having more children

Childcare

- Participants reported a range of childcare options including private/independently paid childcare (i.e., nannies), subsidized childcare (often via the Nurturing Assistance program: <http://www.dfontario.ca/df/en/what-is-nurturing-assistance.html>), and informal or familial childcare support, including help with childcare from participants' partners and mothers
- Some participants received help with childcare daily, whereas others needed assistance with childcare on an occasional basis or task-specific basis

Parenting Challenges

For many participants, having a disability made it difficult to engage in some physical parenting activities.

"Like the pain of my limitations, it does colour every aspect of how I look after him. I wish I could do more for him and I get really frustrated by how limited I feel. I wanted to do more. I like to take him on longer walks and to different activities and I just don't have the energy. I wish I did. That's where it [having a disability] has kind of overshadowed my sense of being a mother."

"With my first son, I would go to [play] groups. And moms would sit on the floor with their kid. I can't sit on the floor."

Though participants' disabilities limited them in many ways, they too came to recognize that many spaces for children and parents are not accessible. For instance, some talked about how the surfaces of a playground made a difference in terms of accessibility (i.e., sand was difficult to navigate in a wheelchair) and how stairs as the only way to get into a space made it difficult for them to participate in their children's activities.

"They go to a school that's not wheelchair accessible and it bothers my son that I can't go see his classroom."

"We went trick-or-treating for Halloween ... all I can do, because no one's house was ever accessible, is go around and be on the sidewalk. So I never got to go to the door or anything with her [daughter] and that was kind of crappy."

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Children and Childcare (continued)

“There’s all these things that are designed to help women on maternity leave not go crazy and none of them were accessible. ... It’s just a complete lack of services and lack of imagination on who has kids and what they might need.”

Some participants shared that they and their partners found creative ways for them to engage in parenting activities.

“I couldn’t really carry her around very far like from her bed to the chair was fine, but I couldn’t carry her around my apartment. Luckily, partner is a very inventive person so he invented all these things to help me. He invented this trolley that I could push her around in. And once we got my scooter, we figured out how to carry her around on my scooter. We built this device because I can’t pick her up from the floor until she was old enough to crawl up [on] me, we got this device where I could put her in a basket and then you could crank it up and lift her up to different heights.”



Microaggressions and Surveillance

Microaggressions refer to “the brief, commonplace, daily verbal, behavioral, and environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative ... slights and insults to the target person or group” (Sue et al., 2007).

Disability or ableist microaggressions include things like messages of undesirability, burdensome, exclusion, assumptions, pity, and astonishment (e.g., the realization that a person with a disability is capable of achievements) (Bell, 2013).

Some participants reported that others did not imagine pregnancy as a possibility for them or recognize them as being pregnant in the same way that they might recognize a pregnant non-disabled woman.

“I had people look at me two or three times when I’m 8 months pregnant ‘you’re not?’ and I’d sort of smile at them and nod my head and they’d go ‘no, but you’re not’ and I was like ‘yes’ and they’d ask again, over and over, and I’d be like ‘yes, I’m pregnant!’ and they’d go ‘oh’ [as if they were surprised] ... I found that I was sort of [ripped off] in that way because everybody else, you know, people would walk up to them [and ask] ‘oh, when are you due?!’ and I didn’t really have any of that...”

Some participants reported that others did not recognize them as mothers.

“I took the stroller and pulled it alongside my [wheel]chair and this random stranger comes running up behind me ‘excuse me, excuse me, is he yours?’”

Participants frequently noted that they were asked questions that non-disabled mothers probably would not be asked and experienced differential treatment, including heightened scrutiny and surveillance.

“I remember being mad that a lot of people thought just because I have a disability that my son was going to be neglected or whatever.... If I was able-bodied, I would have gone home after like 2 days and that would have been the end of it. ... But no, because I had a disability I had all these people I had to meet with and see and prove things to [before I left the hospital with my son].”

“All parents face exhaustion and kids are an intense experience. But then adding ableism and experiences of discrimination onto it, like, it’s challenging. ... parenting is such a judgmental activity. It’s hard to be parenting anyway without people sizing you up all the time. I don’t think I’ve been in a space where I’ve felt so sized up so often. I’ve been in a lot of experiences where people assume I can’t do things [as a parent].”

Pushing Back

While participants encountered many barriers during the perinatal period and early motherhood, their experiences reveal that women with physical disabilities are resilient and defy commonly held beliefs about what women with physical disabilities are capable of or what roles they should occupy.

“Somebody made a comment to me, ‘Oh, you’re doing so well,’ you know, going up these couple of steps. And I just kind of looked at her and I’m like, ‘Yeah, and I have a 3-year-old son that I was pregnant with, too, you know?’ ... sometimes it annoys me that people make comments like, ‘Oh yeah, look at you’ kind of thing. They don’t realize that we’re capable – I’m capable of much more than managing three steps.”

Women with physical disabilities have much to offer in terms of thinking about our bodies and what it means to be a parent.

“I thought pregnancy was the hard part and it really wasn’t. It was easier than [I expected]. All the able-bodied women that I knew were complaining. ... I think a lot of able-bodied women are like ‘ugh, I don’t have control over my body now and all the sudden I have to pee 5 times in the night.’ I know what that’s like already, so it wasn’t really shocking to me to have the limitations, in terms of what I could do. You have to go with it and make adjustments. I think if you are able-bodied, you might have a harder time with that because you are just used being able to do whatever you want to do, whenever you want to do it.”

Research indicates that some non-disabled women experience the bodily changes associated with pregnancy as a burden, discomfort, and/or surprise. Findings from this study suggest that women with physical disabilities may have a different or even advantageous embodied experience of pregnancy compared to non-disabled women; women with physical disabilities may be better able to adapt or even embrace the bodily changes associated with becoming and being a mother given their experiential knowledge of living with a disabled body, a body that is not always controllable or congruent with how one might perceive themselves.

In some ways, participants subverted intensive mothering ideology, that is, the ideology that holds that mothering is “child-centered, expert-guided, emotionally absorbing, labour-intensive, and financially expensive” (Hays, 1998). Rather than being individually, physically responsible for many childcare tasks, participants had to rely on others. Participants embraced interdependence, revealing that being a parent is more than just engaging in physical activities or play with your child, and that, in reality, for most, “it takes a village to raise a child.”

“Whether I’m the one doing the ironing or somebody else is doing the ironing, I’ve got to direct that. Or are they bonding more with your kid? No. I’ve never had an issue of my child bonding more with the other person. It’s just helping with the physical stuff.”

Pushing Back (continued)

Participants shared that being a parent with a disability provided opportunities for learning about difference for their children.

"[My son] asked me one time about something and I said, 'well, why is that?' He's like, 'we're all different and it doesn't matter' so he knows. He's learning. That's something that I love being a mom and being disabled about, because there are so many parents and children who still make fun of people who are different and it should not be that way. I'm proud that I will have a child or children that don't do that."

"I know my son has become very sensitive to accessibility. He likes everything to do with the public transit system. He wants to grow up and be an engineer and design the city – and redesign and make sure everything's accessible. Or we go somewhere and things are not accessible and we heard him commenting, oh, that's not right, that shouldn't be. ... I didn't have kids to raise advocates, but they see it from another perspective."



Recommendations

For Women with Physical Disabilities

Advocate for what you know and how you experience your body.

“Make sure you know your body and you know what you need to be able to ask the right questions because if not, you could easily get lost and they could just end up doing what they think is right.”

Know your rights. Don't be afraid to ask for help. If possible, have others to advocate for you. Advocating for yourself all the time can be exhausting!

“I guess the main part is having a good team in place and you really have to advocate for yourself and not be afraid to ask questions. Let people know what your needs are because in a lot of ways people know their disability best. ... continuing to advocate for yourself. But it gets exhausting, especially when you're pregnant. Again and again, and to make sure you have some moral support, whatever your partner or family situation is; I found that really essential. And when I was exhausted I would just say to my husband, I need you to tell someone this. I can't repeat it; this is the 10th time I've repeated it.”

Try to establish a relationship with care providers; consistency of care can be important especially because not all providers will have experience with women with physical disabilities or your specific disability.

Do advanced planning to ensure the best outcomes for you and your child (Long-Bellil et al., 2017). Do your best to communicate with your both perinatal and disability-related care

providers and encourage them to communicate with one another.

Many women in this study reported that they did know any other mothers with physical disabilities and would have liked to. Share your experiences with others – in person, online, connect with groups, etc. (if available, and if you want)

“It would be great to sit and talk to other moms [with disabilities] because there's a certain part of the experience that I don't think other people get.”

See lezzoni et al. (2017) for more recommendations about pregnancy from women with physical disabilities to their peers.

For Community Members

Be more understanding and open-minded.

“I hope people [can] be understanding ... more sympathetic and supportive as opposed to judgmental when they see someone with a disability and a child. ... We constantly judge each other as parents. ... I think if everyone approached the process with a bit more sympathy and understanding it might be easier to ask for help and to get the help that you need, both from the medical community and from the community at-large.”

Think about where your assumptions might come from. Ask questions respectfully (i.e., don't be intrusive). Women with physical disabilities already encounter enough barriers on the journey to parenthood; they don't need negative comments from strangers on top of that.

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Recommendations

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“I think people need to know that there are mothers with disabilities that are doing fine. I think that’s the critical piece, right? ... this sort of concern around hypervigilance on the part of other people [is problematic]. You can feel a bit over-monitored or wonder would somebody ask another mom that question. I think all of that only gets combatted with experience. It’s the same thing with lot of the stuff around disability and stigma and not understanding. It only really gets combatted if you learn about [it] in a different way. Usually it’s through personal interaction with somebody that you meet or you meet somebody and you suddenly realize that this is not the craziest way to be in the world. This [being a person with a disability] is a real, legitimate life path that a person has and they eat eggs and whatever [like everyone else does].”

For the most part, women with physical disabilities live their lives just like non-disabled women.

For Researchers

In Ontario, we now know more about the perinatal care experiences and outcomes of women with intellectual and developmental disabilities at a population level (e.g., see Brown et al., 2016; Brown et al., 2017); however, we know very little about the perinatal care experiences and outcomes of women with physical disabilities. Specifically, we need (more) research on:

- The fertility rate of women with physical disabilities
- Prenatal care; labour and delivery

interventions, including pain management; type of birth; satisfaction with care; breastfeeding outcomes

- Maternal and infant outcomes; mediators and risk factors for adverse outcomes, including postpartum depression
- Perinatal health and social service providers’ attitudes and knowledge of women with physical disabilities
- Why some women with physical disabilities become mothers and others do not (i.e., do all women with physical disabilities have the same opportunities for childbearing?)

It is also recommended that researchers work with care providers and women with physical disabilities to develop resources.

For Perinatal Health and Social Service Providers

Be honest about what you do not know. Lack of knowledge might lead to unsatisfactory care experiences, or worse, poor outcomes.

“They had experiences with persons with disabilities but not specifically with persons with cerebral palsy. So, I wish she had made it more straight with me about that. ... it would have been more beneficial if they actually had somebody who had been through the experience of having someone with cerebral palsy or like a physical disability—like if they had said to me ‘you know what, we had this you know patient and they had this and this is what happened’—if they sort of told me some of those stories, it would have put me more at ease.”

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Recommendations

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If you don't know something about a patient's disability or disability-related needs, ask questions in a respectful manner.

Educate yourself. See the References and Resources pages of this report.

Trust women with physical disabilities' embodied knowledge; they know their bodies best.

Communicate and if possible collaborate with disability-related care providers. Some participants in this study reported that their disability-related providers had knowledge that their perinatal care providers did not.

"I asked so many times for them [obstetrics] to touch base because I know my rheumatologist has had many pregnant women [as patients].... He has a lot of experience but they never contacted him and I still remember, he was so angry after this whole [situation] because he came to visit me in ICU."

Disability-related providers could serve as an important resource during pregnancy and labour/delivery, and in turn may help mitigate poor outcomes.

Work with researchers and women with physical disabilities to develop resources. For instance, there is a need for resources regarding breastfeeding and parenting specific to mothers and parents with disabilities.

"There was a real focus on just getting me through the pregnancy. At the time, there wasn't a lot of focus on what we're going to do after, in terms of supports and how we were going to manage the logistics of looking after a newborn."

For Policymakers

More research funding is needed to address the perinatal health of women with physical disabilities in Canada. The National Institutes of Health had a specific call for projects on the topic of pregnancy in women with disabilities. Many of the studies funded through that call (e.g., Iezzoni et al., 2013; Mitra et al., 2016) fill important gaps in the literature, yet findings from these studies are specific to the American context and thus do not necessarily reflect the realities of women with physical disabilities in Canada.

Ensure that legislation and policies regarding accessibility are implemented in perinatal care settings; arguably, much of the disability-related legislation in Canada focuses on people with disabilities as consumers and fails to address their right to health (i.e., disability should not only be understood as a poor outcome).

Consult women with physical disabilities when creating spaces for pregnant and parenting women and their families, including NICUs, maternity wards, and playgrounds. Making spaces more accessible for women with physical disabilities makes them more accessible for everyone.

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Resources

Interactive site for clinicians serving women with disabilities – An American Congress of Obstetricians and Gynecologists (ACOG) recorded slide program develop to assist women's reproductive health clinicians with their care of women with physical, sensory, and developmental disabilities: <https://www.acog.org/About-ACOG/ACOG-Departments/Women-with-Disabilities/Interactive-site-for-clinicians-serving-women-with-disabilities>

Pregnancy and Spinal Cord Injury – An information booklet for women with SCI produced by Vancouver Coastal Health's Sexual Health Rehabilitation Service, BC Women's Hospital and Health Centre's Maternal Fetal Medicine Service, Rick Hansen Institute, and Spinal Cord Injury BC: <http://scisexualhealth.ca/wp-content/uploads/2015/05/Pregnancy-and-SCI-booklet-V7.pdf>

The Disabled Woman's Guide to Pregnancy and Birth – A useful guidebook by Judith Rogers based on interviews with 90 women with disabilities: <https://www.amazon.com/Disabled-Womans-Guide-Pregnancy-Birth/dp/1932603085>

Eliminating Inequities for Women with Disabilities: An Agenda for Health and Wellness – A book edited by Shari E. Miles-Cohen and Caroline Signore that covers a range of topics including psychosocial health, interpersonal violence, health care policy, health promotion, disease prevention programs, reproductive and sexual health, and parenting with disability: <http://www.apa.org/pubs/books/4317418.aspx?tab=2>

Pregnancy and Parenting with Arthritis – Findings from a project identifying patient information needs regarding pregnancy and parenting conducted by the Canadian Arthritis Patient Alliance: <http://www.arthritispatient.ca/projects/pregnancy-parenting/>

Centre for Independent Living in Toronto – Parenting with a Disability Network: <http://www.cilt.ca/parenting.aspx>


Wheelchair Accessible Tips and Tricks I Learned as a First-Time Parent – Tips from a mom who uses a wheelchair: <http://www.newmobility.com/2016/12/wheelchair-accessible-tips-first-time-parent/>

Through the Looking Glass – A US-based, non-profit organization does research, offers training, and provides services for people with disabilities, including parents: <http://lookingglass.org/home>

The Only Parent in the Neighbourhood: Mothering and Women with Disabilities – A report by the DisAbled Women's Network/ Réseau d'action des femmes handicapées (DAWN-RAFH) Canada: <http://www.dawncanada.net/issues/issues/mothering/the-only-parent-in-the-neighbourhood-mothering-and-women-with-disabilities/>

Able Mothers: The intersection of parenting, disability and the law – A report by Laura Track for the West Coast Women's Legal Education and Action Fund: <http://www.westcoastleaf.org/wp-content/uploads/2014/12/2014-REPORT-Able-Mothers.pdf>

For more resources, visit <https://latarasoff.com/resources/>



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