

The “Other” Mother: Mothering with a Physical Disability in a Disabling Society

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ABSTRACT

Many women who live with physical disability are subject to the discriminating attitudes of a disabling society on a daily basis. When women who live with physical disability become mothers, they often face discrimination by health care professionals who may be misinformed about disability and pregnancy. Although feminism recognizes that able-bodied women often have negative experiences with health care professionals, there still exists an oversight of women who live with disability in feminist literature. By using feminist research methods, women who live with disability can be better incorporated into feminist literature, and can better convey their experiences to health care professionals and policy makers. By valuing and using these experiences, health care professionals and policy makers can work together with women living with disability in order to create a more socially and physically accessible society

Women living with physical disabilities are disabled not only by their individual impairments, but also – and often more so – by the social barriers placed in front of them. These barriers remain when a woman living with physical disability enters motherhood. Throughout the processes of pregnancy, childbirth, and motherhood, women living with physical disability often do not receive adequate professional assistance or social supports. This lack of support not only prevents women living with disability from gaining confidence in their motherhood, it also reinforces a divide between mothers who are viewed as able-bodied and mothers living with disability by cultivating a misunderstanding of impairment and motherhood. This creates social stigma surrounding those living with disability, casting doubt onto their mothering capabilities.

Acknowledging the need for better social and professional resources for mothers living with physical impairments, as well as recognizing and applying the knowledge and experiences of these women, can be achieved by gathering research that employs feminist methods, such as feminist standpoint epistemology. Gathering information by means

of feminist research methods can assist health care professionals in recognizing the value of the experiences of women living with physical disability, and how to better address their needs. The use of feminist research methods will assist in dismantling the social, physical, and informational limitations that reinforce the stigma surrounding mothering with a physical disability.

Many women living with a physical impairment report a lack of proper support from health care professionals when dealing with pregnancy and childbirth. Because of lack of research on disability and reproduction, “the attitudes of medical professionals towards disabled women as child bearers have often been based on myth rather than fact.”¹ These attitudes, combined with the general lack of knowledge many health care professionals have in terms of pregnancy and disability, can affect the care that women with disabilities receive, as well as their personal experiences with pregnancy. Carol Thomas, in her work on the female experience of disability, argues that it has become clear that women who live with disability have their decisions and experiences regarding pregnancy, childbirth and parenting affected by the ableism they may face.² Throughout a woman’s pregnancy, childbirth, and post-natal care, providers can be misinformed or biased about impairments, prescribe inappropriate treatments, and ignore women’s knowledge of their bodies and needs.³ When a woman who has a physical impairment becomes pregnant, the fear of “risk” comes to the forefront of physicians’ discourse: “would the health and/or survival of the foetus be put ‘at risk’ because the condition was hereditary or because of drug treatments? Would [the woman’s] own health be placed ‘at risk?’”⁴ The “risk factor” of being a mother with a physical impairment carries over from pregnancy into motherhood, where the child becomes “at risk” as a result of their mother’s disability:

1 V. Kallianes and P. Rubinfeld, “Disabled Women and Reproductive History,” *Disability and Society* (1997), 208.

2 Carol Thomas, “The baby and the bath water: disabled women and motherhood in social context,” *Sociology of Health and Illness* (1997), 623.

3 Kallianes and Rubinfeld, “Disabled Women,” 208.

4 Thomas, “The baby and the bath water,” 627.

[One] mother also experienced what she considered undue scrutiny by health care professionals who suggested her child was not meeting developmental milestones since she could not walk to stimulate him and was propelling him in a stroller when she needed to transfer him from one room to another.⁵

This notion of risk being transferred from mother to child can be linked to discriminatory attitudes towards disability that are possessed by many medical professionals. Despite claiming to be “scientifically objective”, “medical knowledge inevitably draws on deep-rooted cultural antipathy for, and prejudices about, people with ‘abnormalities’.”⁶ Disabled women feel as though they are under surveillance, a feeling that is well-founded as it is often assumed by professionals that they are incapable unless they can prove otherwise; “guilty until proven innocent.”⁷ The need to prove one’s capabilities proves difficult when one requires assistance for completing a certain task: often when assistance is required, incompetence is assumed.⁸

Women who live with physical disability are not alone in experiencing condescending “expert” attitudes from physicians and other health care professionals. Most women have negative interactions with health care professionals at some point in their lives, and experience a lack of control over their own bodies. Lack of control often results in a negative pregnancy and childbirth experience for many women⁹. While women who feel in control of how their pregnancy is managed often feel empowered, women who lack control may find their experience “disempowering, frustrating and disappointing.”¹⁰ Many women opt for having a “natural birth”, though the definition of what constitutes a natural birth varies from woman to woman. In general, it has been found that a constant aspect of natural births for many women is “not a complete lack of biomedical intervention, but rather [the] ability to make decisions and

5 Patricia McKeever et al., “.It’s More of a Production’: Accomplishing mothering using a mobility device,” *Disability & Society* (2003), 184.

6 Thomas, “The baby and the bath water,” 632

7 *Ibid.*, 636.

8 Victoria Radcliffe, “.Being Brave’: Disabled Women and Motherhood,” (Masters Thesis, University of Leeds, 2008), 36.

9 Katie M. Cook, “The Role of Choice and Control in Women’s Childbirth Experiences,” (Masters Thesis, University of Waterloo, 2010), 3.

10 Cook, “The Role of Choice,” 43.

thereby form their own birth experience.”¹¹ Feminism has encouraged women to take control over reproductive rights and have an active role in childbirth. Many women now want to “give birth rather than to be passively delivered”, and it is recognized that “the treatment of obstetric patients at the hands of (mostly male) obstetricians can denigrate the woman’s role in the birth process.”¹² Many women have experienced the condescending attitudes of health care providers during pregnancy and childbirth. This creates space for solidarity with women who live with disability, who are most often treated as “incapable of self-directed lives and choices, especially involving [...] pregnancy.”¹³ Within the context of pregnancy and childbirth, the concerns of the disability rights movement and the feminist movement are quite similar. In fact, able-bodied women and those living with impairments share many goals, including: “elimination of social attitudes that define women and disabled people solely on the basis of biological or physical characteristics; striving for self-determination; [and] giving voice to women’s experiences.”¹⁴ Giving voice to women’s experiences is an important aspect of feminist research and methodology, and one that can greatly assist bringing awareness to the struggles that women living with a physical disability face during pregnancy, childbirth, motherhood, and beyond.

Feminist research, and more specifically feminist standpoint epistemology, provides the basis for a better understanding of the experiences of oppressed women, and applies the knowledge of these women to activism towards social change.¹⁵ This process requires both knowledge building and a particular method of doing research that reflects the need to include women’s voices and experiences in the world that they live in. To better understand the experience of being a woman who lives with disability, there needs to be an emphasis on the lives of these women “as they themselves experience them, in order to achieve an accurate and authentic understanding of what life is like for women

11 Ibid., 3.

12 S.G. Doering, D.R. Entwisle, and D. Quilan, “Modeling the Quality of Women’s Birth Experience,” *Journal of Health and Social Behaviour* (1980), 12-13.

13 Kallianes and Rubenfeld, “Disabled Women,” 208.

14 Ibid., 203-204.

15 Sharlene Nagy Hesse-Biber and Patricia Leavy, *Feminist Research Practice* (Thousand Oaks: Sage Publications Inc., 2007) 55.

today.”¹⁶ Standpoint theory guides researchers to put the realities and experiences of marginalized groups of people at the center of their research, in order to better understand how social structures create this marginalization, and how social structures can be transformed to alleviate this marginalization.¹⁷ Feminist methods of gaining this understanding include in-depth interviewing, ethnography (the close study of a group of people, such as parents living with a physical disability) and autoethnography (self reflection on one’s personal experience as a member of a group of people). While these research methods are applied outside of feminist theory, what makes them feminist is the awareness of personal standpoints, as well as recognizing and working to overcome possible hierarchy in the researcher/researched dichotomy. Women living with disability need to convey their experiences as they have lived them in order for there to be a better understanding of disability, and for all women to “achieve a more objective standpoint on society as a whole.”¹⁸

For women living with physical disability, the opportunity to give some background on their experiences is rarely given when it comes to medical care, especially in pregnancy and childbirth. It is generally assumed by health care professionals that women living with disability will need particular forms of help, and that only the professionals themselves know best how to provide necessary assistance.¹⁹ In her article “Invisible and Centre Stage”, written to advise health care providers and policy makers, and based on her own experiences dealing with pregnancy and disability, Liz Crow writes of a positive experience with one hospital where she “was listened to by the midwives, offered suggestions [...] these staff knew that I was the expert of my own situation.”²⁰ However, not all of her experiences during her pregnancy and childbirth were positive, and when she did speak up about how she could be better be assisted she worried about creating conflict with those who would be supporting her through childbirth.²¹ Many women living with physical

16 Hesse-Biber and Leavy, *Feminist Research Practice*, 56.

17 Mary Swigonksi, “Feminist standpoint theory and the questions of social work research,” *Affilia* (1993): 172-173.

18 *Ibid.*, 73.

19 Thomas, “The baby and the bath water,” 639.

20 Liz Crow, “Invisible and centre stage: A disabled woman’s perspective on maternity services,” *Midwives: The official journal of the Royal College of Midwives* (2003): 159.

21 Crow, “Invisible and centre stage,” 160.

disability have experiences with healthcare professionals who, although generally well intentioned, take over situations to the point of being unhelpful, or lack the information and skills required to assist them properly.²² This form of assistance is grounded in a theme of ignorance: few medical professionals will ask the women themselves what assistance (if any) they want, and how it could best be given in order to suit the woman's particular needs.²³ Policy makers and health care providers could rely on feminist research methods such as in-depth interviews and ethnographies to understand how to better ask questions of the women they are assisting in regards to their disability, as well as gain a better understanding of particular impairments in general.

Understanding the lives and experiences of women can also be achieved through personal narratives. Much of the literature on childbirth, for example, “focuses on factors related to labour and delivery and does not consider the way in which a woman plans and experiences her birth, thus missing many insights regarding these processes.”²⁴ Narratives can be valuable to implement policies “that foster a positive birth experience for women”²⁵; they can also create connections for different women who share their experiences.²⁶ By utilizing and valuing women's experiences through narratives, one can also better understand how women with physical impairments perform mothering.

Narratives can be both formal, such as through research participation or auto-ethnography; and informal, such as through personal blogs. An example can be found in the personal narratives of blogger “Heather”, a mother who lives with cerebral palsy, in her blog, “Raising a Child as a Disabled Mother”. Heather writes about her experiences raising her young daughter Kiana, in an effort to create a resource for other women in similar situations. In her blog, she gives accounts of how she gets creative with using her own assistive equipment to assist her in caring for Kiana:

22 Thomas, “The baby and the bath water,” 636.

23 Ibid., 639.

24 Cook, “The Role of Choice” 22.

25 Ibid., 22.

26 Ibid, 23.

The second walker I bought was a Rollator. The kind with 4 wheels, brakes, and a seat. I strapped a booster seat to it and as soon as Kiana could sit up on her own I used this to transport her around. This works great.²⁷

She also uses her blog to communicate how being a mother with a physical impairment may be challenging in ways that differ from being an able-bodied mother, but far from impossible:

At six months, or maybe earlier, I started teaching Kiana that she needs to ‘help mama’: when she is in the crib, in order for me to easily lift her out, she needs to stand up and lift her arms for me... Babies are adaptable and they adapt to their parents’ disability. Kiana and I work together to help each other.²⁸

Personal narratives such as these demonstrate that, while a woman may not be fully physically capable, that does not take away from her capability as a mother. Most women find themselves requiring support and assistance – either from family, friends or health care professionals – while they adapt to motherhood. A woman living with disability may need extended support in caring for herself and/or her children, however “requiring assistance [...] does not mean a woman with impairments will become a ‘bad’ mother.”²⁹ Many women who live with physical disability feel they are able to spend more time with their children, provide strong emotional support for them, and likely raise children who are “non-judgmental, caring and thoughtful [...] as a result of living in a home where impairment is a part of everyday life.”³⁰

Many women who become mothers experience some form of criticism of their parenting methods, but women living with disability are particularly vulnerable to outsider judgment.³¹ Unfortunately, mothers living with a disability remain excluded not only from parenting literature,

27 Heather, September 26, 2010, “Walkers,” Raising a Child as a Disabled Mother <http://thelindseyohana.blogspot.ca/2010/09/walkers.html>

28 Heather, September 18, 2010, “Help Mama,” Raising a Child as a Disabled Mother <http://thelindseyohana.blogspot.ca/2010/09/help-mama.html>

29 Radcliffe, “Being Brave,” 33-34.

30 Ibid., 29.

31 Thomas, “The baby and the bath water,” 633.

but also from feminist work.³² There are various arguments as to why feminism has largely excluded women with disabilities from its focus. One of the most notable arguments is that “as women with impairments were still perceived as weak and dependent they were largely excluded from feminist literature. Their ‘difference’ also disrupts the notion that all women are united and wish for liberation in the same way.”³³ The progression of feminism has meant addressing various intersectionalities that contribute to otherness, including race, class, and gender. Addressing the struggles of those who live with disability, and better understanding how these women might be liberated, means integrating women living with disability into feminism as experts of their own experiences. Through feminist literature’s inclusion of the experiences and knowledge of women living with disability, a new understanding of disability would emerge, influencing a more socially and physically accessible society.

Providing information on physical disability in the form of narratives and feminist standpoint research would be useful to health care providers, who in turn could foster a more accessible practice for women who live with physical impairment. Social and physical accessibility are important for all people who live with disability, and mothers who live with physical disability would benefit greatly from having their individual needs addressed and recognized. Ideally, this would start with health care professionals, and branch out to society at large. Liz Crow argues that physical accessibility and social accessibility are one in the same:

When I am on the outside needing to get in, what I see is a lot of people missing the point. My being on the outside is not about me, but about them. It is about the assumptions and the ways of working that exclude whole groups of people.³⁴

Assisting in the development of a more accessible society can be a very serious issue when it comes to mothers who live with physical impairments. Crow writes of a situation where a woman was at risk of having her child taken away because of her use of full-time personal assistants—or, rather, the misunderstanding of how a personal assistant might aid a mother who has physical impairments:

32 Radcliffe, “Being Brave,” 6.

33 Ibid., 10.

34 Crow, “Invisible and centre stage,” 158.

Inhumanity aside, the council's action showed a complete lack of understanding of the role of a [personal assistant] or how, as disabled adults, we manage our lives. The [personal assistants] were not there to care for the child, but to assist Penny to be a parent. The presence of her [personal assistants] specifically allowed Penny to create consistency and security for her baby.³⁵

Discriminatory professional attitudes, especially those of health and social services, can cause harm to both mother and child by deterring mothers with disabilities from asking for assistance due to the very real fear of having their children taken away.³⁶ There are immense issues at stake for some women with disabilities in their experiences of pregnancy, childbirth and motherhood. Communication and the elimination of discrimination are "vital to providing a good and relevant service" to these women and their families.³⁷

Social and physical accessibility is necessary beyond the realm of health care and social service professionals. A lack of physical accessibility can affect how much a mother is able to do both in the home and in the community, both for herself and for her family. In the home, physical barriers to completing household and childcare tasks can lead to assumptions of inadequate parenting, such as with difficulty doing the dishes or cleaning up after young children.³⁸ Physical inaccessibility extends to the community at large as well, for example when mothers are unable to join their children during events that take place in inaccessible buildings.³⁹ As mothers who live with physical disability move through "physical and social spaces primarily designed for adults who can walk, they [are...] made to feel 'out-of-place' as mothers."⁴⁰ In cases such as these, we see that physical accessibility and social accessibility mesh into one another. The more physically accessible communities are, the more socially accessible they become; not only by allowing those with impairments to access space, but by allowing them to be present

35 Ibid., 161.

36 Jenny Morris, "Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights," *Hypatia* (2001), 7.

37 Crow, "Invisible and centre stage," 161.

38 McKeever et al., "It's more of a production," 179.

39 Ibid., 186.

40 Ibid., 183.

amongst other community members who will thus better understand what disability does, and does not, entail. As more people learn about the personal experiences of living with a physical disability, the stigma surrounding disability will begin to fade.

Despite the difficulty of navigating around disabling physical and social spaces, mothers who live with physical disability overcome many hurdles presented to them. Mothers with physical disabilities maintain their care-giving role to all members of their households and, even where an able-bodied partner is present, mothers living with physical impairments are often the main caregivers to their children.⁴¹ Women who live with physical disability make up a significant portion of society, and their inclusion into feminist literature will contribute to the feminist movement in its aim to represent all women.⁴² It is crucial that women who live with physical disability gain control and independence in their lives, and in motherhood. Independence is synonymous with the freedom to make important life decisions and have control over what assistance is needed, how and when it will be delivered, and by whom.⁴³ Women who live with physical disability can better attain this control and independence through sharing their lived experiences. These experiences can be shared by participating in feminist research such as in-depth interviews and ethnographies, and by women producing personal narratives. By having their experiences heard and valued by health care professionals, feminist scholars, and society at large, the process towards social and physical accessibility for mothers with physical disabilities will be greatly accelerated.

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41 Thomas, "The baby and the bath water," 639.

42 Radcliffe, "Being Brave," 21.

43 Ora Prilleltensky, *Motherhood and Disability: Children and Choices*. (Hampshire: Palgrave Macmillan, 2004), 16.

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