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# Shifting Expectations: Medicine, Nature, and Disability in Pregnancy Texts

A Thesis Presented

by

# Laura Abbasi-Lemmon

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Requirements

for the Degree of

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in

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# **Stony Brook University**

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#### Abstract of the Thesis

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In this thesis, I consider the complex interactions between discourses of medicine, nature, and disability which determine what pregnant women can or cannot, or should or should not do to maintain an acceptable and "healthy" pregnancy that results in a desired, nondisabled child. In this thesis, I employ two interdisciplinary methods, critical discourse analysis and qualitative interviewing and ground my project in feminist disability studies and the concept of reproductive justice. I analyze interviews I conducted with five currently pregnant women from Long Island, New York and three pregnancy manuals, What to Expect When You're Expecting, Ina May's Guide to Childbirth, and The Disabled Woman's Guide to Pregnancy and Birth). Through my study of these texts, I found that dominant pregnancy discourses are marked by ableist expectations of and from pregnant women and not all women have the privilege (particularly able-bodied privilege) to expect something from their pregnancies. I end this thesis with a consideration of the CenteringPregnancy model of prenatal care, as a potential way towards a pregnancy discourse defined by disability-inclusive reproductive justice.

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#### **Chapter One**

#### Introduction

Surely there are simple, happy pregnancies, but even then our bodies change so greatly that we are bound to have questions. During pregnancy the normal functioning of the body as we experience it is called into a question as it is during an illness. How irrelevant that doctors to tell us it [is] normal for a woman to be pregnant. What do they mean by normal?

-Boston Women's Health Collective, Women and Their Bodies: A Course (1970)

Pregnancy is a complicated experience bound up in biomedical, cultural, and personal meanings. In the United States, the dominant voices in pregnancy, prenatal care, and childbirth are medical professionals, namely obstetricians. Meanwhile, people who are pregnant are trying to make sense of their pregnancy in the context of their own lives. They must reconcile the external messages from physicians, family, and advice literature with their own embodied experiences of pregnancy. Pregnant women are responsible for creating a pure environment for their fetus, through a "healthy" diet, exercise, and extensive pre-conception work. They are told that they are sick or alternatively, that they have inherent abilities beyond any non-pregnant person. Pregnancy is supposed to be an amazing, joyous experience that all women desire, which should always result in a wanted, nondisabled baby. Experiences that are different from the mainstream are either not represented at all or they are labelled unhealthy and disregarded.

In this thesis, I employ feminist disability studies to explore the experience of pregnancy, including those experiences that are ignored or disregarded. What does it mean to live in a body that dominant discourses mark as abnormal or sick? Or alternatively, what does it mean when that same body is placed on a pedestal of hyper-ability, innately capable of handling all aspects of pregnancy? Who is allowed to claim privileged or authoritative

knowledge of these meanings and in what contexts are they able to make that claim? Finally, are there other possible ways to understand pregnancy in the contemporary Western context? To answer these questions, I use critical discourse analysis of three different pregnancy manuals and qualitative interviews with five pregnant women. Through these different pregnancy texts, I work towards a more inclusive way to think about pregnancy.

In what follows in this introduction, I briefly discuss existing feminist scholarship on motherhood, pregnancy, pregnancy advice literature, and biomedical prenatal care. Rather than an exhaustive overview, I will highlight work that has deeply influenced this thesis and my central assumptions about pregnancy and how it does so. Also, I will incorporate a summary of notable feminist disability studies (and disability studies more broadly) scholarship, which inspires my analyses in the following chapters. Following that, I will outline my chosen interdisciplinary methods and some information on the participants who shared their experiences with me. I will end this chapter with some thoughts about my place in this project, as an outsider and as an always-potential participant.

#### Feminism and Pregnancy

As suggested by the epigraph (from *Women and Their Bodies: A Course*), feminists' challenges to how pregnancy is enacted, how cultures make sense of it, and its possible meanings are not new. The Boston Women's Health Collective's *Women and Their Bodies: A Course* (1970) is an excellent example of feminist challenges to the medical establishment. A precursor to the popular and long-running women's health text, *Our Bodies, Ourselves* (first commercially published in 1973), *Women and Their Bodies* contained detailed and easy-to-understand information on everything on women's health from information on

menstruation and pregnancy, to a critique of capitalism's influence on medical institutions, with a politically-driven feminist take. This text, which I refer to throughout this thesis, contains still relevant challenges to medicine and its related discourses.

In addition to texts like *Women and Their Bodies*, there have been other feminist challenges to medical practices surrounding women's healthy, like what prenatal care should do and how it should be done. Feminists have also questioned the authority of pregnancy manuals.<sup>1</sup> Feminists have rallied against hospital protocols for childbirth and pushed back on the routinization of technological surveillance during pregnancy.

There have been some changes in medical practices that feminists support. For example, at Stony Brook University Hospital, a large academic medical center on Long Island, episiotomies, the surgical cutting of perineal tissue to avoid tears, are no longer a routine practice, but "rooming-in," or keeping the newborn in the room with the post-partum mother is the standard.<sup>2</sup> During delivery, the woman is still not given full range of motion, but she is no longer restrained, flat on her back in the lithotomy position. The Stony Brook Midwives are a popular and well-respected practice that serves all kinds of women. It should be noted that this is at a large academic medical institution in the northeastern United States, meaning they are well-funded and have the resources to adapt to changing practices in medicine.

<sup>&</sup>lt;sup>1</sup> I am using "manual" here to refer to what are often called *guides*, I am following Marika Seigel's suggestion. She argues that calling the texts "manuals" highlights the directive nature of their contents (Seigel 10, 30-32), Additionally, it also calls attention to biomedicine's view of body as system or machine and the medical provider as a mechanic to fix it when something deviates from the norm (Martin 54).

<sup>&</sup>lt;sup>2</sup> I gathered this information at an event, in June 2015, called "Meet the Midwives," sponsored by the Stony Brook Midwives. Following a presentation of the midwifery services, attendees were given tours of the labor and delivery wing and given the opportunity to ask questions about the midwives, hospital policy, and other relevant topics.

Many feminist scholars came to the conclusion that pregnancy's *natural* connection to women is the reason that women are oppressed (O'Brien 49). To escape oppression then, women need to shun childbearing. In fact, in the pregnancy section of *Woman and Their Bodies*, there are several pages devoted to the reasons one should consider *not* having a child. For many women, this critique is insufficient or irrelevant. Refusing childbearing is not always a viable option. Whether they choose to become pregnant or are pushed into carrying an unplanned (or even unwanted) pregnancy, childbearing and motherhood continue to be a part of women's realities.

This is not to say that feminists have not acknowledged and analyzed the significance that pregnancy and motherhood hold for many women, positive and negative. In what follows, I outline a few key works that have been central to my thinking on this project, beginning with the publication of the monograph *Of Woman Born: Motherhood as Experience and Institution*. In 1976, Adrienne Rich's influential feminist text opened up a new conversation about motherhood. Working through history, religion, and her own experiences, Rich argues that motherhood has been used as a means to control women, like feminists that came before her. However, she shifts from previous perspectives in where she locates the problem: for Rich, motherhood is an oppressive institution because it has been culturally constructed to be that way. This suggests that to escape oppression, women do not have to stop having children and being mothers. Instead, we as a culture need to redefine what it means to become and be a mother.

Feminist Anthropologists on Women's Reproductive Lives

Like Adrienne Rich's text, the work of feminist anthropologists, namely Emily

Martin and Rayna Rapp, has informed my interactions with the participants and how to

respect the complexity of their narratives. These scholars have tried to make sense of how women interpret and understand their reproductive lives and experiences. Emily Martin's *The Woman in the Body: A Cultural Analysis of Reproduction* provides a useful model for integrating women's experiences into a critical feminist analysis of pregnancy. Through more than one hundred interviews with women and girls of varying ages, she relates how women have had to work with, around, and against medicine and cultural expectations in relation to their reproductive lives. These experiences serve as the basis for her claims about the assumptions that medicine and science make regarding "the nature of women, of me, [and] of the purpose of existence" (Martin 13).<sup>3</sup> Martin's text was deeply influential for this thesis, because her work demonstrated different ways of using qualitative interviews and her questionnaire inspired my interview protocol. For example, she asked her pregnant interview subjects what their ideal birth experience would be like, which I found valuable for eliciting what women expect from their birth.

Rayna Rapp's work, *Testing Women, Testing the Fetus* was influential for me because of how she carefully wove disability into her analysis, alongside her participants' narratives and her self-reflexivity. Rapp focuses on the complex reactions to and meanings made from confronting prenatal testing, specifically amniocentesis. Much like Martin, Rapp bases her study on interviews with pregnant women and new mothers, specifically those who are faced with the choice to undergo prenatal testing. Through these narratives, as well as those from genetic counselors, lab technicians, and others with connections to the

<sup>&</sup>lt;sup>3</sup> While Martin does provide discussions of the racialized aspects of these experiences and assumptions, it is important to note that she does not mark whiteness. Only the experiences of women of color are clearly labeled with race. See for an obvious example, "Appendix 2: Biographical Profiles" (Martin 209-24). The profiles of black women are labeled as such, while other women's profiles are not labeled at all, so the reader is forced to assume that they are white.

amniocentesis process, Rapp provides careful, self-reflexive analysis. She argues that even things that we take to be scientific facts, like genetic abnormalities, are culturally constituted and therefore meanings and significance vary based on one's history and community (13).

# **Feminist Disability Studies**

Feminist Disability Studies (FDS) is difficult to define. To work toward a functional definition, I refer to the work of Rosemarie Garland-Thomson, a prominent feminist disability studies scholar. In a 2001 publication, Garland-Thomson describes feminist disability studies as a union of feminism and disability studies as a way "to argue that cultural expectations, received attitudes, social institutions, and their attendant material conditions create a situation in which bodies categorized as both female and disabled are disadvantaged doubly and in parallel ways" (Re-Shaping, Re-Thinking, Re-Defining 5-6). In 2005, Garland-Thomson's working description of the field changed slightly: "Feminist disability studies scrutinizes how people with a wide range of physical, mental, and emotional differences are collectively imagined as defective and excluded from an equal place in the social order" ("Feminist Disability Studies" 1558). Taken together, these descriptions create a more inclusive and functional definition of feminist disability studies.

In the first quote, Garland-Thomson alludes to a central project of feminist disability studies: the illumination and dismantling of the intersectional mechanisms of oppression that work upon gendered, dis/abled bodies. In the second quote, there is a more flexible and open understanding of what those gender, dis/abled bodies can be. She employs the ungendered term *people*, implying that bodies, regardless of gender all fall under the lens of

ableist and sexist discourses, admittedly in different ways.<sup>4</sup> Some arrangements of sex, gender, and dis/ability are profoundly pathologized, while others are viewed as natural. More crucially, both of these descriptions point to the tangled relationship of sexist and ableist discourses that recognizes and values specific bodies at the expense of other bodies. The work of feminist disability studies is, then, to interrogate this intersection of oppression as a means to dismantle it.

believe it allows me to attend to the specificities of material bodies, without losing focus on the discursive construction of the meanings of those bodies. I view bodies through an interactionist model as described by Alexa Schriempf in the essay on how the intersecting oppressions of ableism and sexism impact disabled women. She reconsidered the social model of disability, which made *disability* distinct from *impairment*. Schriempf articulated a different relationship between *disability* and *impairment* considered alongside *gender* and sex. In "(Re)fusing the Amputated Body," she developed an interactionist model to avoid the limitations of the social model's disarticulation of biology from society (through the impairment/disability binary). Schriempf's model recognizes that "Disability and impairment are both always about bodies in social situations and thus always about the material and social conditions of not just one's body and its abilities but also of one's environment" (Schriempf 70). She suggests, to use Nirmala Erevelles' term, that they are

<sup>&</sup>lt;sup>4</sup> *Ableism* can be defined as "a system of privilege and power that discriminates against those that are or appear to be disabled and privilege those that are or appear to be able-bodied" (Burch).

<sup>&</sup>lt;sup>5</sup> In the social model of disability, originally defined by the Union of the Physically Impaired Against Segregation, *disability* is a result of interaction with society and *impairment* a matter of biology (Shakespeare 266).

"mutually constitutive" (Erevelles 45). In other words, sex and gender are always interacting with one another *and* with disability and impairment *Feminist Disability Studies and Pregnancy* 

Since most of the primary source material of this thesis is not derived from the experiences of women with disabilities, one may wonder why I have chosen to incorporate the work of disability scholars. One of the issues at the forefront of disability scholarship and activism is the exclusion of the voices of those with disabilities in research. Too often research discounts or excludes disabled people in favor of disability concepts that support the continued devaluation of disabled lives. How is this study any different?

First, I am not claiming that experiences of pregnancy are equivalent to the experiences of disability. Analogizing pregnancy and disability or simply substituting one term for the other flattens out any attempt at intersectional analysis. As Ellen Samuels suggests, doing so would create a situation in which both issues cannot be simultaneously addressed (54). If I claimed that pregnancy was the same as disability, it would become impossible to talk about the experiences of disabled pregnant women.

Also, I argue that ableism, and not disability, is an important motivating force behind the problematic discourses of pregnancy. Disability does not create discrimination, nor does it ascribe value to certain bodies at the expense of others: ableism does (Burch). The discriminatory power of ableism influences the discourse of medicalized pregnancy, which narrowly defines what a "healthy", "normal", "natural", and/or able pregnant body is. The pregnant woman's perceived level of ability or disability (before, during, and after her pregnancy) and her gender, inscribed on her body, intersect to inform what she should, should not, or cannot do. It is through the insights and frameworks of feminist disability

studies that I am able to unpack this limiting, ableist definition of a pregnant body and bring to light all of the work that goes into maintaining the status of "able" or "healthy". By incorporating disability into wider feminist discussions and the particular insights of feminist disability studies, I am able to propose a different way to think about pregnancy, prenatal care, and reproductive justice.

# **Critical Discourse Analysis**

In this thesis, I employ Critical Discourse Analysis or CDA to read through pregnancy texts and narratives. CDA is not a precisely defined method, nor is it associated with any one particular discipline, though it is particularly useful for research in fields that work towards political change, like women's studies and disability studies (Meyer 14; Van Dijk 252). The emphasis on the multi-directional flows of power and on practical applications of research means that CDA has transformative value. Additionally, there is no singular set of tools that form CDA. It is often an interdisciplinary operation that is adapted to the needs of the project at hand. There are not discretely defined steps of data collection and analysis (Meyer 18).

There are several essential assumptions about texts and about research that unite CDA as a practice. Most crucially, CDA understands power to be implicated in the creation, transmission, reception, and interpretation of texts in ways that are often "subtle, routine, [and] everyday" (Van Dijk 254). Power does not simply flow from the powerful to the oppressed, to be internalized and reproduced verbatim. Instead, power is "jointly produced" through discourse by both the powerful and the oppressed (ibid 255). The pregnancy manuals I have chosen are, for example, endorsed with medical authority, but read by those who work to incorporate the material into their own lives. Readers may

enthusiastically share what they have learned or disregard (or challenge) something that does not fit within their own experiences. In other words, pregnant women work with, around, and against the pregnancy discourses presented to make meaning of their own pregnancy experiences.

Scholars using CDA accept that research is never truly neutral, so the researcher must explicitly position themselves in their work and align themselves with the goals of their work (Van Dijk 253). The questions that researchers ask and how they choose to answer them are connected to the social power and resources of the researcher. My positions as a white United States citizen in a United States graduate program, as a cisgender woman, as a feminist, and as a non-mother (or a not-yet mother), for example, all inform this thesis, from conception to execution (which I will discuss further below). In doing this research, I am aiming to contribute to a feminist understanding of pregnancy, informed by feminist disability studies and reproductive justice.

Relatedly, this project could be used practically, to help change the way we think about pregnancy. Van Dijk writes that the success of any CDA "is measured by its effectiveness and relevance, that is, by its contribution to change" (ibid 253). Similarly, the activist-academic boundary in feminist and disability studies is often purposefully blurred. In other words, CDA research works at the level of discourse, but is intended to actually improve the lives of oppressed people.

Scholars using CDA begin with the perspective of those who are in the position to "suffer," those that are most restrained or defined by the work of discourse, so that the work can be of use to those same people (Fairclough 186). In this study, those with the least power are those who become patients under the hegemonic discourse of pregnancy:

pregnant women. To put this research into practice, I needed to learn what was meaningful to actual pregnant women. To think from a more powerful perspective, that of medical professionals, would just serve to recreate the dominating discourses of pregnancy.

It is also crucial to define what I mean when I talk about "texts" in the framework of CDA. Just as the researcher must acknowledge that they are not working in a cultural vacuum, the texts being analyzed also have a history and exist as part of a genre that must be contextualized (Meyer 15). An emphasis is placed on the *intertextuality* of texts: the implicit and explicit connections that exist across a certain kinds of texts. This means that direct references, like citation and quotation, are important, but so are indirect references, through form (genre or types of texts), for example. To properly contextualize mainstream pregnancy manuals, like *What to Expect When You're Expecting* (2008), I highlight the intertextual connections to medicine, as well as the larger history of pregnancy manuals.

This necessarily turns CDA research into an interdisciplinary enterprise (ibid 24; Wodak 69). Ruth Wodak, for example, incorporates ethnography into her research on national identity, to work with and from the perspective of the affected groups. I have followed her methods and incorporated narrative interviews with pregnant women to guide this project. This serves as a way to meet the goals of CDA: it grounds the project in the voices from below, but also, encourages accountability, to incorporate what was important to them.

#### **On Language Choices**

As I have explained at length in the discussion of critical discourse analysis, language is never neutral. Similarly, Rosemarie Garland-Thomson suggests "feminist disability studies questions our assumptions by using precise language that may seem

convoluted when talking about disability" (Garland-Thomson "Feminist Disability Studies" 1558). Like CDA and FDS scholars, I am then both concerned with the language not only of the text that I analyze, but also the language that appears in my analysis. Throughout this thesis, I have worked to speak precisely and respectfully to the experiences of the participants and the texts, which sometimes necessitated using problematic vocabulary. In what follows, I outline the debates surrounding a few terms that will appear frequently throughout my thesis.

#### Pregnant Woman and Other Feminine Terms

Throughout this thesis, I will use the terms *pregnant woman*, feminine pronouns, and other feminine terms for the individual who is carrying the pregnancy in their uterus. I acknowledge the fact that not all those who experience pregnancy are cisgender women (i.e. those that are both biologically identified as "female" and identify as "woman"). There may be pregnant people who are intersex or that identify as a different gender or gender non-conforming (i.e. those that are biologically identified as "female," but do not identify their gender as "woman"). I do not intend to diminish their experiences by using exclusive terminology. Rather, because this is an analysis of dominant pregnancy manuals and the experiences of pregnant people that identify as women, I retain the term "women" to reflect how the discourses construct pregnant people as *always* cisgender women and how the participants see themselves.

#### On Becoming a Mother

The term *mother* is also a loaded term, beyond the issue of gender. It also conveys what is expected of the individual carrying the pregnancy, not just during the pregnancy, but in the years that follow. To use the term *mother*, as I do, implies that the pregnant

person carries a fetus that will become their child; they intend to *mother* them. While this seems like a commonsense point to make, it is important to remember that there are women who carry pregnancies who will not be considered a mother in this sense. For example, a woman that is acting as a surrogate for another party is generally not considered a mother to the child once it is delivered. Not coincidentally, surrogates and other pregnant people who will not become mothers are absent from the selected primary texts and are not represented among the participants of this project. All of the women that I interviewed intended to raise their child as its mother. In all of the pregnancy manuals that I analyzed, the reader was always identified as an expecting parent, namely a mother-to-be. Therefore, I use the term *mother* to attempt to accurately capture the experiences and discourses that I have found in the discourses I explored.

In a similar vein, becoming a mother or feeling like a mother does not have a universal definition or timeline. Three of the five participants answered my question: "When did you or do you expect to feel a connection with the child?" which the participants appeared to interpret as "When did you or do you expect to feel like a mother?" I received three different answers, but they all accepted the label mother in the end.6 One participant, Ariel, said that, because of her Jewish faith and her experience with her first pregnancy, she would not feel like a mother to the fetus until it was born. The other two, Veronica and Melissa, both said that they "knew" they were the child's mother during their pregnancy. Melissa said from the moment she gets a positive pregnancy test, she feels like a mother (or a "mommy"): "It's an instantaneous feeling like I'm the baby's mommy and that I need to

.

<sup>&</sup>lt;sup>6</sup> I incorporated this question after completing three interviews, when I realized that I was not sure if my participants thought they were mothers during the pregnancy, or not until after they had delivered their child. The final two participants were asked over the course of the interview, while I emailed the other three and only received one response.

love and protect the baby from that second until forever!" Veronica, on the other hand, who seemed less sure of her answer, said that she felt like a mother "when I started to feel her kick...I started to feel her, that's her in my stomach." They all accepted that they are or would be mothers to the child they carried, but they all shared very different understandings of when that label would mean something to them. Even as I use this term to refer to participants, I am aware that, at the time of the interview, not all of them may have understood *mother* in the sense that I use it here.

#### Eugenics and Its Legacy

Francis Galton, who coined the term "eugenics" in 1883, believed that people's moral and mental characteristics were passed down from their parents (Kline 13). To produce the best possible children, for the health of the wider population, eugenicists looked for ways to encourage quality potential parents to have more children and to prevent "unfit" parents from having children (ibid). "Unfit" was left indistinct and flexible so that it could be used to support ableism, racism, sexism, homophobia, and other forms of oppression and discrimination (Kline 2; Ordover xxvii). Eugenics, as a means of population control rose to prominence between the late nineteenth century into the 1950s (Rose).

In this thesis, I do not argue that the authors of these pregnancy manuals are themselves, eugenicists. I recognize that the eugenics came from a historically situated period and refers, as Nikolas Rose argues, to population control as enacted by governments. I argue instead that the available mainstream discourses of pregnancy are bound up in the ongoing legacy of eugenics. In other words, the way we think about pregnancy today has been profoundly affected by the eugenics period, so these texts are reproducing mainstream eugenics-influenced pregnancy discourses.

#### **Narrative Interviewing**

To guide my research, to find out what mattered to those receiving the messages of the pregnancy manuals I was analyzing, I decided to look to those who would have first-hand experience of pregnancy: pregnant women. I interviewed five pregnant women to learn about their experiences and feelings. I view these interviews as alternative texts, co-created by the interviewee and interviewer, under the influence of dominant pregnancy discourses (Josselson 1). These interviews were narrative, based on psychologist Ruthellen Josselson's description: "The aim of [narrative] interviewing is to document people's experience, self-understanding, and working models of the world they live in, so that we may later attempt to make meaning of these phenomena at levels of analysis beyond simple descriptions of what we heard"(2). In other words, through narrative interviews, I elicited stories, narratives, "to obtain contextualized accounts of participants' experience" and learn about how they understand their social reality (ibid 5).

The five interviews took place in person (except for one interview which was conducted via Skype) and were conducted in English.<sup>7</sup> Each meeting lasted for about one to two hours, during which I followed a semi-structured interview protocol. I focused on asking "experience-near" questions about their experiences of pregnancy, their day-to-day lives as pregnant women, and their plans for the rest of their pregnancy through labor and

<sup>&</sup>lt;sup>7</sup> According to the recent American Community Survey, nearly thirty percent of Nassau county residents and twenty percent of Suffolk county residents speak languages other than English (U.S. Census Bureau "Nassau County, New York"; U.S. Census Bureau "Suffolk County, New York"). Because I conducted these interviews only in English, I lost the opportunity to learn how pregnant women who speak languages other than English make sense of their pregnancy experiences.

delivery (Josselson 156).8 From their answers, I hoped to learn how dominant pregnancy discourses were received, interpreted, or perhaps rejected.

Throughout this thesis, these interviews appear as guiding themes for each text that I analyze. I was determined to find a way to place value and importance on voices that were part of a very small and non-representative sample. In the end, I have elected to begin with my data collected from the interviews, to look for issues that mattered to the women that spoke with me. In their stories, I heard what made them happy about their pregnancies, what caused tension, what scared them. I then looked to see how that was reflected in the pregnancy manuals. In using the interviews this way, I am following the guidance of CDA: I am privileging the voices of those from "below" instead of those with authority over pregnancy.

# Pregnancy and Childbirth on Long Island, New York

In the communities of Long Island, there are few choices for pregnant women for different kinds of prenatal care and childbirth. There are about two dozen hospitals and innumerable obstetricians, but there are minimal accessible alternatives, like birth centers or hospitals that facilitate water births. There are midwifery practices who attend births in hospitals, but there are no licensed midwives in the area who can attend homebirths (Findletar-Hines). According to the website, Choices in Childbirth, the nearest standalone birth center is in Brooklyn, NY, nearly fifty miles away from Stony Brook, NY.9

<sup>&</sup>lt;sup>8</sup> "Experience-near" questions refer to questions which directly address a participant's specific experience with the phenomenon of interest and not broad generalizations. For example, instead of "What do you think about pregnancy?" I would ask, "What has pregnancy been like for you?"

<sup>&</sup>lt;sup>9</sup> Choices in Childbirth is a New York based non-profit organization which seeks to provide healthy options for maternity care. Among the information packets and workshops, they also offer a list of "Mother-Friendly Care Providers" which includes many different services, like birth centers ("About Us")("About Us")("About Us").

All of the women interviewed for this study have experienced their pregnancy in this environment. They are all immersed in an area that only performs pregnancy and childbirth in a limited, medicalized way. According to sociologist Claudia Malacrida's recent study, available resources have an important effect on how women make sense of their own pregnancies("Always, Already-Medicalized")("Always, Already-Medicalized"). In a context where midwifery (including homebirth midwifery) was available and well-known, pregnant women often thought positively about non-hospital births and other alternative narratives of pregnancy. Where midwifery is unavailable, Malacrida found her participants closely wedded to medicalized conceptions of pregnancy and childbirth. Long Island, New York more closely matches the latter setting where there are minimal options in prenatal care and childbirth. Arguably then, the participants are more inclined to make sense of their pregnancy in a medicalized way than if they had access to other pregnancy and childbirth resources.

#### **Introducing the Participants**

At the center of this project are the narratives of five pregnant women from Long Island. To participate in my study, the participants had to be pregnant adults who were willing to share their experiences with me. The participants shared stories about their current pregnancies, but also their past pregnancies, how they came to decide to have a child, and their biggest hopes and fears for childbirth. Due to the intimate nature of what they shared, I will be using pseudonyms to protect their identity. For each participant

(listed alphabetically below), I will provide a limited biography that focuses mainly on their lives as mothers, but also their education and their work. $^{10}$ 

Ariel

When I interviewed her, Ariel was in her second trimester with her second child. She is in her late 20s and is finishing up her last year of medical school. She is white and identifies as an observant Jew. Ariel and her husband live in an apartment in Nassau County (on the western end of Long Island), where he works as an engineer.

Jennifer

At the time of the interview, Jennifer was pragmatically concealing her pregnancy so that it would not interfere with her work as a pediatric physician. She was only telling her co-workers about her pregnancy on a need-to-know basis. She is a white, married woman in her thirties, living in Suffolk County (on the eastern side of Long Island). At the time of our interview, she was nineteen weeks pregnant and she has a toddler.

Lian

Lian, a Chinese woman in her mid-twenties was in her final trimester with her first child when I interviewed her. She came to Long Island for her graduate degree which she received in May of 2015. She has been living in central Suffolk County with her husband who is currently a graduate student and she was currently unemployed. As an immigrant from China, English is her second language, so periodically during the interview, she would have to look up terms using her cell phone.

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 $<sup>^{10}</sup>$  Over the course of the interviews, I did not directly ask about household income. Class is certainly a relevant variable in discussions of pregnancy and prenatal care, but will not be included in this thesis.

#### Melissa

Melissa is a white, married woman from a nearby community who proudly informed me that she had received her undergraduate degree from Stony Brook University a few years ago. She is employed as an elementary school teacher, but has been on an extended maternity leave (without pay) for the last several years, since the birth of her first child. She has two children and was twenty-five weeks pregnant with the third at the time of our interview. Her first pregnancy, many years ago ended with the stillbirth of her child. *Veronica* 

As she was currently voluntarily unemployed and often home alone, Veronica was excited to share her pregnancy experiences with someone. She is a married, white woman in her early thirties. She and her husband were living with her mother in Nassau county while their home was being renovated. She was thirty-three weeks pregnant with her first child. Because of a few different health concerns, Veronica's pregnancy had been labelled high-risk, meaning that she had to see more doctors more often over the course of her pregnancy.

# Final Notes on Participants

As you can see from these short biographies, the participants differ from one another in some ways, but also have many things in common. In my advertisements to attract participants, I only included my email as a means of communication, which means that they all had internet access. With the exception of Lian, all of the participants were white, from the United States, and spoke English as a first language. All of them identified as (cisgender) women in heterosexual marriages with the fathers of their children. Lian and Veronica were the only first time mothers and only Lian had not planned to become

pregnant. Finally, though it is not indicated above, all of the women were seeing obstetricians and planned to give birth in hospitals. Some were interested in having cesarean sections (Melissa and Jennifer) and the others were all interested in having access to pain relief (epidurals).

# **Thinking Self-Reflexively**

As I was reading through pregnancy advice manuals and talking with the participants, I found my position as a researcher to be unsteady and complicated. At the onset of this project, I (perhaps naively) assumed that I was solely an observer, an outsider. I have never been pregnant. I have no children. I am not currently trying to conceive a child. On those grounds, I sometimes found myself able to distance myself from the literature. I was able to define myself as someone outside of the target audience of pregnant or soon-to-be pregnant women and new mothers. My inexperience with pregnancy and motherhood, which I shared with the participants early in the interview, also created a distance between myself and the participants. They were sharing sensations and thoughts that I could not identify with. I felt like an outside observer, just as I did with the literature.

Nevertheless, I have been frequently reminded that I *am* the audience of the pregnancy advice literature. I am a woman of childbearing age, so I am positioned as an always potentially pregnant mother-to-be. Even the participants seemed to see me that way. Here is an excerpt from Melissa's response when I asked her about her previous experience of a cesarean section: "It's *your* whole body and *your* arms are out on like on these boards...It's scary because *you're* numb and everything." She was framing her experiences as a teaching moment for me. Her use of *you* draws me into her story,

explaining to me the experience, as though it is something that might impact me in the future.

Moreover, I occupy social positions that make me nearly ideal future mother in contemporary U.S. culture. I am an educated white woman in a stable heterosexual marriage with an educated white man. While our economic resources as a couple are currently limited, we have accrued substantial cultural capital through our educations.

Based on these criteria, I am not just an always potential mother-to-be, but a mother-to-be who feels encouraged to have children.

However, when disability and bodily difference is taken to account, I find myself in a far more complicated relationship with the pregnancy literature and the interviews. While not something easily forgotten in the first place, most of the pregnancy advice manuals served as constant reminders that my body falls outside the "norm." In addition to the social categories I listed above, I am also a fat woman with asthma (and related chronic health conditions). According to these texts (and the unsolicited comments of near-strangers), if not brought "under control," my weight and my asthma will preclude the possibility of having a healthy pregnancy and a healthy child.

As I immersed myself in the pregnancy literature, the tension between my position as always potentially pregnant and someone who cannot possibly have a healthy pregnancy was overwhelming. In part, this speaks to why I have chosen to think through a feminist disability studies lens. When bodily difference is ignored, I am a near-ideal

<sup>&</sup>lt;sup>11</sup> I follow the lead of many feminist disability scholars who argue that while not interchangeable, fatness and disability more broadly are understood through similar ableist and medicalized frames (Mollow 200; Herndon).

potential mother, but under different circumstances, when bodily difference is incorporated, I am someone who should not be a mother.

As I have emphasized throughout this introduction, this study is based on the experiences of pregnant women. As someone who is not currently pregnant and has never been pregnant, this study cannot be about me. However, I have already indicated that I am implicated in contemporary pregnancy discourses just on the basis of my age and gender. I also feel a personal connection to this work, because I do hope to become a mother one day. There were themes in the manuals that affected me profoundly, often because of how the manuals present someone like me. I could not so easily set those reactions aside.

Throughout the text, I will incorporate my reactions to passages or themes that specifically triggered strong responses from me. I do this in the interest of being self-reflexive, as part of my commitment to CDA and crucially, because my experiences with these texts are bound up in how I made sense of them.

# **Overview of Chapters**

The chapters that follow are each focused on analyzing one particular pregnancy advice manual and the accompanying understanding of pregnancy. In the next chapter, I focus on the bestselling book, *What to Expect When You're Expecting* and the mainstream, medicalized discourse of pregnancy. In this chapter, I argue that medicalized pregnancy (and its related discourse) has authority in our culture because it promises to soothe fears of bad pregnancy outcomes. The legacy of eugenics in reproductive medicine leads some women, notably disabled women, to be considered inherently riskier and in need of greater surveillance and intervention. I also consider the implications of expectations of pregnancy, of pregnant women, and who has the privilege of expecting something of their pregnancy.

The third chapter centers on *Ina May's Guide to Childbirth* (2003), from the famed midwife Ina May Gaskin and natural birth advocate, and the natural pregnancy and childbirth movement. Stories from two participants guide the analysis, which led me to remain skeptical of the inclusiveness of the discourse of natural pregnancy. I found that Ina May Gaskin's work is based on an essentialized and ableist understanding of a pregnant woman who can always produce perfect children perfectly. While natural pregnancy and childbirth advocates argue that their way will lead to better pregnancy outcomes and build up expectations for pregnancy, they fail to acknowledge what happens when there are poor outcomes. In this chapter, I look for the nascent expectations of natural pregnancy and childbirth discourses and consider if disability can be incorporated as anything besides a source of blame.

In the fourth chapter of this thesis, *The Disabled Woman's Guide to Pregnancy and Childbirth* (2006), from disability activist Judith Rogers serves as the central text. I use this text to consider what pregnancy and prenatal care, informed by reproductive justice and inclusive of disability, could look like. With the insights of the participants and the analysis of *The Disabled Woman's Guide*, I attempt to revalue the authority of women's embodied pregnancy knowledge and to create means to critical access to biomedical prenatal care. I also look to see how expectations shift when the experiences of disabled women are centered.

Finally, I end with CenteringPregnancy, a model of prenatal care, as a real-life example of a possible response to the critiques of the dominant pregnancy discourse and how that might shift expectations of pregnancy towards reproductive justice. I return to the three questions of expectations I introduced in Chapter Two, regarding what is

expected of and from pregnant women and who has the privilege to expect anything of and from pregnancy. I argue that the CenteringPregnancy model has the potential to shift these expectations in positive ways and lead to a new kind of pregnancy manual.

# **Chapter Two**

# Pregnancy Manuals, Fear, and Medicine: What to Expect When You're Expecting

We all know it takes two to conceive a baby, but it takes a minimum of three—mother, father, and at least one health-care professional—to make that transition from fertilized egg to delivered infant a safe and successful one.

-Heidi Murkoff and Sharon Mazel, What to Expect When You're Expecting (2008)

Sometimes I don't even need to ask the doctors whether it is regular, because the book says it's common and regular...if I met the problems, I followed the advice.

*-Lian,* Interview (2015)

#### Pregnancy as a Culturally-Defined Experience

Over time and across the world, people have interpreted and represented pregnancy through particular cultural lenses. Cultural historian Clare Hanson's *A Cultural History of Pregnancy* has demonstrated that the discourses that define how people at particular moments talk about, define, and experience pregnancy are culturally shaped. For example, before the contemporary practice of obstetrical medicine had emerged and became professionalized, midwives and other women were used as support during the pregnancy, providing advice and cures to the uncomfortable symptoms of pregnancy (Hanson 17). Now, in the United States, texts like the *What to Expect When You're Expecting* (2008) and obstetricians serve as the experts on pregnancy. Because pregnancy today is placed squarely in the realm of medicine, our contemporary understandings and experiences of pregnancy in the United States are predominantly medical.

The influence of medicine on pregnancy impacts what pregnant women should and should not do from preconception through childbirth. It influences who is defined as an "expert" on pregnancy, who gets to experience pregnancy, and how that experience will

proceed. Women are encouraged to consult medical professionals (and technology, like home pregnancy tests) at the moment they discover they are pregnant, undergo various forms of prenatal testing, and change their habits and routines to be more "healthy" for the safety of their unborn child. In this chapter, I argue that medicalized pregnancy (and its related discourse) has authority in our culture because it promises to soothe fears of poor pregnancy outcomes. The legacy of eugenics in reproductive medicine leads some women, notably disabled women, to be considered inherently riskier and in need of greater surveillance and intervention. Through this manual, I also begin to unpack the concept of expectations: who and what can be expected and who deserves to have those expectations. *Making Sense of Pregnancy through Medicine* 

The participants in this study were using medicine to make sense of their pregnancies. That is, all of the participants that I interviewed were seeing an obstetrician for their prenatal care and live in an environment where that is the "normal" thing to do. Seeing a medical doctor was especially non-negotiable for Ariel and Jennifer. As people working in medicine, they both indicated that they were too aware of the potential risks of pregnancy to see a midwife. They wanted someone that could "handle" anything: "If I need a C-section, a midwife would not do it. And for my first pregnancy, I needed one. There are limitations with a midwife, so I would rather see somebody that could take care of all aspects and if there are any complications" (Jennifer).

For Veronica, on the other hand, seeing an obstetrician was her only option. As her pregnancy was defined as high-risk, she had to see both a general obstetrician and her "high risk doctor" (a specialist in Maternal-Fetal Medicine). She had not indicated any interest in seeing a midwife, but if she had, she most likely would have been "risked out,"

meaning she would have been referred to an obstetrician, because her pregnancy was likely to require interventions beyond the training of midwives. Even though they came to medicine to handle their pregnancies for different reasons, the important thing to note is that they all accepted the necessity of medical intervention in their pregnancies.

# A Brief History of Pregnancy Manuals

Medicalized discourses of pregnancy do not just come from and flow through obstetricians. Pregnancy manuals are also a source of pregnancy discourses, often imbued with authority by physicians and medical professionals. According to technical communication scholar Marika Seigel, obstetrician J.W. Ballantyne's *Expectant Motherhood: Its Supervision and Hygiene* (1914) was the first book length pregnancy manual (42). Ballantyne is also credited with the creation of prenatal care, meaning that he helped to define pregnancy as a medical event (ibid 36; Hanson 90). With his manual (and other related manuals from his contemporaries), Ballantyne was implicitly suggesting that the ongoing problems of maternal and infant mortality were a matter of ignorant expectant mothers. In other words, the pregnant women did not have appropriate, medically defined understandings of pregnancy, so they did not know how to care for themselves during the prenatal period.

In the pregnancy manuals that followed *Expectant Motherhood*, the necessity of medical intervention in pregnancy was increasingly naturalized and pregnant women were expected to receive prenatal care. In fact, the books that were published in the middle of the twentieth century in the United States, during the baby boom, were developed to be suitable substitutes for overworked obstetricians (Seigel 70). As the epigraph from Lian

indicates, *What to Expect* still can function as a substitute for a doctor and calm a nervous pregnant woman.

There have been manuals that disrupt the discourse of medicalized pregnancy, like the feminist health manual, *Woman and Their Bodies: A Course* (1970). That manual, for example, presents women's knowledge of their own bodies as a valuable alternative form of expert medical knowledge. The mainstream manuals, like *What to Expect When You're Expecting*, are what Siegel refers to as "system-maintaining" texts (71). As the name suggests, system-maintaining pregnancy manuals serve to bolster the pre-existing system of prenatal care and medicalized pregnancy.

Reflections on Prenatal Education and Research

To locate potential materials representative of pregnancy discourse, I turned to women that I knew that had been pregnant recently. I informally asked them who or what they looked to for information about their pregnancy. I was surprised to learn that books were still popular among these women. This is reflective of a recent study, which determined that pregnancy advice books were a primary source of information for first-time mothers (Declerq et al. 10). As the cover of the fourth edition of *What to Expect When You're Expecting* claims, there have been more than sixteen million copies sold of just that one particular manual. This all suggested to me that pregnancy manuals were a source of pregnancy information that could impact or frame the experiences of the participants.

Here, I must acknowledge that I assumed that most pregnant women, at least those that had the resources to access prenatal care, would conduct research about the progression of pregnancy through manuals, cell phone apps, or internet research. I assumed this because I cannot imagine not researching an experience like pregnancy. I

realize now that I was primarily basing my assumption on my own methods for dealing with changes in my life. Also, I am reminded of an experience with a friend few years ago. Once she had announced her pregnancy publically, she began to carry around her copy of *What to Expect* everywhere and she read religiously it whenever she had a moment. This experience was the most contact that I have had with a pregnant woman as an adult. I assumed that this was how most pregnant women performed pregnancy, because it aligned with the way that I would probably proceed.

When I began research for this project, I was surprised to learn that at least one of my participants, Veronica, had not done any research about her pregnancy. She said that she had considered taking childbirth classes, but instead decided that she would "wing it" since she had heard that many women forget "in the moment" anyway. She never explicitly told me why she had not done other prenatal research. Perhaps because, as a high-risk pregnancy, she spent so much time with medical professionals investigating and surveilling her pregnancy, she did not feel it necessary to do more research on her own. Perhaps she felt it unnecessary because she was in close contact with her mother and sister who had experienced pregnancies before and could answer her questions.

Regardless of the reason, Veronica's narrative reminded me that there are women who might not look into a pregnancy manual or attend a childbirth class. I was wrong to assume that women would automatically go to pregnancy manuals and other sources of educational material when they discovered they are pregnant. As I will argue below, this does not invalidate my choice to use pregnancy manuals as typical texts of pregnancy. It does, however, serve as an important reminder that even within a particular location, at a particular time, there are many ways to perform pregnancy and to learn about it.

# On Intertextuality and Participants' Experiences with Pregnancy Manuals

All of the participants were familiar with the manual *What to Expect When You're Expecting* which serves as the focus of this chapter.<sup>12</sup> Only one woman, Lian, was referring to it for information for her current pregnancy, though she was not using it as her primary source of pregnancy information. Others had referenced it during previous pregnancy, or, at least, knew the name of the manual. Generally speaking, the participants knew the text, but had limited direct connect with it.

Why then am I pairing these interviews with these texts? How can they be connected? The concept of *intertextuality* provides an answer. At its most basic level, *intertextuality* is about connections that exist across texts. Whether they are written, spoken, formal, or informal, any kind of text emerges from a particular place and time, using conventions that align the text generically and politically, and that locate it historically. Not all of my participants have been exposed to *What to Expect*, but they operate in a cultural moment for pregnancy that feeds on and is fed by the discursive work of *What to Expect*. In other words, the manual provides a shared language to talk about pregnancy, which it pulled from medical discourse.

For example, when I was planning my interview questions, I began with "How many months pregnant are you today?" It was intended as a straightforward question to elicit background information. I assumed that the measure would make sense to my participants. However, in the first interviews, when I asked this question, the participants were momentarily confused. Then they gave an answer measured in weeks. When I was developing my interview questions, I did not know that pregnancy is usually broken down

<sup>&</sup>lt;sup>12</sup> The other two texts that I address in this thesis, *Ina May's Guide to Childbirth* and *The Disabled Woman's Guide to Pregnancy and Childbirth* were never mentioned over the course of the interviews.

into weeks in medicine and in pregnancy manuals. According to *What to Expect* and other pregnancy manuals, fetal development and different pregnancy symptoms are said to occur at specific weeks. Even though the participants have not read *What to Expect*, they are experiencing their pregnancies immersed in the discourses espoused by this prominent pregnancy manual.

# Contextualizing What to Expect When You're Expecting

When Heidi Murkoff, the first author of the fourth edition of *What to Expect*, tells the story of how she came to write the bestselling pregnancy manual, she starts with when she was pregnant with her first child ("About Heidi"; Murkoff and Mazel xxii). She could not find a pregnancy manual that satisfactorily addressed her questions and concerns about her experiences of pregnancy, so she wrote the first edition of *What to Expect* (originally published in 1984) soon after the birth of her daughter. Murkoff is not a medical professional; she has no pregnancy-related qualifications (e.g. doula, childbirth educator). Instead, she bases her authority on pregnancy and birth on her own experience as a mother, though she frames the text with endorsements from medical professionals to make up for her lack of medical credentials, which I will return to later. In the acknowledgements, the reader finds out that Murkoff wrote the text with a medical advisor, as well as with the insights of physicians who are not mentioned or cited anywhere else.

<sup>&</sup>lt;sup>13</sup> Sharon Mazel, the second author on the fourth edition has not always been involved in the *What to Expect* books. Most importantly, she was not involved in the first edition, meaning that the tone and format of the text were in place prior to her involvement, which is why I focus on Murkoff's contributions to the text.

The Format of What to Expect When You're Expecting

What to Expect is a long manual, at more than six hundred pages. It is divided into seven sections: before, during, and after one's pregnancy, a section for multiple pregnancies, for "dads," for dealing with illnesses (acute and chronic), and finally a few chapters on "complicated" pregnancies. Before the body of the text, there are two separate locations with medical endorsements. Before the title page, there are two full pages with reviews from eight medical professionals (seven physicians and one nurse), three mothers, and two professional women in related industries (maternity clothing and a childcare magazine). Immediately following the table of contents is the foreword, from Dr. Charles Lockwood, an obstetrician, professor, and medical advisor for the book.

The book is predominantly text, with only a few detailed illustrations of fetuses and pregnant women. Much of the text is organized in a question and answer format, which works with the conversational tone of the text. In each of the pregnancy months, concerns and symptoms are presented in bolded text, so that a woman could skim the text to find what is relevant to her. The authors then respond, using a combination of plain and medical language. Often the responses end with a deferral to medical provider through different versions of "Consult your practitioner." Overall the text contains much of what one would expect to see in a mainstream pregnancy manual: the unquestioned acceptance of medical authority over pregnancy, tempered by a friendly, easy to read tone.

What to Expect When You're Expecting as a Typical Text

What to Expect is arguably the most popular pregnancy manual in the United States.

According to the corporate website of What to Expect, ninety-three percent of women who read a pregnancy manual read What to Expect. Because this was a self-reported and uncited

statistic, I searched for other evidence of the dominance of *What to Expect*. On Amazon.com, the 2008 paperback edition of *What to Expect* is the most popular pregnancy manual under the category "Pregnancy & Childbirth." It has been on the New York Times Bestseller List for more than six hundred weeks and has been named one of the top twenty-five most influential books from the last twenty-five years ("25 Books That Leave a Legacy"). Because *What to Expect* has been such a significant text, it has helped define what a contemporary pregnancy manual, like the *Mayo Clinic Guide to a Healthy Pregnancy* (2011) or even a web-based manual, like *The Bump*, looks like and what sort of information is necessary for pregnant women to know.

# A Healthy Body for a Healthy Baby

In her essay, "Are Mothers Persons?" feminist philosopher Susan Bordo observed that, when we look to the legal treatment of pregnant women, we can see women turned into "mere fetal containers" that are always potentially risky to the fetuses they carry (77). This is, in turn, used as an excuse to intervene in pregnancies, with or without the mother's consent. Bordo cites cases that led to forced cesarean sections or incarceration, all in the name of the fetus. The life and well-being of the mother is de-prioritized in favor of the life of the fetus. In less drastic terms, this is played out in *What to Expect When You're Expecting*. Murkoff and Mazel continually advocate for maternal sacrifice to make sure that one's baby is the healthiest possible. This is especially apparent in the preconception chapters, which suggest the one begins the frantic preparation for a healthy baby prior to conception.

<sup>&</sup>lt;sup>14</sup> The Kindle e-book version of the text is ranked fourth under the same category. In fact, five titles from the *What to Expect Series* show up within the top forty best-sellers.

This unwavering commitment to sacrifice in favor of creating a healthy child, as enacted in *What to Expect* is not timeless and neutral. Rather, it bears traces of the eugenics movement from the late nineteenth and early twentieth centuries. Eugenics, a term coined by the English scientist Francis Galton in 1883, is usually associated with the use of forced sterilization and genocide in order to prevent the spread of so-called undesirable genes (Ordover xii). However, the eugenics movement is more complex. In fact, varied forms of eugenics were practiced all over the world (Cowan and Garland-Thomson). The form practiced in the United States (and Western Europe), was based in the notions of scientific heredity, meaning that American eugenicists believed that the quality of parents determined the quality of the child, which in turn would determine the quality of the population. To promote the quality of the population, eugenicists enacted (often violent and cruel) measures in the United States and elsewhere to prevent procreation between anyone who was not white, educated, nondisabled, and middle or upper class, which was referred to as "negative eugenics" (Kline 3). There was also a "positive eugenics" measures, which encouraged the "fit" (meaning white, educated, nondisabled, and middle or upper class) to reproduce (ibid).

Most importantly, the determination of quality, of who was fit and unfit, was determined by racism, sexism, and ableism. As historian Wendy Kline has suggested, mothers (and all potential mothers) came to embody both the threat to and hope for the quality of the population (28). Accordingly, this worked alongside the development of obstetrics and the increased popularity of pregnancy manuals which support increased surveillance of expectant women's bodies (Seigel 65). For example, Mary Mills West, the author of an early twentieth century pregnancy manual, *Prenatal Care*, which presented

medical knowledge about pregnancy as the only valid source of pregnancy knowledge, worked with the American Eugenics Organization. Together, they organized what came to be known as "better baby contests" in the Midwest (ibid). At these contests, women were awarded for maintaining their pregnancy through obstetrical medicine and raising ideal (white, able-bodied) babies. Through obstetrical medicine, (white) women were told that they were expected to produce perfect, nondisabled children. This clearly suggests that historically, there are clear connections between prenatal care, pregnancy manuals, and eugenic ideologies.

It is important to note that I am not defining the discursive work of *What to Expect* or any other contemporary pregnancy manual as eugenics, nor are the authors necessarily eugenicists. I am arguing that the eugenics movement had a profound effect on how we make sense of pregnancy in the contemporary moment through obstetrical medicine.

When Murkoff and Mazel stress making changes to prepare for pregnancy, there are echoes of the eugenic ideals of "fit" mothers and making better babies.

The Threat of the Unhealthy Expectant Mother

The first edition of *What to Expect When You're Expecting* was published in 1984, when the idea of an "unfit" mother, in the form of the raced, classed, and gendered "welfare queen" had captured national attention (Seigel 98; Douglas and Michaels 196). It was also at this time that the concept of fetal rights began to take hold. The shifted focus onto the fetus turned pregnant women into inherently dangerous fetal "prisons" (Bordo 86). *What to Expect* was created in this environment, where women were expected to protect their babies from their inherently dangerous ("gendered, racialized, and class-marked") bodies (Seigel 98). The manual is a way to manage the always presumed sick or unhealthy

expectant mother by encouraging her to accept the interventions of medicine and build up expectations of and for pregnant women.

Urgency and Being Always Potentially Pregnant

In What to Expect, the hypervigilance and submission required of an expectant mother begins before pregnancy has even begun. The theme of the "Before You Conceive" chapter is to locate and eliminate all potential pregnancy pitfalls, in frantic preparation for becoming a suitable fetal incubator. This means addressing any and all medical concerns, like weight, substance use, or chronic health conditions, as well as employment issues, environmental hazards, and financial concerns. These issues must be under control "before you begin your next big adventure" (ibid 5). To explain the potential issues and pitfalls, they list bolded, bullet points followed by a brief explanation. For example, I have reproduced a typical entry below:

**Work out those work issues**. Find out everything you can about your work rights when pregnant (see page 187). If you're planning a job switch you might want to consider finding that perfect family-friendly job now so you won't have to interview with a belly. (ibid 11, emphasis original)

In each of the bullets, they list actions to take, along with more general advice. They maintain a casual and friendly tone, using non-medical terms like "belly." Also, the use of the imperative and well as emphasis on what must be done "now" clearly indicates a level of urgency.

Depending on what interventions are necessary, they sometimes recommend postponing conception until all issues have been addressed adequately (which can only be determined in consultation with a health care provider). Because this chapter is set up as a kind of checklist, they also direct readers to their branded pregnancy journals and organizers, which allow the eventually expectant mother to track her preconception

progress and become a pregnant consumer (ibid 3). While intensive and wide-reaching, What to Expect frames the preconception period as a time to complete a certain number of discrete tasks and upon completion, the reader will be ready to conceive a child. Permission to be Pregnant

Murkoff and Mazel argue that an essential preparatory task is to "Get chronic illnesses under control" and to "be sure you have your doctor's permission to become pregnant" if you have a chronic illness (ibid 5)<sup>15</sup>. I have asthma, a chronic illness, so I felt that this passage was speaking directly to me. I found the directive in the text discomforting. The implication is that only nondisabled women can freely choose when they have a child, while disabled women have to involve a figure of medical authority in their decisions. Seigel suggests that comes from *What to Expect*'s goal of managing women's risky bodies:

Similarly, populations of pregnant women who fall into "high-risk" categories, are subject to more surveillance—more violations of their civil rights during pregnancy—and are less likely to have a true choice about the conduct of their labor and delivery...Risk positions determine not only whether a particular action or decision is defined as a choice but also constrain how and what kinds of choices risky groups can make. These groups must first and foremost consider how their choices put other groups, or society or humanity in general, at risk. (98)

As a potentially "risky" or unhealthy pregnant woman, I must submit to increased surveillance not just during pregnancy as Seigel indicates, but also during the preconception period, for the good of the population. I do not have the freedom to choose when I become pregnant nor do I have the authority over my body to say that my asthma is

<sup>..</sup> 

<sup>&</sup>lt;sup>15</sup> Here, I use the term chronic illness, instead of disability to reflect the terminology of the text. Murkoff's and Mazel's definition of chronic illness appears to include diagnoses like asthma, heart conditions, fibromyalgia, depression, and epilepsy, which suggests that they are unconcerned with a precise distinction between what long-lasting diagnoses are chronic illness and what might be called disabilities (5; also see Chapter 21: "If You Have a Chronic Condition"). Regardless of the meaning in the text, generally speaking I do not draw a hard line between what is a disability and what is a chronic illness.

under control. To determine my suitability for pregnancy and the severity of my asthma, I must consult my medical provider according to *What to Expect*. Just as legal issues have shifted their focus from pregnant women to the rights of their fetuses, here to, the rights and authority of those who experience chronic illness (or other disabilities) are ignored in favor of the not-yet-conceived child. In other words, *What to Expect* denies that the bodily knowledge of chronically ill disabled women is significant or valuable. Instead, medical professionals will know what is best.

## It Takes Three: Success through Medicine

In the second chapter, "Are You Pregnant?" the authors offer up the different options for prenatal care immediately following a discussion of the initial symptoms of pregnancy. As quoted in the first epigraph, Murkoff and Mazel place a great deal of importance on "that third member of your pregnancy team," a medical practitioner (21). Moreover, that medical practitioner is almost always an obstetrician. They present alternative provides, like midwives, as riskier, or something that requires greater investigation. For example, under the sections on certified nurse-midwives they not only describe the training these providers receive, but also suggest that you make "sure to select one who is both certified and licensed" and consider getting a physician as a "backup" just in case there are complications (ibid 25). Under the sections describing obstetricians and family physicians, there is no question about their qualifications. Similarly, when discussing the "Birthing Choices," the different environments in which one can give birth, there is greater emphasis on what a hospital can offer, above and beyond that of a birthing center staffed by midwives, or a home birth (ibid 22-24). They include the riskiness of the latter two, for instance, but never mention any possible risks of giving birth in a hospital, like

infections. Implicitly and sometimes explicitly, What to Expect presents medicine as the only possible option for a successful pregnancy experience.

"Check with Your Doctor"

What to Expect is written by a woman who has had children herself, but advice is never presented as coming from her. It is kept at a distance, as if it were a neutral presentation of facts about pregnancy. In fact, as previously mentioned, the text begins with a foreword from a male obstetrician, Charles Lockwood. In his foreword, Lockwood praises the manual and says it is "like having a personal obstetrician to guide you through that adventure [of pregnancy]" to have the most "normal pregnancy" possible (Murkoff and Mazel xx, xxi). His foreword functions as an endorsement to increase the credibility of the text presented within: a licensed physician has declared the text acceptable and useful for his patients.

This deferral to medical experts is reinforced throughout the text, when the authors refer nonspecifically to scientific "studies" that support their suggested advice or through their incessant reminders to "Check with your doctor" or "Consult your practitioner" before making any decisions (for example, ibid 7).<sup>16</sup> The practitioner (and the manual, in a pinch, as Lian's quote indicates) is positioned as the ultimate authority on anything that might occur during pregnancy.

The pregnant patient is also obligated be proactive and to appropriately engage their provider's advice whenever they have a question. For example, under the heading, "What You Can Expect at Your First Prenatal Visit," it says,

<sup>&</sup>lt;sup>16</sup> Interestingly, of the three pregnancy manuals that I discuss in this thesis, What to Expect When You're Expecting is the only one that does not include a legal disclaimer on the copyright page that indicates that the book should not be a substitute for prenatal care with a medical professional.

There will also be plenty of advice to take in—on everything from what you should be eating (and not eating) to what supplements you should be taking (and not taking) to whether (and how) you should be exercising. So be sure to come with a list of questions and concerns that have already come up, as well as a pen and a notebook (or the *What to Expect Pregnancy Journal and Organizer*). (Murkoff and Mazel 124).

To be a responsible expectant mother, the woman is expected to take notes on her health care provider's advice and come prepared to solicit more advice. This is another signal that the expectant mother is complying with risk management strategies of medicine.

In interviews with the participants, I also learned that sometimes, even if they did not trust their doctor or feel comfortable with them, they still refused to switch, believing that it would have negative consequences for their pregnancies. Veronica, who had to be hospitalized early in her pregnancy due to a misdiagnosis from her obstetrician, was still going to the same practice. She said "It's too much to switch at this point" (at thirty-three weeks). Ariel did not have a negative experience, but she felt uncomfortable with her primary obstetrician's partner, who she had to see sometimes. In neither of these cases did either of the women indicate that they had expressed their concerns to the doctor or questioned their authority in anyway. It appeared that Veronica and Ariel had both internalized the message that medicine is the ultimate authority over their pregnancy in such a way that neither felt comfortable questioning their doctors.

## Challenging Medicine

It is essential to remember that the participants and the readers of *What to Expect* will not necessarily internalize the manual's discursive work fully. I have found that pregnant women often may take in and reinterpret meaningful pieces of information, while rejecting that which does not fit with their world view. Even if Veronica and Ariel do not challenge their doctors, they could still find safer ways to question their doctors. I asked all

of the participants if they had disagreed with their care providers regarding any part of their prenatal care. Ariel and Veronica were the only two that answered positively. They both questioned their doctors for "pushing" prenatal tests (in Veronica's words) which they had felt were unnecessary. This suggests that I should nuance my previous statement. To incorporate the fact that they had, in fact disagreed with their physicians, I would argue that they have internalized the message that medicine is the ultimate authority over their pregnancies (because they have left the overarching structure of prenatal care intact), but they have the right to refuse that which does not fit into their worldview

Similarly, I found that cultural and familial beliefs may override the authority of doctors, if it is viewed as a safer path. When I interviewed Lian, she told me that she had to reconcile what her U.S.-based doctor and her Chinese mother told her about sex during pregnancy:

I think, my mother said during the first three months and in the last month, maybe you should have less sex, so the baby is safe. It's more safe. I think I followed her advice...Maybe in China, I know the doctors here said it's okay to have sex like as usual. But I think it's dangerous in the first three months and the last month...For safety we decided we should decrease the times of sex.

Even though her doctor and *What to Expect* refute the idea that sex is dangerous during pregnancy, Lian valued the input of her mother, who she spoke with frequently about her pregnancy. While the overall system of medicine in pregnancy is left intact, Lian refuses to internalize the apparent wisdom of medicine on this one particular issue. This reveals that pregnant women do not uncritically or passively adopt everything that they are told about their pregnancies.

#### **Creating Expectations**

As I have suggested throughout this chapter, *What to Expect When You're Expecting* provides detailed and prescriptive advice for pregnant women. There is a sense, when you read this book (as someone who may be considering pregnancy or is currently pregnant), that everything you need to know to produce the expected outcome is contained within the text. If you do what is expected of you and you "do everything right," *What to Expect* seems to suggest that you can expect a healthy, nondisabled child (Landsman 17). This reminded me of disabled feminist Anne Finger's memoir *Past Due*, which tells the story of Finger's first pregnancy. She writes, "We have set the stage for a new round of struggle: the struggles that arise from *expecting* our births to be joyful occasions...I have heard people talk about the right to have healthy children—as if we could legislate biology" (Finger 41-42, emphasis mine). In other words, in relation to pregnancy, expectations become extremely loaded and bound up in what we think pregnancy is or should be and what qualities a child should have to be brought into the world.

To think about pregnancy discourses then, necessitates thinking about expectations. What is expected from a pregnant woman? What is expected from a pregnancy? And who has the privilege to expect anything from pregnancy? From these three questions (which I will revisit in Chapters Three and Four), I argue that medicalized pregnancy, represented by What to Expect When You're Expecting builds up expectations of a healthy child, which in turn requires extensive work on the part of pregnant women, including submission to medical authority. Furthermore, by uncovering the work required to maintain the label of "healthy" during pregnancy, I demonstrate how ableism impacts presumably able-bodied women.

Repeatedly in the text, there are reminders that *What to Expect* assumes that a woman's body is under her control. That is, they seem to assume that their reader is someone who is able-bodied and follow the advice of their prenatal care provider. This is made clear in the structure of the text. Of the more than six hundred pages and twenty-three chapters of the text, only one nineteen-page chapter discusses chronic illnesses and disability and it is placed all the way at the end of the text (Chapter 21: "If You Have a Chronic Condition"). There are just a few extremely brief discussions of chronic illness and disability elsewhere in the text, like in the preconception chapter that I previously discussed. The potential mother is always assumed to be nondisabled.

Moreover, this hypothetical nondisabled mother's pregnancy is assumed to follow along a predictable or expected path. Her body then is expected to be able in a particularly narrow way. If her pregnancy progresses differently from what is expected in the text, she is no longer healthy and requires intervention from her provider. For example, in a section called "The Overdue Baby" the authors write:

Even if you do end up among those 2% of women who are truly overdue, your practitioner won't let your pregnancy pass the 42-week mark. In fact, most practitioners won't even let a pregnancy continue that long, choosing instead to induce by the time your baby has clocked in 41 uterine weeks. (Murkoff and Mazel 351)

In this passage, the authors are affirming the authority of obstetricians to determine when a child is ready to be born and override the authority of the woman who is carrying that child. Crucially, the authors foreground the choosing of the care provider who "won't even let a pregnancy continue" along its course, should it deviate too much from the standardized gestation period of forty weeks. If the pregnant woman's body no longer does what is expected, the text refers her to her care provider who can put her back on the

expected path. The hypothetical mother might be expected to be able bodied, but there is much expected of her to maintain that status.

What to Expect also reveals what pregnant women expect of their pregnancies. The text represents the expected child as healthy and able-bodied. Pregnant women are told that they should expect this specifically able-bodied child assuming they follow the guidance of the text and their prenatal care provider. Here we can see the ableism of what we expect from pregnancy: the expectation is not just that any child is born, but specifically an able-bodied child will be born at the end of a predictable pregnancy. In What to Expect (and in Ina May's Guide to Childbirth), the expectation is that pregnancy will always result in a happy and healthy, nondisabled child, assuming one accepts the prescriptive advice of the pregnancy manual and the prescribed medical interventions in pregnancy.

The final question, regarding the privilege of expectations, could be rewords to ask who has the right to expect a "healthy" pregnancy resulting in a healthy and nondisabled child? I refer to critical linguist Mel Chen's discussion of the racialization of lead poisoning in their book, *Animacies*. White middle-class mothers were appalled that their children's expensive toys were contaminated with lead (Chen 176). She quotes a woman who says, "These are not cheap, plastic McDonald's toys...But these are what is supposed to be a high-quality children's toy" (qtd. in ibid). This mother connected the purity of her child's toys with the expensiveness of that toy. In other words, she was suggesting that if the toys were inexpensive the lead poisoning would be less unexpected. In essence, those who only purchase inexpensive toys from McDonald's do not get to expect non-toxic toys for their children. This mother also fails to acknowledge the dangers of the expensive, yet toxic toys

to the laborers that built them in China. This suggests that the privilege of controlling one's exposure to toxicity is determined by one's race and class.

This is instructive for considering expectations in pregnancy, because it reveals who has the privilege of control or at least, seeming to be in control. What to Expect for example, recommends that pregnant women control their exposure to potential toxins in the environment: "Have the exhaust systems on your car checked to be sure there is no leakage of noxious fumes and the tailpipe isn't rusting away" (Murkoff and Mazel 83). In this passage, there is the assumption that the reader has the means to have a well-maintained car and that is sufficient to protect her from environmental toxins. The reader who could follow this advice (because they had the financial resources) would have the privilege of having (or appearing to have) control over the expectation of a "healthy" pregnancy. In other words, the expectations of pregnancy that What to Expect conveys (meaning, the expectation of health of both mother and child) are determined by class- and ability-based privilege.

Medicalized pregnancy clearly is a meaningful discourse to pregnant women in the United States, considering the popularity of *What to Expect* and the manual's seemingly natural expectation that all pregnant women will access prenatal care from a medical provider. Just below the surface, however, there is a foundation of ableism, which limits how women can make sense of their pregnancy. In *What to Expect When You're Expecting*, pregnant women are denied authority over their experiences and their bodies. Instead, they are expected to submit to medical surveillance and the advice of those with medical authority, so that they do not have to fear the unexpected. If their bodies are doing what is expected and receive the label "healthy," they have the privilege of expecting their perfectly

healthy and nondisabled child. If pregnant women do not or cannot do as expected, they lose the privilege of expecting anything from their pregnancy.

#### **Chapter Three**

# Perfect Pregnancies from the Wild Woman Within: Ina May's Guide to Childbirth

I often suggest to pregnant women that they imagine themselves as a large mammal when they are in labor. Many say that it helps them to find the wild woman within and to tap into the ancient knowledge that is the potential of all women.

-Ina May Gaskin, Ina May's Guide to Childbirth (2003)

Natural pregnancy and childbirth is a popular alternative model for prenatal care that works to distinguish the state of pregnancy from an abnormal or sick state. Instead, those that advocate for natural pregnancy and childbirth firmly believe that pregnancy is defined as "normal" and "healthy", meaning that obstetrical medicine should not occupy a privileged place in prenatal care. There are a range of different voices in natural pregnancy and childbirth, each with a particular understanding of what should take the place of obstetrics. In this chapter, I focus on the work of one particular voice, the famous midwife, Ina May Gaskin and her manual *Ina May's Guide to Childbirth* (2003). This manual is one of the most popular natural pregnancy and childbirth manuals and unlike many other "natural" manuals, includes information about the full duration of pregnancy, not just labor and delivery.

In what follows, I lay out two relevant histories. First, I will define the natural pregnancy and childbirth movement and outline its path from its origins in the 1930s, to its contemporary form. I will also sketch out a history of The Farm, a spiritually-oriented commune in Tennessee, and its significance for Ina May Gaskin's work as a midwife and an author, including the text that I will analyze later in the chapter, *Ina May's Guide to Childbirth* (2003). By outlining these histories, I aim to create a point of reference, to see

how both Gaskin, in her text, and the participants in the interviews make sense of natural pregnancy and childbirth.

## What is "Natural" Pregnancy and Childbirth?

Throughout this chapter, I use the term *natural* to describe the particular models of childbirth that Grantly Dick-Read, Ina May Gaskin, and other natural pregnancy and childbirth advocates (who I will return to later in the chapter) have described and promoted, but what does it really mean? It appears as though the definition remains unstable. The most commonly used definition found in popular pregnancy literature suggests that *natural childbirth* is unmedicated labor and delivery (e.g.Murkoff and Mazel 24-25). This means that labor is not induced or augmented with a synthetic oxytocin, called Pitocin, and no pain medication (e.g., an epidural) is administered. For most, it involves some non-medicinal methods of pain control, including hypnosis, controlled breathing, or warm baths. Midwives and doulas are commonly incorporated, but obstetricians may still facilitate a natural childbirth.

There are some points where this definition loses its clarity. For example, it is unclear if the method of conception (through heterosexual sex or through technological intervention) matters. Because "natural" is left vague, a woman who conceived her child through assistive reproductive technology could still have a natural birth, but a woman who conceived her child through heterosexual sex might not have a natural birth. Also, certain techniques like the artificial rupture of the membranes (or "breaking" the amniotic sac using a sterile instrument) is not medicinal like Pitocin, but still may be frowned up

among natural childbirth advocates. Similarly, natural childbirth seems to not depend on setting though free-standing birthing centers and home births seem to be preferred.<sup>17</sup>

Also, I choose to incorporate pregnancy in this discussion of natural childbirth. I refer to it as "natural *pregnancy* and childbirth" because in many ways, the course of one's pregnancy is influenced by one's chosen birthing method. Gaskin writes, "One of the greatest influences on what happens to you during labor (especially as this relates to medical interventions, procedures, and medications) depends upon whom you choose to be your care provider" (Gaskin *Guide* 305). In other words, going to an obstetrician when you prefer a homebirth would not make sense. Ideally, you would instead go to a midwife who routinely attends homebirths.

In the appointments that lead up to labor and delivery, along with the research that the pregnant woman does on her own, are intended to prepare her for one kind of birth or another. Therefore, a preference for natural childbirth would encourage behaviors and attitudes in pregnancy that would fall under the loosely defined umbrella of "natural." This is not to say all natural pregnancies end in natural childbirth or vice versa, nor am I suggesting that they are one in the same. Instead, I am suggesting that natural pregnancy and natural childbirth tend to flow together in pregnancy literature.

As I analyze Gaskin's text in the rest of this chapter, I will use the term natural pregnancy and childbirth, but I do so cautiously. As I have suggested, as it is used popularly, "natural pregnancy and childbirth" fails to maintain a clear meaning. More crucial though, is to address the assumptions that the term is based on: that there is an unnatural way to give birth and that way is somehow bad or dangerous or unhealthy. The construction of a

<sup>&</sup>lt;sup>17</sup> Free standing birthing centers are non-hospital facilities usually staffed by midwives and create environments that facilitate low-intervention births (American Association of Birth Centers).

"natural" way to pregnancy and childbirth relies on an essentialized and ableist conception of a pregnant woman who can always produce children perfectly without intervention. While natural pregnancy and childbirth have been and continue to be promoted as ways to empower women, reminding them that their bodies are not "lemons," there are rarely provisions for those that do require medical intervention (Gaskin *Guide* 315). They are left as footnotes or small percentages in birth outcomes. The natural pregnancy and childbirth movement disregards the narratives of those that cannot or will not go without intervention in order to valorize those that can embody a "natural," "healthy" pregnancy.

## The Origins of Natural Pregnancy and Childbirth

Along with the increasing professionalization of male obstetricians in the late nineteenth century, there was a growing reliance on instruments, like forceps, in obstetrician-attended deliveries. These instrumental interventions were often extremely painful and increased likelihood of perineal tearing (Leavitt 148). Simultaneously, upperclass women began to have access to what became known as "twilight sleep" labors. They were given a combination of scopolamine and morphine, which caused women to forget their experience, though it may not have done much to "manage" pain (ibid 147). Interestingly, many of the early calls in the United States to adopt "twilight sleep" methods were from those active in the women's movement of the early twentieth century, looking to claim control over some of their birthing experience (ibid 154). Instead of being awake and aware of the painful extraction of their child, they wanted the option to forget. An unintended consequence of this method was the solidification of the position of the hospital as the ideal location for birth and the authority of obstetricians over births.

Grantly Dick-Read, a British obstetrician, believed that the pain that made women want a "twilight sleep" delivery could be avoided, "naturally." He coined the term "natural childbirth" with his 1933 pregnancy treatise, *Natural Childbirth* (Hanson 138). He developed what might be called a holistic approach to pregnancy and childbirth, based on his assumptions about "primitive" births. He further argues for acknowledging spirituality in childbirth. He argued that the emotional state and expectations of the laboring mother are factors that determine the amount of pain that they will experience. He also implicates the technological approaches of his contemporaries in poor pregnancy outcomes and disability. Dick-Read is credited with the development of prenatal childbirth classes (ibid 142). His second publication, *Childbirth Without Fear* (1942) is still in print and remains popular among natural pregnancy and childbirth advocates.

In the United States, the work of Dr. Fernand Lamaze, a French obstetrician, is arguably more well-known. Marjorie Karmel's *Thank You, Dr. Lamaze*, published in 1959, introduced his method to the United States. Lamaze based his work on his observations on Russian women's deliveries (Boston Women's Health Collective 127-28). The Lamaze method is based on the assumption that labor is stressful, but still advocates for minimal interventions during labor. Lamaze believed that preparation would allow women to be awake and aware during childbirth, while minimizing pain. This is why feminists of the 1960s and 1970s, like the Boston Women's Health Collective, picked up the work of

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<sup>&</sup>lt;sup>18</sup> In Dick-Read's work, "primitive" is a broad term that he never defined. It could refer to any non-western, non-European people or even poor western people (Hanson 139).

<sup>&</sup>lt;sup>19</sup> Poor pregnancy outcomes are generally defined to include infant death (stillbirth), maternal death, low birth weight, and preterm births. As I argue in Chapter One, one may also include disability as a poor pregnancy outcome if the goal of pregnancy is understood to be to deliver a "healthy" or "normal" baby (Seigel 13).

Lamaze: they saw it as a way to prepare for childbirth and maintain authority over the birth experience.

Even though the works of natural pregnancy and childbirth advocates gained currency, birth in the latter half of the twentieth century was increasingly medicalized and has remained that way. A frequently cited indicator has been the cesarean section rate. The World Health Organization has repeatedly indicated that the rate should be no higher than ten to fifteen percent and should only be performed when medically indicated (1). In the United States today, the primary cesarean section rate is more than thirty percent (Osterman and Martin 2). On Long Island, the rate is even higher, at more than forty percent (Ochs). These statistics are commonly referenced in natural pregnancy and childbirth literature, as a way of indicating that something is wrong with the United States maternity system.

Today, books from Dick-Read, Lamaze, and other obstetrician advocates like Dr.

Robert Bradley, along with Ina May Gaskin (who I will discuss further below), are still popular sources for information about natural pregnancy and childbirth. In addition, women also may come across films and blogs during their pregnancies to learn about alternatives to medicalized birth. Director Abby Epstein and actress Ricki Lake are, for example, prominent voices among natural pregnancy and birth advocates. Through some preliminary interviews, I found that many women first learned about natural childbirth when they encountered Epstein and Lake's *The Business of Being Born*, a 2008 documentary that advocates for home birth and midwifery.

In the discourse of natural pregnancy and childbirth today, there are a range of arguments for minimizing medical interventions, but now the rhetoric emphasizes

promoting healthy outcomes, mostly for the child. This differs from earlier in the history of natural pregnancy and childbirth, specifically with the work of feminists, like the Boston Women's Health Collective. They had argued for "prepared" childbirth (their preferred term for low-intervention pregnancy and birth) and the Lamaze technique because it allowed for the centering of women's needs (Boston Women's Health Collective 127). <sup>1</sup> The Collective preferred "prepared" to "natural" because "The only thing that is natural is that a woman's body is biologically equipped to bear and give birth to a child" (ibid). In comparison, by calling it "prepared" childbirth, the Collective is emphasizing the work that goes into doing what is assumed to come naturally to women. They argue that women need to "prepare" to make sure that their needs and desires are addressed in their birth experiences and as they transition to motherhood (ibid 128). Regardless of terminology, the most important reason to prepare for childbirth, in the eyes of the Collective, was to improve women's own experiences of childbirth.

In comparison, in their documentary, Lake and Epstein emphasize the medical benefits for the fetus/newborn and the potential for bonding between mother and newborn. They may remind the viewer that women who deliver vaginally with no pain medication report shorter recovery periods, but it is framed as time that could be spent better nourishing one's new baby. In its contemporary form, as expressed in this film, natural pregnancy and childbirth is no longer about centering the needs of the mother. The focus has been shifted to the needs of the fetus and to the delivery of a healthy, able-bodied child. Over time, the rhetoric and the authoritative voices in natural pregnancy and childbirth have shifted, and now, as I will discuss in the next sections, Ina May Gaskin and her midwifery model of childbirth is one of the more powerful voices in the movement.

## The Farm Community and Ina May Gaskin's Discovery of Midwifery

Ina May Gaskin is a central figure in the contemporary discourse on natural pregnancy and childbirth. She is a certified professional midwife<sup>20</sup> who has written several books and given lectures all over the world on her areas of expertise, namely, midwifery, natural childbirth, and home birth. Interestingly, her academic background is not medical or science-based: her master's degree is in English. It was through her experiences as a part of The Caravan, a traveling spiritual group, and the early years on The Farm commune that she discovered her interest in childbirth and midwifery. Moreover, the religion that the former leader of The Caravan and The Farm preached places a unique emphasis on sexuality and childbirth that undergirds Gaskin's writings. To better understand Gaskin's work, it is then useful to know a bit more about The Farm Community.

# The History of The Farm

In the late 1960s, Stephen Gaskin developed a massive following based on what he called the "Monday Night Class" in San Francisco (Kern 202; Stevenson 26). At this class, Stephen would preach about a hybridized spirituality, which incorporated, among other things, a message of nonviolence and psychedelic drugs (Verluis and Shipley 144, 45, 49). Ina May first met Stephen during these classes, while she was married to her first husband (Granju).

During a five-month span from October of 1970 to February of 1971, Stephen's Monday Night Class became a traveling "Astral Continental Congress" or The Caravan (Kern 202). With about 250 of his followers in renovated school buses and VW vans, Stephen

<sup>&</sup>lt;sup>20</sup> A certified professional midwife or CPM is also known as a "direct-entry" or lay midwife, meaning she has had no previous training as a nurse. In comparison, there are also certified nurse midwives, or CNMs who are licensed nurses who have received post-graduate training in midwifery (Gaskin *Guide* 306).

traveled across the country to share his message with other preachers. At this point, Ina May, Stephen, and their respective spouses were engaged in a "group family situation" (Granju). It was also during her time on The Caravan that Gaskin would witness her first non-hospital birth. It was an experience she described as "wildly beautiful" (Gaskin "Reducing Fear of Birth"). According to Ina May, it was at this point she became interested in natural childbirth and began her hands-on training as a midwife (Gaskin *Spiritual Midwifery* 16).

Upon their return to San Francisco, the members of The Caravan found themselves increasingly disillusioned by the Haight-Ashbury hippie scene (which was becoming infused with heroin, methamphetamine, and violence) and decided to find a location where they could find cheap land to establish a commune (Verluis and Shipley 147, 49). In 1971, the group ended up in Summertown, Tennessee, a rural area near a large Amish community. At its peak, The Farm housed more than one thousand people, but now claims roughly two hundred permanent residents (Kern 202).

## The Farm Church and Midwifery

The faith of The Farm, known simply as "The Farm Church," developed from Stephen's lectures since the 1960s and informs the basic moral code for the community. According to Douglas Stevenson, a long-time member of The Farm, spirituality is in fact the foundation for the community and affects all that they do (26). This is especially relevant for The Farm Midwifery Practice (the formal name for the midwifery practice that Ina May founded in the community), since childbirth is one of the most important sacraments of the

faith. At the center of the theology is the monogamous, heterosexual married couple<sup>21</sup>, exchanging spiritual energy (or *juice* as Stephen called it) through sexuality (Kern 205-06). The three primary sacraments are then moments that highlight this sexual exchange: marriage, sex, and childbirth. Accordingly, those that facilitate the sacraments (e.g. the community's midwives) are held in high regard.

Ina May rose to prominence as what she calls a "spiritual midwife" in the context of this faith, in this community. Her first book, *Spiritual Midwifery* (originally published in 1975 by The Farm's simply named Book Publishing Company) lays the groundwork for her midwifery-model of maternity care, based on the spiritual beliefs of The Farm. The book, which is peppered with black and white photographs of ecstatic women delivering babies, images of beautiful newborns, and anatomical illustrations, was intended more for potential midwives than for pregnant women. In her advice to midwives, Ina May reminds her readers that birth is a sacrament: "Every birth is Holy. I think that a midwife must be religious, because the energy she is dealing with is Holy" (*Spiritual Midwifery* 270). In what follows, she outlines some guidelines for midwifery, including the importance of compassion in care for pregnant women, continuing education for midwives, and an imperative to not discriminate when a woman requests their help. The "holiness" of birth, inspired by the faith created by her husband Stephen, serves as the basis for her conception of midwifery.

<sup>&</sup>lt;sup>21</sup> Soon after the establishment of The Farm community in Tennessee, they ended the practice of group marriage to appease their very conservative neighbors (Kern 203). It was not until 1984 however, that Ina May and Stephen would become a strictly monogamous couple (ibid).

## The Participants on Natural Pregnancy and Childbirth

In the remainder of this chapter, I will analyze Ina May Gaskin's book, *Ina May's Guide to Childbirth* (2003). I have based my reading of the text on themes found in narratives from two of the participants: Melissa and Veronica. Neither participant was performing or considering natural pregnancy and childbirth at the time of the interview, but their pregnancy experiences had put them into a complex relationship with the discourse. Both women agreed to medical intervention for different reasons, but when either of them considered their bodies and experiences in relation to natural pregnancy and childbirth, they appeared ashamed of what their imperfect bodies had done and were doing.

# Melissa's Story

Over the course of our interview, Melissa shared that her first pregnancy a few years ago ended with the stillbirth of her son via an emergency cesarean section. Just before we went our separate ways, Melissa said that up until the end of that first pregnancy, she had been seeing a midwife and was interested in a water birth (a popular technique among natural childbirth advocates). She had been interested in natural pregnancy and childbirth, but after her loss, she has intentionally distanced herself. Since then, she has had two scheduled cesarean sections and planned to have another for her current pregnancy. She now relies heavily on prenatal testing and the advice of her obstetrician. When asked about why she elected to undergo a variety of prenatal test, she replied, "Now they [the obstetrician] monitor me very closely, luckily. It's too bad it wasn't then." Melissa's narrative suggests that she feels as if she had submitted to medical surveillance, her first pregnancy would have had a better outcome. Now she is "lucky" for the surveillance. To put

this in the terms of the natural pregnancy and childbirth movement, she had trusted her body, but it had failed to produce a healthy child. As a result, she became invested in medical interventions, so that her subsequent pregnancies will have better outcomes. *Veronica's Story* 

Veronica was pregnant with her first child, so it was not her own past experience that had put her in a problematic relationship to natural childbirth and pregnancy. She instead was influenced by her sister's experiences of pregnancy. Her sister, a personal trainer, was able to have three natural pregnancies and births. Veronica called her sister "tough" and said she wished she could "follow in her footsteps." Her sister was also a source of criticism, questioning Veronica's diet and reminding her that she might get stretch marks.

In contrast, due to a few pre-existing and newly discovered medical conditions, Veronica had found her pregnancy labeled high-risk. Because of the combination of medications and necessary changes in her activity level (e.g., she was encouraged to relax and not do any strenuous activity, like exercise), Veronica's body had changed in ways that made her incredibly uncomfortable. She is quick to distance her own behaviors from her larger body. When she mentioned her bodily changes, she shared the following: "At my baby shower, I was self-conscious because I got so big and whatever. But people get it, that I'm on medicine. I look different, but not because I gorge myself all day." She reminded me numerous times that her weight gain was beyond her control, differentiating herself from those women that "send their husbands out for forty chocolate bars" to satisfy cravings.

Also, Veronica was not planning on a natural birth in the sense that I am using it in this chapter, but it was important to her that I knew that she was planning on attempting a

"natural" (meaning vaginal, but with medicinal pain management) birth like her sister had done three times before. Veronica acknowledged her reliance on medicine, but she was clearly very unhappy with what was happening to her body. She also often made connections between her experience and that of her sister, as if she had been able to have her sister's experience, a "natural" experience, she would feel better. Veronica seemed to feel that, unlike her sister (who embodied the discourse of the natural pregnancy and childbirth movement for her), her body was no longer something she controlled because of her reliance on medicine.

#### About Ina May's Guide to Childbirth

In contrast to Gaskin's *Spiritual Midwifery* (her midwifery treatise), her follow-up text, *Ina May's Guide to Childbirth* (the *Guide*), published nearly thirty years later in 2003, is intended for pregnant women.<sup>22</sup> Even though it is much shorter than other pregnancy manuals (348 pages compared to 640 pages of *What to Expect When You're Expecting*), it provides substantial information on prenatal care, possible medical interventions, non-medical solutions to pregnancy and birth discomforts and pains, as well as numerous birth narratives, from women who have given birth with Gaskin and the Farm Midwives (which I return to below).

Unlike many pregnancy manuals, it does not explore the week-by-week or month-to-month changes of pregnancy, nor does it dwell on the discomforts and unusual symptoms of pregnancy in the manner of *What to Expect* (discussed in Chapter 1). It is primarily comprised of text. There are some black and white photographs of women giving

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<sup>&</sup>lt;sup>22</sup> There is an updated version of the text from 2008, but it is only available as an e-book and is less popular. According to Amazon.com's list of bestsellers, under the category "Pregnancy & Childbirth," the paperback version I refer to is ranked second (after *What to Expect When You're Expecting* and just before *Mayo Clinic Guide to a Healthy Pregnancy*), while the updated e-book is ranked forty-fourth.

birth and of happy women with their new babies. There are also simple illustrations of how women in "traditional" or "primitive" cultures gave birth to supplement Gaskin's text.

Throughout the text, Gaskin adopts a tone like that of *What to Expect When You're Expecting*, meaning that she presents herself as a knowledgeable, friendly voice. She uses predominantly plain, romanticized language or connects medical terms to simplified, easy-to-remember definitions. "Oxytocin" for instance, becomes, "the love hormone" and contractions become "rushes" (Gaskin *Guide* 165, 33). Gaskin also reminds the reader that most of her knowledge was gained from witnessing births first-hand and not from any sort of higher education. When she is presenting information that may surprise because it deviates from what is expected, she begins her sentences with phrases like, "In my experience" or "I learned" (Gaskin *Guide* 192, 98). Because of these tactics, the *Guide* is a relatively easy-to-read manual. Moreover, Gaskin's language presents her as a friend to her readers, someone who is just trying to help you, the reader, have the best possible pregnancy experience.

Also, Gaskin's text differs from other mainstream pregnancy manuals because she takes a political stance regarding pregnancy and maternity care in the United States. In the end of the book, she includes her "vision for midwifery and mothers" calling for changes as varied as reforming obstetrical medical education, paid maternity and paternity leave, and a national system for collecting data on maternal deaths (Gaskin *Guide* 311, 14-15). In Appendix C, she includes information of "The Mother-Friendly Childbirth Initiative" which developed a system to define those maternity care providers that are "mother-friendly," meaning they prioritize the needs of women and their babies (Gaskin *Guide* 325-28).

Ina May's Guide to Childbirth as a Typical Text

I selected this text because it represents a popular form of natural pregnancy and childbirth rhetoric that circulates in the United States. In my preliminary research, I found that this was the text that women most often referred to when discussing natural pregnancy and childbirth. Accordingly, on Amazon.com, Gaskin's book is also the topranked pregnancy manual that explicitly focuses on natural pregnancy and childbirth. Also, Ina May Gaskin is a significant cultural figure, often referred to as the "midwife of modern midwifery" (Gaskin "The Feministing Five"; Granju). For example, she is referenced as one of the inspirations behind *The Business of Being Born* (2008) and she appears in the follow-up mini-series, *More Business of Being Born* (2011). Gaskin is a major figure in the natural pregnancy and childbirth movement, but her work also reaches out into the wider culture. *Ina May's Guide to Childbirth* is then a text that is typical of the natural pregnancy and childbirth movement, as inflected through Ina May Gaskin, as a midwife.

### Sharing Stories and the Feminist Women's Health Movement

Gaskin's *Guide to Childbirth* begins with women's birth narratives, a frame also used in her first midwifery text, *Spiritual Midwifery*. Though she never mentions it directly in the text, Gaskin was clearly influenced by feminist critiques of medicine and maternity care, especially in her belief in the value of sharing of birth stories In a 2012 interview, she said "Feminism was very powerful to me" when she was a new mother in the 1970s ("The Feministing Five"). She said that she was particularly struck by writer and activist Robin

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<sup>&</sup>lt;sup>23</sup> As of this writing, *Ina May's Guide to Childbirth* is ranked second on Amazon.com's list of bestsellers under the category "Pregnancy & Childbirth."

Morgan's phrase, "Sisterhood is powerful" (qtd. in ibid). Morgan's inspiring phrase, along with the faith of The Farm, encouraged Gaskin to value narratives shared between women.

In the text, Gaskin does not openly reference feminism, but there are similarities between *Women and Their Bodies* and Gaskin's manual. In the *Guide*, Gaskin is using the narratives to disrupt the power of birth "horror stories," but she also uses the connections made to learn more about pregnancy and birth in ways that align her with the writings of the Boston Women's Health Collective.

In the introduction, Gaskin writes, "Positive stories shared by women who have had wonderful childbirth experiences are an irreplaceable way to transmit knowledge of a woman's true capacities in pregnancy and childbirth" (Gaskin *Guide* 4-5). She argues that the birth "horror stories" that circulate popular culture prevent women from having pleasurable birth experiences (ibid 3). She then shares 125 pages of triumphant birth stories from dozens of women who have given birth with Gaskin and the Farm Midwives. Gaskin wanted these stories to be inspirational tools for pregnant women. She wants women to know that birth is not as scary and risky as the stories that circulate popularly.

Through these stories, an intertextual connection emerges between Gaskin's book and the feminist health movement, and more specifically, Boston Women's Health Collective's *Women and Their Bodies: A Course* (1970), the precursor to the feminist health text *Our Bodies, Ourselves* (first released in 1975). In the "Course Introduction" the authors share how they came to write this course: "We discovered there were no 'good' doctors and we had to learn for ourselves. We talked about our own experiences and we shared our own knowledge" (3). Additionally, they encouraged women to read through the course in groups, to share the experience (ibid 4). Just like Gaskin, the Collective was encouraging

women to share their experiences of their reproductive lives in their own terms, to revalue and reinterpret outside of the pathologizing gaze of medicine.

However, unlike the Collective, Gaskin is the sole author of her text. She does indicate that the narratives were authored by others, though several are framed by her commentary. As the sole author on a text that is a collection of narratives and advice, Gaskin becomes a guru, or a spiritual teacher to guide her readers. She claims a level of individually-held expertise that the Collective refuses. The Collective begins their course with a refusal of total authority over their text. First, they acknowledge their position as non-experts in medicine. Then encourage further input on the text: "It took a long time to put together this course, but we don't consider it a finished product. As more women use, teach, and learn from the course, it must be expanded and revised to meet our needs" (Boston Women's Health Collective 5). In contrast, Gaskin opens her text with her credentials, as a midwife for more than thirty years, in a practice that has attended more than two thousand births (Gaskin *Guide* xi). She presents her unique experiences as the source of her knowledge, which suggests she was the only person who could write this particular manual.

Gaskin and the Collective do share some commonalities, in that they emphasize the importance of women learning with and from other women. The Collective did this literally, with lay women teaching other lay women through sharing experiences. Gaskin instead presents herself as a sole author and guru who has the capacity to aggregate and explicate women's stories for the benefit of her readers in a way that no one else could. Women's narratives are essential in both texts, but the authors' relationships to those narratives shifts.

## The Appealing Power of Natural Childbirth and Pregnancy

As a researcher, I had trouble distancing myself from Gaskin's work, because my personal feelings towards her work are conflicted. The Guide draws on celebratory and empowering rhetoric. Gaskin encourages women to remember that they have capabilities beyond what men and traditional medical authorities say they can do. In fact, she says that if men could deliver babies or "If men had such an organ [a uterus], they would brag about it" (Gaskin Guide 144). Gaskin encourages her readers to think positively about their bodies, even if they had been told that their bodies were insufficient or "lemons" before. I was reminded of what Anne Finger, a disabled feminist, wrote about her desire to deliver a healthy child naturally: "I wanted something perfect to come out of me" and she wanted to be responsible for it (Finger 172). Like Finger, my ability to have a healthy pregnancy is often doubted (by myself and others), so Gaskin's encouragement to think positively about my body was refreshing and new (Gaskin Guide 142). It made me think that I could produce a perfect, healthy child. In these moments, I felt that I could be just like the women telling their amazing birth stories in the opening of the Guide. In many ways, I wanted the discourse of natural pregnancy and childbirth to be a meaningful alternative discourse for pregnant women and it raised my expectations of what pregnancy could be like for me.

Her explanations of the medical and midwifery models of pregnancy also fit well with my understanding of medicine and its interaction with bodies that I have gained through the insights of disability studies. Like disability studies has articulated for disability, Gaskin argues that there is a medical model of pregnancy that labels pregnancy as a sickness and medical condition that must be treated by medical professionals (ibid 185). Gaskin's alternative, the midwifery model, like the social model in disability studies,

instead argues that society have turned variation in pregnancy into something labeled sickness. I will return to these models later, but I wanted to flag this striking and appealing intertextual connection between Gaskin's work and disability studies.

The draw of Gaskin's writing was significant and powerful for me, but as I gathered narratives from the participants and thought more broadly about who can experience pregnancy, the limitations of Gaskin's midwifery model of pregnancy (and natural pregnancy and childbirth more broadly) emerged more clearly. Her reliance on the concept of "normal" and her apparent obliviousness to or ignorance of things that are not "normal" are a failure to remember that there is no universal or monolithic Pregnancy Experience, nor does the experience of pregnancy force the idea of Woman into a neat, clean category. In the sections that follow, I will unpack her central argument about the powers of pregnant women and consider the role of ableism in natural pregnancy discourse.

### "Let Your Monkey Do It" and the Primitive Power of Women

The crux of Gaskin's argument in the *Guide* is that women's bodies are competent and that birth is a natural, *normal* process. She argues that we have lost connection to the primitive power of birthing women because the "medical model" of pregnancy is the dominant model of pregnancy in the United States (Gaskin *Guide* 185). Much like the individual or medical model of disability used in disability studies, variation (e.g., of symptoms, of labor duration) under the medical model of pregnancy is pathologized and is positioned as a problem to be corrected by medical science. Because pregnancy is a state of abnormality or sickness in this "male-derived framework,", medicine needed to develop cures that do not rely on the capacity of a woman's body (ibid 185).

Gaskin offers up what she calls the "midwifery model" of pregnancy as an alternative to the medical model. In the midwifery model, "pregnancy and birth [are] inherently healthy processes" (ibid 184). Natural variation in pregnancy and childbirth are assumed, which limits what symptoms necessitate a medically-indicated intervention. In the text, she suggests that only five to fifteen percent of women will need any medical interventions in the birth process (ibid). For example, Gaskin believes most inductions are unnecessary and cause more problems than they solve for mother and child (ibid 207-09).

In order to take advantage of the midwifery model, Gaskin believes that women need to tap into a force she believes is present in all women. She characterizes this force as ancient, instinctive, natural, primitive, and the "true capacity" of women (ibid 5). This force is available to any woman that lets her "monkey do it" (ibid 243). Gaskin writes: "Letting the primate in you do the work of labor is a short way of saying to not let your over-busy mind interfere with *ancient wisdom* of your body" (ibid, emphasis mine).

The implication here is that women are disconnected from an eternal and innate essence of woman-ness and, more importantly, that there is an eternal and innate essence of woman-ness. This is problematic on two fronts: first, it assumes that there is an essential Woman and, second, that this Woman's body is "beautifully and admirably designed to give birth" (ibid 270). Despite her acknowledgement that there is natural variation in pregnancy and birth, Gaskin fails to account for disability and variation in women's bodies.

#### **Making Sense of Poor Pregnancy Outcomes**

If I try to incorporate the narratives from Melissa and Veronica into Gaskin's natural pregnancy discourse, this logic ceases to work. According to Linda Layne, a feminist anthropologist, the women's health movement had to erase narratives of poor pregnancy

outcomes to rhetorically distance itself from the pathologizing rhetoric of medicine. The *Guide* similarly relies on positive stories of pregnancy for the same reason: to bolster the appeal of natural pregnancy and childbirth, it must remind you of all the reasons that women's bodies should be trusted and ignore the possibility for complications.

The Omission of Poor Pregnancy Outcomes

The success of this message depends, in part, on the obfuscation of poor pregnancy outcomes, and hiding the narratives of women like Melissa and Veronica. In the *Guide*, births that resulted with poor outcomes or disability do not get to be part of the triumphant birth narratives. <sup>24</sup> They become the five to fifteen percent of women (referenced earlier) who need medical interventions or they are only included in Appendix A as poor outcomes (Gaskin *Guide* 322). They are the "high-risk" pregnant women that have been "risked out" of midwifery practices (Findletar-Hines). The only times negative outcomes or disability are mentioned in the body of the text, Gaskin references one's reproductive histories (i.e., if a woman has had a miscarriage in the past) or they are presented as contraindications for a test or procedure (i.e., a risk of amniocentesis is miscarriage.). This rhetorical move has had unintended complications. It compounds the silence surrounding pregnancy loss and complications because Gaskin provides no non-medical vocabulary for the poor outcomes or disability.

The only way to make sense of poor pregnancy outcomes and disability is a problematic shift to individual responsibility (Layne *Motherhood Lost* 149-50). In natural pregnancy and childbirth, pregnant women are expected to trust in their bodies and not in

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<sup>&</sup>lt;sup>24</sup> Here, I am intentionally separating "poor pregnancy outcomes," like miscarriage, low birth weight, or stillbirth from pregnancies that result in disability. I wanted to make it clear that I do not view disability as an inherently poor or negative outcome of pregnancy, though as I will discuss further in Chapter Four, it is usually not a desired outcome of pregnancy.

medical interventions. When a natural pregnancy or birth ends in a poor outcome or disability, there are no interventions to blame, only the mother. Anne Finger articulates the problem of individual responsibility in natural pregnancy and childbirth:

It's true, when you take control of your body, of your birth, you take control of everything: the pain along with the joy, the bad with the good. I understand why people want to surrender their lives to someone else's power, to the power of the machine. Having surrendered, you may feel hollow inside, blank, an automaton being acted on by forces beyond your control, but at least you don't feel this awful sense of responsibility. (Finger 200-01).

When a woman pursues a natural pregnancy and childbirth, she is supposed to rely on herself and her innate woman-ness. In this discourse, a poor outcome is then either ignored, or the result of a failure to connect with the true power of women. There is no room for a more nuanced analysis of poor outcomes and disability in the celebratory discourse of natural pregnancy and childbirth.

Incorporating Disability and Blame

Ableism flows through this shift to individual responsibility and complicates

Gaskin's shift away from the medical model of pregnancy. Because the individual woman

becomes responsible for her own pregnancy and birth experience, any negative outcomes

or disabilities are blamed directly on the failure of one's body. This is characteristic of the

medical model of disability (discussed above). That is, the problem of unexpected or

undesirable pregnancy outcomes is placed on an individual's body, while one's access to

quality prenatal care, supportive family members, a safe home environment, or other social

concerns are ignored.<sup>25</sup> This sits uneasily next to her claim that women's bodies are not

"lemons" and are inherently able to carry and give birth to a child. When natural pregnancy

 $<sup>^{25}</sup>$  I will discuss these social issues further in Chapter Four, when I consider the concept of reproductive justice.

and birth practices do not create a desirable outcome, there is no other possible conclusion that one's body is insufficient. Ableism, as it flows through Gaskin's argument, makes that insufficiency particularly difficult for women like Melissa.

In Gaskin's *Guide*, disability also becomes a source of very particular blame. In one of the few explanations offered for a neonatal mortality at The Farm practice, Gaskin writes: "involved a mother whose legs were paralyzed from polio, whose cord prolapsed at the first sign of labor" (Gaskin *Guide* 322). This is noteworthy for several reasons. First, as I noted, it is one of the only explanations for a poor pregnancy outcome at The Farm. Second, it is the only open acknowledgement of disabled pregnant women. Finally, it is particularly interesting that this explanation was framed this way considering the fact that the cause of the cord prolapse was most likely unrelated to the mother's paralysis, meaning the woman's disability did not need to be mentioned (Phelan and Holbrook). This a startling example of ableism in natural pregnancy and childbirth discourse: a disabled woman is, in effect, being blamed for the death of her child *because* she was disabled.

### **Expectations in Natural Pregnancy and Childbirth**

As I finish my analysis, I return to the different types of expectations that I began to discuss in Chapter Two. In many ways, the expectations of pregnancy for those following the advice of natural pregnancy and childbirth manuals are not all that different from those who read *What to Expect When You're Expecting*. That is, pregnant women who choose to follow Ina May Gaskin's also expect that if they follow appropriate advice and trust their bodies, they expect that they will produce a healthy, nondisabled child. In fact, Gaskin's invariably triumphant pregnancy narratives close off the possibility that women should expect anything but a perfect child.

In Gaskin's articulation of the natural pregnancy and childbirth movement, the expectations of pregnant women, what they are expected to do, is different from those who follow a more medicalized understanding of pregnancy. Gaskin expects women to get in touch with their inner monkey or innate woman-ness and put complete trust in their bodies. This is based on the assumption that there is an innate quality that is universal to women that allows them to carry and deliver children successfully, without intervention. This is very different than the women of the previous chapter, who were expected to submit to the authority of their doctors. Instead of assuming that obstetricians and other medical professionals know their bodies better than they do, natural pregnancy and childbirth advocates assume that they can know their body completely and deliver their expected perfect child perfectly.

Instead of expecting all pregnant women to experience their pregnancy as sickness or disability, *Ina May's Guide to Childbirth* expects pregnant women to be exceptionally able. The universal woman-ness I noted above is, to be more accurate, a universal, *able-bodied* woman-ness. The reader of Gaskin's text is assumed to be able-bodied and capable of experiencing a pregnancy without medical intervention.

This also leads to who has the privilege of expecting something from a natural pregnancy and birth. The narratives in Gaskin's text are exclusively from presumably ablebodied women who only experience positive pregnancy outcomes or those that have had prior poor outcomes from medicalized birth experiences. In other words, the only stories presented put natural pregnancy and childbirth in an unrelentingly positive light and cast medicalized pregnancy and birth as something dangerous to be overcome. Because of this framing, only those who have the privilege of accessing natural pregnancy and birth-

oriented providers (like Ina May Gaskin and the Farm Midwives) have the privilege of expecting a positive pregnancy and birth experience like those presented in the text. This means that only those who would be able-bodied and "low risk" have the opportunity to expect a good pregnancy outcome.

Despite the powerful appeal of natural pregnancy and childbirth, particularly Ina May Gaskin's unflagging positivity towards women's bodies, my analysis reveals that not every pregnant woman can have such overwhelmingly positive, low intervention experiences. As Melissa's and Veronica's stories highlight, there are women that are disregarded or excluded from the celebratory experience of pregnancy. There is no inner monkey or innate Universal Woman-ness that all women inherently have access to by virtue of being biologically female. Furthermore, natural pregnancy and birth advocates, like Gaskin, consistently present their movement as an alternative to mainstream medicalized pregnancy, but they still fall into some of the same ableist assumptions of medicalized pregnancy. By failing to acknowledge a range of pregnancy experiences, including those with poor outcomes, the natural pregnancy and childbirth discourse builds up expectations of pregnancy that are ableist and limiting for only those who can produce perfect children perfectly, without intervention.

### **Chapter Four**

# **Integrating Disability, Transforming Pregnancy**

My doctor was willing to listen to me, even though I'm not an M.D...He said to me, 'I'm the expert in delivering babies, but you are the expert on hydrocephalus and pregnancy.

-Holly, qtd. in The Disabled Woman's Guide to Pregnancy and Birth (2006)

We owe it ourselves to know as precisely as possible all that is happening to us, so that we know what questions to ask, how to pursue demands we might make on doctors and friends in order to lessen any discomforts we might be feeling and to insure that we get humane treatment. There are many things we don't know about this crucial event, and it's difficult to get information as a result of our long-standing inertness, and of doctors' attitudes toward us as we climb on the medical conveyor belt of pregnancy.

-Boston Women's Health Collective, Women and Their Bodies: A Course (1970)

There are more than four million parents in the United States who have disabilities according to recent estimates (Kaye).<sup>26</sup> Medical researchers estimate that at any given point in the year, more than 150,000 chronically physically disabled women in the United States are currently pregnant (Iezzoni, Yu, et al. 561).<sup>27</sup> Despite the fact that many disabled women experience pregnancy (and many others may desire it), there is little research on disabled women's pregnancy experiences. The legacy of eugenics and related faulty understandings of disability have forced disabled people to fight for the opportunity to conceive, carry, birth, and parent children without unnecessary or unwanted interventions (e.g., Jarman 49; Iezzoni, Wint, et al.; Rogers 33). Based on the stories contained within *The Disabled Women's Guide to Pregnancy and Birth* (2006), their experiences are just as varied

<sup>&</sup>lt;sup>26</sup> Working with a parenting organization for disabled people, Through the Looking Glass, Dr. Steven Kaye estimated this figure using a number of different national data sources, including the American Community Survey of 2009 (Kaye).

<sup>&</sup>lt;sup>27</sup> They defined "chronic physical disability" as movement difficulty stemming from persisting or reoccurring "physical health conditions," like multiple sclerosis or cerebral palsy (Iezzoni, Yu, et al. 557). Also, as indicated, this figure only includes chronically physically disabled women. Rates of pregnancy among women with other kinds of disabilities (e.g., sensory or cognitive) were not readily available.

and complex as nondisabled women's experiences, if not more so, and merit scholarly attention.

In this chapter, I analyze a non-typical pregnancy manual, *The Disabled Woman's Guide* to see how disability can be incorporated meaningfully into pregnancy discourse and how a centering of disabled women's pregnancy experiences may change expectations of and from disabled and nondisabled women's pregnancies. I look to *The Disabled Woman's Guide* to consider what pregnancy experiences, informed by reproductive justice and inclusive of disability, could look like. I connect my analysis to disability studies and disability experiences in order to provide a new model of pregnancy, for both disabled and nondisabled people. I open up a space to talk about pregnancy that is not characterized solely by fear and normative expectations, or by appeals to an essential, universal womanness, but instead, a space that values critical access to prenatal care and authority over one's own experience.

## **Defining Reproductive Justice**

Before beginning my analysis of *The Disabled Woman's Guide*, I define and contextualize the concept of reproductive justice. "Reproductive justice" came out of the first SisterSong Women of Color Reproductive Health and Sexual Rights National Conference in 2003 (Roberts, Ross and Kuumba 93; Ross). At this conference, more than six hundred scholars and activists came together to work towards a reproductive health movement that foregrounds the knowledge and experience of women of color (Roberts, Ross and Kuumba 93). According to Loretta Ross, the co-founder and director for SisterSong, reproductive justice has three primary principles: women have the right to decide to have children (and under what conditions), to not have children (and how to

prevent or end a pregnancy), and to "parent the children she already has with the necessary social supports in safe environments and healthy communities, and without fear of violence from individuals or the government" (Ross). In order push back against reproductive oppression (the control of communities through individual bodies), this framework fills gaps in feminist discussions surrounding reproduction and brings reproductive issues into conversation with broader concerns including parenting, women's health, poverty, and social services. In particular, they focused on gaps that most profoundly impacted women of color and especially poor women of color.

Reproductive justice was built upon the foundations of the Black women's health movement, the framework of human rights movements, and is theoretically based on the concept of intersectionality (Ross). Reproductive justice is, on a practical level, concerned with issues of service delivery and advocating for reproductive and sexual health care services (ibid). In part, reproductive oppression stems from absent or inadequate health services that inhibit access to the primary principles listed above. At the same time, the movement's founders push for activists to think of reproductive oppression and the fight for reproductive justice, not in isolation (as with the issue abortion in the pro-life/prochoice debate), but as part of a broader discussion on human rights. This is a recognition that varied forms of oppression, like racism and sexism (and ableism), are intertwined and must be challenged holistically in order to create a just system.

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<sup>&</sup>lt;sup>28</sup> Intersectionality is a term from critical race scholar Kimberlé Crenshaw in 1989 to describe the interactions of varied systems of oppression (e.g. sexism, ableism, racism). Instead of suggesting that disabled women are doubly oppressed, as women and as disabled people, an intersectional analysis would argue that the disabled woman experiences sexism and ableism as simultaneous intersecting forces. In other words, she is not disabled and a woman, but rather a disabled woman.

Reproductive justice is derived from the contributions, concerns, and desires of women of color to "reveal what is not being talked about in the women's movement and, just as importantly, to mobilize us toward action" (Roberts, Ross and Kuumba 94).

Reproductive justice is then simultaneously a movement and a theory, developed from the voices of those most often silenced or ignored, in order to push back on the systems of oppression that regulate, manipulate, and destroy bodies deemed risky, unworthy, or unfit (Ross).

Incorporating Disability into Reproductive Justice

When SisterSong introduced the term reproductive justice and started the movement to combat reproductive oppression, they did it as a way to re-center discussions of reproductive rights on the needs and desires of women who continually fell outside the scope of mainstream pro-choice feminism, specifically women of color (Roberts, Ross and Kuumba 93, 95; Ross). The needs and desires of disabled women were not explicitly named, meaning the movement did not begin as completely inclusive of disability.

If this term comes from and is based on the experiences of women of color, who are apparently presumed to be nondisabled, and does not name the needs and desires of disabled women, why then am I applying this to a discussion of disabled women's pregnancy experiences and manuals? First and foremost, SisterSong has encouraged people to "embrace and adjust the framework [of reproductive justice] to fit their own needs" as long as "the theoretical origins and its concomitant movement building practices originating in the experiences of women of color will be respected with the same integrity and generosity with which we offer our perspectives" (Ross). In other words, as long as the history and original connotations of reproductive justice are meaningfully represented, the

creators of the concept want people to take up and adapt it so that it becomes more inclusive.

Among disability studies and disability rights activists, any discussion on reproductive issues focuses primarily on the implications of terminating a pregnancy based on the (potential) disability of the fetus. The reproductive justice movement provides a much-needed framework to think outside of the pro-life/pro-choice binary, which has so often used the specter of disability or a limited frame of disability rights (based on the views of those in positions of relatively privileged disabled people, like physically disabled white heterosexual men) to make arguments about abortion (Shakespeare 269). For example, Michelle Fine's and Adrienne Asch's collection *Women with Disabilities* (1988) included a chapter on conflicts between disability activists and feminists about what it means to abort a (potentially) disabled fetus. Nearly three decades later, the specter of a disabled child is still being used divisively in pro-life *and* pro-choice rhetoric (e.g., Jarman; Kafer). While abortion rights are extremely relevant in the current political climate and must be discussed, taking disabled (expectant) mothers into consideration requires the broader view of reproductive justice, beyond just discussions of abortion access.

If the focus shifts to disabled expectant mothers, instead of on their fetuses, new conversations about conceiving, carrying, and giving birth can emerge. Karen Weingarten, a feminist and disability studies scholar, argues that by focusing on the potential disability of the fetus, those both for and against the abortion of fetuses that have received prenatal diagnoses of disability, are using women's bodies to achieve their own ideological ends. In the terms of reproductive justice, this is yet another form of reproductive oppression. She then suggests that the most useful way forward in discussions of reproduction and

disability is to think of those that are "already alive" and work with them to determine what can be done to create a viable and meaningful life (Weingarten). The framework reproductive justice provides similarly pushes women and their communities to the center of these conversations for the same reasons that Weingarten articulates. In this chapter, I focus on disabled mothers because there needs to be attention on pregnancy itself and how women, disabled and nondisabled, are affected by and make sense of it to work past ossified debates of what potential outcomes of women's reproductive lives are acceptable.

Relatedly, integrating disability into reproductive justice offers up a fuller and more nuanced picture of the environment in which women are living their reproductive lives.

Alison Kafer, a feminist disability scholar, argues for an integration of reproductive justice into disability studies and activism because

Reproductive justice insists upon a cross-movement approach to reproductive issues, recognizing that questions of reproduction cannot be disentangled from those of race, class, and sexuality, not to mention poverty, welfare, health care, social services, environmental justice, and so on. Disability is an essential piece of this assemblage, and reproductive concerns about disability cannot be untangled from these other factors. (162)

Thinking about reproductive issues through reproductive justice, as Kafer illustrates, requires making connections and thinking broadly about the circumstances and effects of reproductive decisions and disability is a part of that. In other words, ableism, just like sexism, racism, and other forms of oppression, uses disability to influence the decisions that people make or even the decisions that they have the chance to make about their reproductive lives. Whether the ableism is enacted through a desire for a nondisabled child, through forced sterilization because of one's disability, limited access to adequate healthcare, or a pregnancy manual that fails to include any experiences of disabled women, it is still functioning as a form of reproductive oppression. In these cases, ableism becomes

a tool to control women's bodies and their communities. In my analysis of *The Disabled* Woman's Guide, which will be the focus of the rest of this chapter, thinking through reproductive justice has lead me to consider how disabled women maintain authority over their experience, make reproductive decisions, and how they negotiate access to their health care providers in ways that shift what is expected of pregnant women and what pregnant women can expect of their pregnancies.

## Introducing The Disabled Woman's Guide to Pregnancy and Birth

The Disabled Woman's Guide to Pregnancy and Birth, from Judith Rogers, is a pregnancy advice manual like What to Expect and Ina May's Guide. Like the other manuals, it provides information on the emotional and bodily changes during pregnancy. It also includes information on how to interact with your health care providers during prenatal visits. What sets this text apart from the dominant manuals is that it focuses on the needs of physically disabled women.<sup>29</sup> Rogers based the book on interviews with ninety physically disabled women who have had a child (1).<sup>30</sup> While the primary audience is those with physical disability, Rogers writes that "any pregnant woman may benefit from the problem-solving approaches and specific solutions suggested here"(xii). She often affirms the common ground between disabled and nondisabled pregnant women because "Disabled mothers believe that a pregnant woman with disabilities should be seen primarily as a pregnant woman" (ibid 81). Disabled women may have different issues to consider, but they are still pregnant women.

<sup>&</sup>lt;sup>29</sup> Because I will be focusing on this text which is based on the experiences of physically disabled woman, I hesitate to generalize my analysis to all pregnant women with other kinds of disabilities (e.g., sensory, cognitive). When I speak of disabled pregnant women generally, it is with the recognition that disability experiences are varied, even among those with similar physical disabilities.

<sup>&</sup>lt;sup>30</sup> At no point does Rogers specifically define what she means by "physical" disabilities. She includes interviewees with conditions including scoliosis, Charcot-Marie-Tooth, multiple sclerosis, and fibromyalgia.

#### Disabled Mothering

For women who fall outside the nondisabled norm, there are different expectations for them as mothers, starting from pregnancy. While they are pregnant, disabled women may experience intrusive questions or uninformed obstetricians (lezzoni, Wint, et al.; Rogers 85). Once their child is born, they may have other obstacles to face. In sociologist Claudia Malacrida's interviews with disabled Canadian mothers, she found that many disabled women hold themselves to higher standards of mothering as a way of indicating their competence. The need to present competence is attributed to the (often baseless) fear that a disabled woman would not be able to take care of her child because of her disability (Fine and Asch 21; Frederick; Malacrida "Performing Motherhood" 100). Moreover, according to Michael Gill, a feminist disability scholar, research on parenting with disabilities (specifically intellectual disabilities) is frequently based on those disabled parents that have already been declared lacking and were known to social service agencies (140-41). This oversampling creates a skewed image of who disabled parents are. To be viewed as fit to parent, disabled mothers may feel like they have to try harder than a nondisabled woman (Malacrida "Performing Motherhood" 106).31 For many disabled pregnant women, the invisibility of successful disabled mothers means that they have to look to alternative or less popular sources to find out what a mother like them might look like. They may even have to create resources on their own.

<sup>&</sup>lt;sup>31</sup> This is not necessarily unique to disabled women. For example, in sociologist Elena Neiterman's study of pregnancy as a performance, she found that those that are socially disadvantaged or viewed as insufficient potential mothers, like immigrant and teenage pregnant women were more closely surveilled and challenged for their assumed insufficient mothering capabilities (376-77).

*Judith Rogers and Through the Looking-Glass (TLG)* 

The author of *The Disabled Woman's Guide for Pregnancy and Birth*, Judith Rogers, is a disabled mother and occupational therapist who could find no disabled parents to be her role models (xi). Through her disability activist networks, she began to talk to other disabled women who had been pregnant, which turned into research on pregnancy and parenting while disabled (xi-xii). Now, Rogers is the pregnancy and parenting specialist at Through the Looking Glass (TLG), a national organization that supports disabled parents. They provide support as well as adaptive equipment and training to help disabled parents care for their children in ways that make sense for their families.

While it is not explicitly noted in the text, it is clear that Rogers has political investments in disability activism. Her work at TLG and the way that she writes about disability clearly align her with disability activism. Rogers rejects the individual/medical model of disability that locates the problem of disability in the body of an individual as something to be fixed. Instead, she views disability as another way of being and society creates barriers to the full participation of disabled people. For example, early in the text, she takes care to note that social barriers have prevented disabled women from becoming pregnant: "The forces of *social disapproval* and their own fears often work against many disabled women in their decision to have children. Even when they were illegal, abortions were routinely done by American doctors for women with physical disabilities" (Rogers 33, emphasis mine). Disabled women are not incapable of pregnancy, but rather, external forces like "social disapproval" have prevented disabled women from choosing pregnancy.

The Disabled Woman's Guide as a Non-Typical Text

Rogers' political affiliations clearly influence *The Disabled Woman's Guide*, most notably in the chosen source material for the text. As I noted previously, the manual is based on Rogers' interviews with ninety physically disabled women. She frames these women as "experts" on pregnancy, who create a "realistic image of mothering" (1). Unlike other pregnancy advice texts, *The Disabled Woman's Guide* is not framed with the approval of a medical authority. In contrast, the extremely popular manual, *What to Expect When You're Expecting* (2008) opens with a foreword from a male obstetrician praising the manual for its successful translation of (presumed expert) medical knowledge for lay audiences (Murkoff and Mazel xx-xxi). *The Disabled Woman's Guide* instead begins with and integrates the wisdom of women who have experienced pregnancy.

Using interviews as source material makes *The Disabled Woman's Guide* radically different from other mainstream pregnancy manuals. To demonstrate this, I will compare two similar excerpts: one from *The Disabled Woman's Guide* and one from *What to Expect When You're Expecting*. Both of these excerpts refer to discussions that a pregnant woman should have with her health care provider on the possibility of having a cesarean section early in her pregnancy. Both are set up in a "question-answer" format. For this brief comparison, I will just focus on the "questions" which respectively read as follows:

- "Do you think I need a caesarean delivery? Why? Would you set a date or wait for labor to begin spontaneously?" (Rogers 93)
- "I was hoping for a vaginal birth but the doctor just told me that I'll probably have to have a cesarean. I'm really disappointed" (Murkoff and Mazel 320).

These excerpts are typical of each respective text. When read in comparison, we can see, for example, the differences in how pregnant women are expected to make decisions. In *What to Expect*, the doctor "told" the imagined pregnant woman that they have made a decision on how her labor and delivery will proceed without explaining the reasoning. The reader of *What to Expect* submits to the authority of their health care provider.

In contrast, the reader of *The Disabled Woman's Guide* is not "told" she will have a cesarean. In this excerpt, the pregnant woman elicits the health care provider's advice and requires them to share the rationale for their answer. The reader of *The Disabled Woman's Guide* is given more authority over her pregnancy experience and has access to information about her medical care. This comparison shows that the expectations of the disabled mother, as represented in *The Disabled Woman's Guide* is not the same as the mainstream expectations of mothers. *The Disabled Woman's Guide* instead portrays a mother influenced by the disability justice and feminist movements, who has authority over her experience. *An Overview of* The Disabled Woman's Guide

The 528-page pregnancy manual divides the text into chapters, as well as several appendices. There are no pictures and only a few line drawings, mostly to illustrate pregnancy exercises. The book formally begins with an introduction to the women whose experiences helped share the text, with a preface from the author and a chapter outlining information on the ninety women who were interviewed. Following that, there are several preconception chapters, designed to help someone determine if having a child is the best choice for them. The bulk of the latter half of the book focuses on the progression of the pregnancy, divided into chapters on diet, exercise, and one for each of the trimesters of

pregnancy. The last two chapters are on labor and delivery and cesarean sections, respectively.

#### The Universality of Pregnancy Against the Specificity of Disability

As noted above, Judith Rogers believes that her manual is valuable not just for physically disabled women, but also for nondisabled women. She also emphasizes the commonality between disabled and nondisabled pregnant women as earliest pages of the manual in the preface: "Finally, [the manual] offers the insights the women shared about pregnancy and disability including...their insistence that a pregnant woman with disabilities be seen *primarily as a prospective mother*" (Rogers xiii, emphasis mine). Then, she reaffirms this in the first chapter:

The second recommendation is that a woman with disabilities be seen *primarily as a pregnant woman*—both in her mind and in the mind of her physician. In their advice to obstetricians, many of the interviewees emphasized their desires to be treated "just like everyone else." (ibid 2, emphasis mine)

In both of these passages, Rogers is clearly articulating a position that women, both disabled and nondisabled, share connections through the experience of pregnancy. Many of the participants in her study push this even further, saying they feel like pregnancy made them "part of the sorority" (ibid 55).

There is a tension however, between this appeal to the universal experience of pregnancy and the call to recognize the specificity of disabled women's pregnancy experiences. Pages forty-two to fifty-one list out the disability-related concerns of pregnancy, broken down by diagnosis, with recommendations from empirical research and from medical experts. Rogers also encourages her readers to ask their prenatal care provider "What do you know about my disability? How much experience have you had working with disabled women? Have you treated other women with my specific

disability?" (ibid 90). These examples all point to the importance for disabled women to recognize that in many ways their pregnancy experiences are going to be specific to their disability.

In the structure of the text, Rogers also builds in the acknowledgement of the specificity of disability during pregnancy. When choosing pseudonyms for her interviewees, Rogers gave them names that corresponded to their particular disability. For example, the women who have hip dysplegia are named "Hannah" and "Heather Ann" (ibid 11). Practically speaking, this naming technique is helpful for a reader who shares a diagnosis with one of the interviewees. If a reader see advice from someone with initials that indicate that they share a diagnosis, they are able to easily recognize that the advice provided may apply to them.

However, naming the interviewees after their disabilities also works discursively in ways that Rogers may not have intended. As she presents each woman, with their disability-based name and a short biography, which reduces them to their lives to their disability and their pregnancy. For instance, below is Nadia's introductory biography:

Nadia experienced myasthenia gravis symptoms during the second trimester of her third pregnancy, and could not hold onto a bottle or shampoo her hair. She was diagnosed with myasthenia gravis during the third trimester. Nadia had double vision 6 months after the birth of her child and weakness in her facial muscles as well as her arms and neck muscles. She did not have any problems with her legs until after the diagnosis was made. She was started on steroids the day after the baby was born. Nadia felt weak at the beginning of steroid treatment. She also had a thymectomy a month after her baby was born. (ibid 19, emphasis original)<sup>32</sup>

In this passage, we learn very little about Nadia, beyond her diagnosis and symptoms, namely those that related to her pregnancy experience. She is described very passively, receiving symptoms and diagnoses. It reads like a note in a medical record, instead of a

<sup>&</sup>lt;sup>32</sup> Nadia's pseudonym begins with "N" to reflect that myasthenia gravis is a neuromuscular disorder

relatable sketch of a disabled woman who had been pregnant. Furthermore, there are many questions that this passage leaves out, like the circumstances of her life when she became pregnant or how she felt about her pregnancy emotionally, especially because her disability emerged during her pregnancy. As I noted above, Rogers seems to present the information the way she does to allow physically disabled women to make connections to the interviewees. However, by focusing so narrowly on their very specific disability symptoms and their pregnancies, she seems to suggest that disability and pregnancy are the most central and relevant characteristics of her interviewees.

This tension brings to light the complexities of centering the experiences of disabled people, while trying to resist creating a pathologizing gaze and simultaneously holding on to the materiality of disability. This is a tension that Rogers does not (or cannot) resolve in *The Disabled Woman's Guide*. I foreground this unreconciled and uneasy relationship between specificity and universality because I want to make it clear that considering disability does not inherently work to dismantle ableism and sometimes, even disabled people cannot escape the draw of ableist discourses of pregnancy, as I will show in the next section. While I am using *The Disabled Woman's Guide* as non-typical pregnancy manual that can work against ableism in pregnancy discourse, I recognize that it is a starting point and not a perfect or complete model for rethinking pregnancy.

#### **Choosing Pregnancy**

The Disabled Woman's Guide is not a perfect pregnancy manual, but unlike more mainstream manuals, Rogers does not begin with the assumption that her readers are or want to be pregnant. In a text designed to attend to the needs of disabled people, the choice to create a family with biological children is not something that can be glossed over as it is

in other manuals. Because of ongoing influence of the eugenics movement, the decision to have a child has not been readily available to disabled people. In the early twentieth century, eugenicists targeted disabled people (as well as people of color, immigrants, and other marginalized groups) as "unfit" for reproduction, particularly through forced sterilization. Rogers hints at this past in the introduction to second chapter (titled "Emotional Concerns in Having Children"):

Even then [in the 1960s, when abortion was illegal], 5 months pregnant, Sasha had to visit four doctors before she found one who would help her. "The others all pressured me to have an abortion... I hope some changes have come about and that it is no longer considered a cardinal sin for women with disabilities to have babies. (Rogers 33)

This is just one of the many stories from women who were discouraged from having children that Rogers incorporates. In these unsettling stories of discrimination, the (presumably disabled) reader is connected to the history of disabled people in the United States. They are also reminded that choosing pregnancy as a disabled woman requires unique considerations and obstacles which are connected with past and ongoing discrimination against disabled people, including finding supportive prenatal care providers who understand their disabilities and their desires for a family.

### Denaturalizing Motherhood

For many of these women in *The Disabled Woman's Guide* (who had the chance to become pregnant), conception was hard fought; fertility issues were commonly referenced (ibid 51-52). In addition, there are a number of chapters dedicated to making sure that conceiving and carrying a child is the best choice for the reader's family. There are chapters on emotional and physical considerations (e.g., "Emotional Concerns in Having Children"), as well as a chapter that shares narratives of parenting with disabilities ("Parenting with a

Disability"). All of this suggests that, ultimately, Rogers constructs her reader as one who desires a child only after careful, rational introspection.

This is a shift from more mainstream manuals, which never allow for the possibility that one is unsure of becoming a mother. Rogers' manual denaturalizes the expectation that all women are interested in becoming mothers to their biological children and that their bodies are made to be pregnant. Moreover, Rogers makes it clear that biological motherhood is not the only option. In the chapter "The Interaction Between Pregnancy and Disability," she writes, "You may want to consider adoption if you think pregnancy may be too hard on your body and you are open to growing your family in a different way" (ibid 56). Since this is not the focus of the book, there is only a few more sentences on the issue of adoption, but it is notable that Rogers acknowledges that motherhood is not always biological and that not all women want to or can submit their bodies to the changes of pregnancy.

The Expected or Desired Child

In the third chapter, there is a section entitled "The Possibility of Having a Disabled Child." Rogers quotes an interviewee, Sara, to sum up the different threads of how her interviewees felt about the potential for a disabled child:

My first thought was that the baby could be disabled. I just hoped it would be okay. I didn't know whether my disability was hereditary, but if the child was disabled, I knew that I was the best person to cope with whatever was there. I had constant fear that the baby would be disabled...When I found out it [her disability] wasn't hereditary, I was able to breathe easier. (ibid 57)

Sara's quote reveals a concern or fear of producing a disabled child, but at the same time, she recognizes that, through her own experience of disability, she could handle a potentially disabled child's needs. This contradictory sentiment encapsulates the attitudes

that Rogers found among her interviewees. The placement of this section on potentially disabled child so early in the manual and the substantial length indicates that disabled expectant mothers' thoughts on the potential disability of their child are notably complex.

Also, importantly, she makes it clear that she not only desires, but expects a nondisabled child. She said once she knew her disability could not be passed on, her concern for producing a disabled child was eased. In other words, the only kind of disability she thought she could expect was a hereditary one and other kinds of disabilities (e.g. congenital or acquired) would be unexpected. In her memoir, Anne Finger wrote, "I wanted to have a baby. I wanted something perfect to come out of my imperfect body. I wanted a child with a child's smooth skin, not a scar, not a mark, not a blemish" (18). Despite her acceptance of her disability, Finger expressed a desire similar to Sara: when Finger imagined her child, she did not imagine a disabled child, but a perfect one.

Similarly, the fears the women in *The Disabled Woman's Guide* expressed suggest that they expect to have children who are nondisabled. Much like nondisabled women, disabled pregnant women assume if they do everything right, they will get the nondisabled child they expect. Feminist anthropologist Gail Landsman saw this in her study of mothers of disabled infants: "With few exceptions...mothers' narratives include some statement to the effect that she had done 'everything right' and therefore had believed that she would not have a disabled child" (Landsman 17). Similarly, doing "everything right" according to *The Disabled Woman's Guide*, including finding out the inheritability of their disability, leads to the expectation that one will have a nondisabled child.

Representing the disabled expectant mother of *The Disabled Woman's Guide* as one who always desires or planned for her child is also problematic. As philosopher Caroline

Lundquist has pointed out in her essay, "Being Torn: A Phenomenology of Unwanted Pregnancy," scholarly pregnancy literature often dismisses the possibility that women might not want their child. Because the hopes and desires of disabled women are just as varied as that of nondisabled women, it seems equally likely in either population that a child might not be wanted. To create a more inclusive guide to pregnancy, there should be some consideration for pregnancy ambivalence.

#### Redefining Authority over Pregnancy Knowledge

Unlike many other pregnancy advice manuals, the experiential, embodied knowledge of pregnancy is privileged. Instead of continued deferral to medical authority, Rogers encourages the readers to look to those who have gone through the experience before, whether it is the women in the text or friends and family. Before I move on, it is important to note that the primacy of medical knowledge is not completely destabilized in *The Disabled Woman's Guide*. On the copyright page of the text, the reader is reminded that "The purpose of this book is to provide information to readers; it is meant to be a guide and does not provide medical advice. Always consult your doctor for medical advice" (Rogers). Though this is presumably legally required fine print, it still is indicative of and reinforces the power of hegemonic medical knowledge for pregnancy experiences.

Throughout the text, it is also assumed that the mother will have prenatal care from a health care provider (an obstetrician or a midwife). However, as I have suggested previously, the disabled woman may have a different relationship with her provider. In the first trimester chapter, for instance, the disabled expectant mother is informed that she has to bring her obstetrician or midwife up to speed, so to speak, on her disability, her necessary medications, and she must put all of her specialists into conversation with one

another. Rogers writes, "Your doctor needs complete, accurate information about your medication schedule...Your obstetrician and disability specialists should confer about your medications if necessary" (162). She goes on to suggest that the pregnant woman is responsible for coordinating between the doctors and being aware of her medications.

Disabled women's pregnancies still necessitate accessing medical care, but they retain authority in a way that mainstream pregnancy manuals do not allow for.

However, *The Disabled Woman's Guide* stands apart from other mainstream pregnancy manuals because medical knowledge is not the *only* knowledge that is provided. As I noted previously and as the first epigraph suggests, Rogers takes care to privilege the voices of disabled mothers who have experienced pregnancy. In "The Interaction between Pregnancy and Disability," Rogers make this clear, foregrounding the advice of an interviewee named Heather: "Try to know your body. Become aware of what is normal for your body so you can decipher what is a pregnancy symptom and what is a disability symptom" (41). The form and content of this quote reinforce the validity and value of experiential knowledge. The content of the quote clearly points to the value of trying to know one's own body: it allows the pregnant woman to find the impetus of a particular symptom or discomfort. I suggest that the form is revealing as well. The quote is in the third sentence of the opening paragraph of the chapter. The quote is the guiding message of the entire chapter. While medicine remains an institution to be accessed, it is not the only source of knowledge about pregnancy in *The Disabled Woman's Guide*.

Interestingly, Heather's quote is also suggestive of the limits of authority over bodily knowledge. By saying that one should "try to know," Heather is denaturalizing the assumed connection that pregnant women have to their bodily experiences of pregnancy: it is

Gaskin's call to reconnect women with their bodies, but works in a different way. Whereas, in her manual, Gaskin assumes that connection to one's body was something primitive people had and modern people have lost, Heather seems to be suggesting that no one begins with an innate connection to one's body. Instead it is a process that must be worked toward, with an awareness that the knowledge will be imperfect and incomplete.

Returning now to the women's narratives of *The Disabled Woman's Guide*, I want to consider how they function in the text. As outlined in Chapter Three of this thesis, *Ina May's Guide to Childbirth*, a natural pregnancy manual, also deploys women's narratives, but to a different effect. All of the stories in *Ina May's Guide* are triumphant birth stories. In *The Disabled Woman's Guide*, Rogers does not hide the negative aspects of pregnancy experiences. On the first page of Rogers' manual, she writes, "The interviewees did not deny the potential for problems. Sharon spoke for the whole group when she said, 'It may take a toll on your body. You have to decide if you want to make the sacrifice." Gaskin (the author of *Ina May's Guide*) uses stories to convince women that they have the ability to give birth and combat the negative pregnancy and birth stories. Rogers is affirming the disabled women's ability to have children, but she is aiming for an even-handed representation of pregnancy as experienced by her interviewees to manage disabled women's expectations of pregnancy.

### Achieving Critical Access with The Disabled Woman's Guide

In the second epigraph, the Boston Women's Health Collective pushes back on the "medical conveyor belt of pregnancy" to argue that women deserve *critical* access to prenatal care (111). According to technical communication scholar Marika Seigel, critical

access to technology (or in this case health care) is more than just physical or financial access (3). Critical access is being able to understand how something works enough that one knows when and how to access something, and when and how to critique that system if necessary (ibid). Similarly, *The Disabled Woman's Guide* offers a range of resources that unsettle the apparently unquestionable authority of medical professionals. A disabled pregnant woman could gather enough information to have critical access to health care with the aid of this manual. She knows how and when she should access her health care provider. Moreover, she is given enough information to know how and when she can question her health care provider.

In the chapter on the first trimester, the pregnant disabled woman is urged to advocate for her needs as she physically moves through her prenatal appointments. Rogers suggests that if the woman has trouble getting onto the doctor's exam table, she should "encourage your doctor to purchase an accessible exam table...Tell him that by purchasing an accessible exam table he can get tax credits" (167). In this case, the reader has physical access to the office (if not the table), but Rogers is giving her information so that she may have *critical* access: she is being shown when and how she can question the system that she would like to access.

The issue of critical access is also prominent in the discussion on genetic counseling in the third chapter. For disabled women, choosing and visiting a genetic counselor is difficult because of the looming threat of selective abortion to eliminate potential disability. The genetic counselors are supposed to be non-directive and value-neutral in their counseling, meaning that they should respect the wishes of any patients (Rapp 58). However, as feminist anthropologist Rayna Rapp argued prenatal testing "assumes that

scientific and medical resources should be placed in the service of prenatal diagnosis and potential elimination of fetuses bearing chromosome problems" (ibid 59). When disabled women decide to access a genetic counselor, Rogers believes they need to be prepared to access a technology that is designed to identify and eliminate disability. She writes, "It is important to convey your acceptance of your own disability when you meet with a genetic counselor about the possibility of having a disabled child" (58). Rogers then shares a woman's story about how she had to do her own research to determine what her prenatal test results meant for her, because she felt that she could not trust the advice of the genetic counselor. In order to have critical access to genetic counseling, Rogers suggests that one must take responsibility for knowing and firmly communicating their stance on their own disability and the potential disability of their child.

Here, Rogers reveals how important critical access can be for a disabled expectant mother. The health care providers or genetic counselors cannot be expected to be fully versed in disability justice or in how to handle an interaction with a patient/client that has a disability. To shift the power dynamic in favor of the pregnant woman, Rogers offers up extensive information on pregnancy and physical disabilities. The pregnant woman is given the information so that she can decide whether she should seek genetic counseling or talk to her doctor about accessible exam tables and what to do with the information that she receives. Through *The Disabled Woman's Guide*, Rogers is creating a resource so that disabled women can make sense of and critique ableist discourses of pregnancy.

At this point it is crucial to flag that this formulation of critical access to prenatal care is not inclusive of a full range of disabilities, which does not align with my investment

in feminist disability studies. Feminist disability studies scholar, Rosemarie Garland-Thomson wrote,

[Feminist disability studies] focuses on examining the patterns of meaning attributed to those bodies rather than specific forms, functions, and behaviors. Feminist disability studies scrutinizes how people with a wide range of physical, mental, and emotional differences are collectively imagined as defective and excluded from an equal place in the social order. ("Feminist Disability Studies" 1558)

In Garland-Thomson's understanding of feminist disability studies, there is an emphasis on thinking across disability categories. This is not to say that the specificity of different kinds of disabilities is unimportant, but that if the focus narrows too specifically, the most excluded will be left behind.

As I have suggested, this manual is based on the assumption that increased information tailored to one's own pregnancy experience will allow women, particularly disabled women, to work against ableist discourses of pregnancy while accessing ableist medical resources. However, those with cognitive disabilities (which can complicate reading and reading comprehension) may not be able to derive any benefit from this sort of manual. To meaningfully push back against ableism, pregnancy discourses must find ways to take into account a broad range of pregnancy experiences, including those that are physically or mentally disabled, or those that experience chronic pain or illness. As I indicated in earlier in this chapter, I recognize that *The Disabled Woman's Guide* is not a perfect model for creating an anti-ableist pregnancy manual, but just a starting point.

#### **Challenging Ableism and Shifting Expectations**

As I have tried to argue in this chapter, considering disability and the experiences of disabled women shifts the expectations of and for pregnant women. Moreover, in this manual, the shifted expectations push back against ableist pregnancy discourses and are a

step towards reproductive justice. First, unlike *What to Expect* and *Ina May's Guide*, the expectations of pregnant women are not built upon a specific performance of pregnancy. That is, they do not have to be perfect, self-sacrificing mother in order to have an acceptable and narrowly defined "healthy" pregnancy. Instead, Judith Rogers expects her readers, disabled pregnant women, to become informed and actively choose their pregnancies, but negotiate their own experiences with supportive medical professionals.

The pregnant reader of *The Disabled Woman's Guide* is also not expected to automatically have access to an inherent desire to mother biological children or to an innate connection to their body. In the text, Rogers makes it clear that pregnancy is not something that women know how to do or want to do naturally. Instead, she allows her interviewees to clearly share the work that they had put into their pregnancies and trying to make connections to their body, which was often imperfect, at best. At the same time, she does allow for women to be the experts in their own bodily experiences, even if that expertise is limited or imperfect.

The Disabled Woman's Guide also reveals what disabled pregnant women expect of their pregnancies. Rogers's manual is supportive and does encourage disabled women to experience pregnancy, if it is right for them, their lives, and their bodies. However, through her interviewees, Rogers does not shy away from the complexities of being pregnant and disabled and the potential for having a disabled child. She again provides information and narratives to combat the faulty understandings of disability and misinformation to give disabled women pregnancy expectations that are based in real experiences of other disabled women.

Finally, because Rogers centers on disabled women, she shifts the perceptions of who has the right to expect anything from their pregnancy. In the more mainstream pregnancy manuals, disability precludes the right to expect things, including positive pregnancy experiences and quality prenatal care. In *The Disabled Woman's Guide*, disabled women are given tools to expect they can experience pregnancy and to demand the prenatal care that Rogers believes they should expect.

If we look at these shifted expectations, we can see how a broader view of reproductive issues and a centering of disabled women informs a more inclusive concept of reproductive justice. More crucially, it also reveals what reproductive justice can do to shift women's pregnancy experiences. Working towards reproductive justice can give pregnant women, disabled and nondisabled, critical access to prenatal care and authority over their experience.

### **Chapter Five**

# CenteringPregnancy: A Way to Shift Expectations of Pregnancy

But I wrote this paper at a different level of consciousness...It talks about how it feels to be pregnant and describes what is happening to and within our bodies. Basically it assumes: 1) that a wanted pregnancy is good, and 2) that it's necessary and exciting to have some control over the process both by learning as much as possible about ourselves and by changing attitudes and institutions to be more responsive to our needs when we decide to have children.

-Boston Women's Health Collective, Women and Their Bodies: A Course (1970)

Like the Boston Women's Health Collective quote in the epigraph, I believe that a wanted pregnancy is a good thing and that having critical access to prenatal care and authority over one's pregnancy experience improves women's lives. However, my analysis of typical and non-typical pregnancy manuals revealed problematic expectations of and from pregnant women that are bound up in ableist discourses of pregnancy. Are there ways to think about pregnancy that do not reaffirm ableist discourses of pregnancy and ableist expectations of and for pregnant women? What might a pregnancy manual, informed by disability-inclusive reproductive justice look like? To conclude this thesis and to answer these questions, I use the CenteringPregnancy model of prenatal care as a real-life example of a possible response to the critiques of the dominant pregnancy discourse and how that might shift expectations of pregnancy towards reproductive justice.

#### **Review of the Thesis**

In each of the preceding chapters, I have looked at three very different pregnancy manuals to highlight moments in the texts where ableism impacts what women come to expect from themselves and their pregnancies. In Chapter Two, which focused on the popular manual, *What to Expect When You're Expecting*, I argued that the text subscribes to a profoundly medicalized conception of pregnancy that promises to soothe fears of

disability and negative pregnancy outcomes, while creating rigid expectations for and of pregnant women. In *Ina May's Guide to Childbirth*, a natural pregnancy and childbirth manual and the core of Chapter Three, Ina May Gaskin expects her readers to fit within an essentialized and ableist version of womanhood so that they can always produce perfect children perfectly. Through Gaskin's triumphant celebration of the primitive power of women's bodies, she creates extremely high expectations for positive pregnancy outcomes. The final chapter centers on the non-typical pregnancy manual, *The Disabled Woman's Guide to Pregnancy and Birth* and the unique experiences of disabled pregnant women. In this chapter, I argue that shifting focus from nondisabled to disabled women, and thinking through reproductive justice, there are ways to reconsider or revise expectations and to push back against ableist discourses of pregnancy expectations.

Throughout this thesis, I have pushed back against the hegemonic power of medicine over pregnancy, so it may seem counterintuitive for me to support continuing medicalized prenatal care. My goal of this thesis is to rethink and improve pregnancy experiences, and I do not believe that eliminating prenatal care completely would support that goal. I recognize that prenatal care with medical professionals is associated with better birth outcomes (Beckmann et al. 58). Moreover, without adequate care, some women, namely disabled women, may not be able to safely experience pregnancy and manage their impairments. As the Boston Women's Health Collective wrote (regarding childbirth): "We are not saying no hospital, no drugs. We are learning the reason for both and feel that they are an advance for some of us; but for others of us, it is not necessary" (118). I am not saying no doctors, no prenatal care, because, as *The Disabled Woman's Guide* demonstrates,

those interventions are useful and sometimes necessary for some pregnant women, especially those that are disabled.

# The CenteringPregnancy Model

This is where CenteringPregnancy, a model for group prenatal care could intervene to provide accessible, quality prenatal care, while allowing women to maintain authority over their experience. In the early 1990s, certified nurse-midwife Sharon Schindler Rising piloted this program to improve the quality of prenatal care for more women (Schindler Rising, Kennedy and Klima 398). Instead of individual appointments with one's healthcare provider, pregnant women meet with eight to twelve other pregnant women who have roughly the same due date (ibid). At the beginning of the meetings, each woman checks her own vital signs (blood pressure, weight, and a urinalysis) and is responsible for recording the values in her CenteringPregnancy notebook, which is also referred to as her health record (Livingston 9). During these two-hour meetings, there is a thirty- to forty-five-minute period devoted to individual appointments with the health care provider and then, the rest of the time is devoted to a facilitated discussion of a specific health topic (Livingston 3).

# **CenteringPregnancy and Shifting Expectations**

I argue that this model of prenatal care can shift or refocus expectations of and for pregnant women, especially considered alongside Chapter Four's discussion of reproductive justice. First, this model shifts what is expected of the pregnant woman, from recipient of pregnancy knowledge from authorities, to an authority in her own right. She is given the opportunity to have critical access to prenatal care. Second, it provides a space where expectations of pregnancy outcomes and the potential disability of the child can be

changed. Women with different reproductive histories and different levels of ability can share their range of experiences. Third, it has the potential to change who has the privilege to expect something from their pregnancy in a way that is not based on ability or socioeconomic class. Finally, the CenteringPregnancy model also can refocus what could be expected from pregnancy, beyond a child.

All the examples below are based on the scholarly literature on CenteringPregnancy, but not necessarily how it is currently practiced. In other words, I see potential in this particular model to change pregnancy discourses, but that does not mean that, as currently enacted, it is doing those things. For instance, midwives usually oversee the CenteringPregnancy groups and they may choose to exclude a disabled pregnant woman for having a potentially risky pregnancy, even if, according the scholarly literature, there are ways to adapt the model to a pregnant woman who needs more in-depth appointments with her provider. As I said of *The Disabled Woman's Guide*, the CenteringPregnancy model provides a new way forward, but it is not perfect. In the following sections, I consider some of the shifts in expectations and the possible impacts of rethinking pregnancy. I imagine what could change if we continued to challenge and change pregnancy discourses towards reproductive justice.

#### Expectations of Pregnant Women

Through the CenteringPregnancy model, the expectations of pregnant women shift to allow them more authority over their experience. Unlike the pregnant readers of *What to Expect*, the prenatal care providers who lead CenteringPregnancy groups are not considered experts on the group members' bodies. As I outlined previously, women become responsible for their health records. The women take their own vitals and no one

re-checks the values (Livingston 9). They are simply transferred to the electronic medical record. If the women do not understand the values or are unclear about the terminology being used, they are encouraged to ask questions until they are satisfied with the response (Schindler Rising, Kennedy and Klima 402; Novick 407).

Perhaps more importantly, the participants in CenteringPregnancy are expected to become authoritative resources for other pregnant women in their group and to respect the others as authorities as well. In both *Ina May's Guide* and *The Disabled Woman's Guide*, women's narratives are gathered as resources that could improve women's experience of pregnancy. More importantly, CenteringPregnancy actually puts pregnant women in a space together to share their stories directly with one another. In pilot programs, women reported being very satisfied with the chance to share the experience of pregnancy and appreciated the concern the women showed for one another (Schindler Rising 51). If the members of the group come to recognize themselves as authorities over their pregnancy experiences, they may find it easier to share solutions and experiences outside of the expected trajectories (as in *What to Expect*).

Pregnant Women's Expectations of Pregnancy

The second shift in one's expectations for pregnancy is highly dependent on who is actually in the group. For instance, from *The Disabled Woman's Guide*, we learned that disabled women are generally more accepting of potential disability because they are more likely to recognize that disability does not determine one's worth. If women had the opportunity to spend their informative discussions alongside both disabled and nondisabled women, they may find that their fears about disability are not necessarily based on the actual experiences of disabled people. Anthropologists Rayna Rapp and Faye

Ginsburg would refer to this as growing the "social fund of knowledge about disability" (537). That is, through exposure to anti-ableist representations of disability, through the actual experiences of disabled women themselves, the potential disability of the fetus can be reframed in more inclusive terms.

## The Privilege of Expectation

Finally, the CenteringPregnancy model is not bound to any one particular socioeconomic class. As it is practiced now, both low-income and middle- and higher-income
women can access CenteringPregnancy groups (Livingston 6). Also, there are provisions
for those that may need more visits with the provider (i.e. those that are identified as "highrisk"), meaning that disability and chronic illness do not necessitate exclusion from this
model (Baldwin 271). This means that expectations of prenatal care need not be
determined by able-bodied or class privilege. If CenteringPregnancy were made as
accessible and inclusive as possible, more women may come to expect quality prenatal
care, regardless of their status or identity.

Access to CenteringPregnancy also could encourage women to think about their reproductive lives in the broader context of their families and communities, as reproductive justice advocates and activists would. To be clear, this is not to suggest that pregnant women must bear the responsibility for the future of their families and their communities, as that would be reproductive oppression. Instead, I am suggesting that working together in a group may encourage women to expect more from their community. In the CenteringPregnancy meetings, the participants have a shared responsibility for the content of the meeting and are encouraged to become authorities over their experience. If they took that idea beyond their meetings and into their lives, they might want to join

groups that demand support from their families, communities, and governments so that they may parent the child they are carrying safely and without unwanted intervention. This shift, which is already in motion through the reproductive justice movement, might not be internalized or adopted completely. More significantly, I am arguing that CenteringPregnancy might encourage someone to expect something from their pregnancy that does not reproduce ableist expectations of a perfect and nondisabled child.

# **Shifting Expectations**

Thinking critically and imaginatively about pregnancy discourses, what they look like currently and what they could be, shifted how I thought about pregnancy.

CenteringPregnancy, just like What to Expect When You're Expecting, Ina May's Guide to Childbirth and The Disabled Woman's Guide to Pregnancy and Birth, is not a perfect or complete solution. Here, I have presented some of the ways in which it is already working against the problematic discourses that I critiqued in the manuals. Women have a more authoritative role in their pregnancies. Women are working together in groups in ways that might produce and affirm new or previously unrecognized narratives of pregnancy which could be inclusive of poor pregnancy outcomes and disability. More importantly, I see potential in CenteringPregnancy, which considered alongside disability-inclusive reproductive justice. If we shift what we expect from pregnancies to what we expect from our families, our communities, and our governments, as well as ourselves, we are pushing towards new ways to think about pregnancy.

## **Appendix**

### **Interview Protocol**

### **Basic Info**

How many months pregnant are you today?

Do you have any other children? *If yes:* How old are they?

Are you in a relationship? How would you describe your relationship?

Do you work? *If yes:* What do you do?

## **Pregnancy Education**

Who do you talk to/what do you consult about pregnancy-related issues and concerns?

Have you done any research, reading, or any sort of learning about your pregnancy? *If yes*:

When did you start? How have you been learning about your pregnancy? What resources

(books, magazines, apps, etc.) have you referenced? Why did you go to those resources?

# **Their Pregnancy Experience**

How are you feeling today?

Tell me about what lead you to discover that you were pregnant.

Describe a typical day for you, since you discovered you were pregnant.

Have you changed any of your regular activities since you discovered you were pregnant?

(e.g. diet, sleep, exercise, clothing) *If yes:* What lead to the change?

What kinds of strategies/tactics/methods are you using to help make your pregnancy as easy as possible?

What do you find especially difficult, especially easy in everyday life? How have your responsibilities been adjusted during your pregnancy—at home, at work, etc.?

How have you been feeling during your pregnancy? (Physically, Mentally, Emotionally, etc.)
Before you were pregnant, how did you feel about your body? How do you feel about your
body now? How has that changed, if at all? Why do you feel that way?

Do you feel limited by your pregnancy? How so?

Is time passing slowly or quickly? Is it enjoyable time?

Have people (family, friends, co-workers, strangers, etc.) treated you differently? How so? How do you feel about this new treatment? Can you imagine or do you experience positive new treatment? Negative treatment?

How have your relationships (with your work colleagues, family members, etc.) changed during the course of your pregnancy?

Have you felt or do you expect to feel a connection with your child? *If yes*: When did you begin feeling that connection?

#### **Health Care Provider**

What kind of health care provider (HCP) do you see? (OB, Midwife)

What lead you to choose your HCP?

Do you feel comfortable/safe with your HCP?

Ideally, what role do you think a HCP should have during your pregnancy and labor/birth?

Does your HCP fill that role for you? *If no:* What do you want them to change?

Tell me about how your average appointment goes.

Have you had any disagreements with your HCP? Tell me about how that went.

Have they recommended any educational material? Have they encouraged you to learn about your pregnancy? How so?

What sorts of prenatal testing have you received, if any? Have you refused any form of testing? *If yes:* Why did you refuse it? How did your HCP deal with that?

### **Pregnancy Fitness**

Have you taken any fitness classes or any independent physical activities specifically for pregnant women? *If yes:* Tell me more about that experience.

Why did you choose this particular class/activity?

**High Risk** *If their pregnancy has been labelled "high risk"* 

What kind of HCP provider did you go to first? Did you have to change HCPs after they labelled your pregnancy "high risk"? *If yes:* Why did you have to change?

Tell me about what happened when you learned that your pregnancy was classified as "high-risk".

How did your partner react?

Have you changed any actions, routines, habits since you found out (that your pregnancy was high-risk)?

## Birth Plan(s)

Do you have plans for labor and birth? Do you know where you will be and who you will be with?

Do you have a formal birth plan? Tell me about more about that.

If they have a birth plan: Who helped you design your birth plan, if anyone? What resources did you use?

What would your ideal birth experience look like?

Where did you get this idea? Who influenced your desire for this?

What, if anything, is possibly preventing you from having that ideal experience?

## **Relationship(s)** *If they are in a relationship*

[I will replace *partner(s)* with whatever term they use.]

Tell me more about your relationship/your [partner(s)] since you discovered that you were pregnant.

How do you think that your [partner(s)] feel about your pregnancy?

Ideally, what do you think your [partner(s)'s] role should be during your pregnancy?

Have they been fulfilling that role for you (during pregnancy)? *If no:* What could they do

better?

What, if anything, do you want [your partner(s)] to do during your labor and birth?

Do you think that they will be able to fulfill that role for you during labor/birth?

**Work** *If they work* 

Tell me about your work. How has that been since you discovered your pregnancy?

How is your work handling your pregnancy, if they know about it?

Did you need to ask for anything new to make work easier for you? Do you intend to do so as your pregnancy progress?

**Past Pregnancies** *If they have children already* 

Is this pregnancy like your experience(s) of past pregnancies? How is it different?

Are you doing anything differently? *If yes*: Why did you choose to make that change?

### **General Thoughts on Pregnancy**

What has been your biggest challenge during your pregnancy that you did not necessarily expect?

What do you think women need to know about being pregnant here on Long Island on the North Shore of Suffolk County?

If you could change *anything* at all about how women experience pregnancy, what would you change? Why do you think that should change?

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