

“As Long as It’s Healthy...”: Prenatal Health, Disability and Biopower

By

Melodie Cardin

A thesis submitted to the Faculty of Graduate and Postdoctoral Affairs in partial fulfillment of
the requirements for the degree of

Doctor of Philosophy
Communication Studies

Carleton University
Ottawa, Ontario
2021

© 2021
Melodie Cardin

Abstract

The past thirty years have seen widespread adoption of prenatal testing technologies used to detect potential disabilities in fetuses (Lupton, 2011; Rapp, 2011; Tremain, 2006; Weir, 1996). The increased routinization of prenatal testing and the discourse of responsible motherhood coupled with discourses which portray disabled lives as burdensome and full of suffering and pain have increased anxiety in pregnancy. In this dissertation, I employ a Foucauldian feminist analysis and an affirmation/social model of disability (Oliver, 1996; Shakespeare, 2006; Swain & French, 2000) to consider how prenatal testing technologies have bolstered and reinforced medical power and authority; I explore how these factors in tandem with a pervasive language of “risk” have had a profound effect on pregnant people’s experiences.

As Critical Disability scholars have argued (Gibson, 2015; Meehan, 2009), prenatal testing mirrors the official, state-sanctioned historical eugenics programs deployed against disabled people in countries such as Canada and the United States. This dissertation argues prenatal testing techniques constitute a biopolitical tool which operates through widespread and pervasive ableist discourses to eradicate certain disabilities (Fritsch, 2015; Gibson, 2015; Goodley & Runswick-Cole, 2016; Mitchell & Snyder, 2003). This reproduces many of the difficulties associated with disability, in terms of both stigmatizing attitudes and failure to adequately support and meaningfully include disabled people. It also significantly affects pregnant people’s experiences, fostering anxiety due to internalized fears of producing a baby that does not conform to norms of ability and “health.”

This dissertation employed semi-structured interviews with recently pregnant people in Ottawa, ON, and Foucauldian discourse analysis of online pregnancy forums and Twitter. It sought to understand how experiences of pregnancy have been affected by prenatal testing, and

how discourses of disability as “abnormal,” and of mothers as primarily responsible for parenthood have impacted their decisions around testing and termination. This research found a continued framing by medical professionals of disability as tragic, and a lack of adequate supports for parents of disabled children leading to further ableism and fear around having disabled children; moreover, participants expressed a profound sense of anxiety related to testing results and a lack of agency in opting out.

Acknowledgements

I am so grateful to the eighteen mothers who shared their experiences with prenatal testing and pregnancy for this dissertation: The lovely parts, the hard parts, and sometimes, the trauma. Your time and your experiences are precious, and I am grateful for the gift of them.

I also wish to acknowledge the contribution to this dissertation by the unknown people whose comments from online sources are included.

I have been inspired, challenged and nurtured through this degree by a wonderful community of scholars. Foremost, I am so grateful for my supervisor, Dr. Miranda Brady. Her guidance and mentorship style has been unfailingly generous, feminist, reciprocal, knowledgeable, thoughtful, and supportive. It has been an honour to work with her.

Thank you to Dr. Stuart Murray for his help, especially with applications of Foucauldian theory. Thank you to Dr. Rena Bivens for pushing me to consider intersectionality and ethics much more thoroughly. Both of them asked me complex and important questions, at the right time, and both were unfailing in their absolute attention to detail.

Thank you to Dr. Nancy Hansen from the University of Manitoba and Dr. Therese Jennissen from Carleton University for generously reviewing the dissertation.

Thank you to a few other wonderful mentors whose doors were always open: particularly Dr. Ira Wagman, Dr. Sarah E.K. Smith, and Dr. Sandra Robinson.

Thank you to so many colleagues for sharing in the highs and lows of getting our degrees together: particularly Bethany Berard, Dr. Emily Hiltz, Nadia Hai, Jessica Chapman, and Kit Chokly.

I am grateful to be able to acknowledge financial support: a Social Sciences and Humanities Research Council Doctoral Award, Ontario Graduate Scholarships, a John Lyndhurst

Kingston Foundation Award, a David and Rachel Epstein Memorial Scholarship, support from the Faculty of Graduate and Postdoctoral Affairs and the Faculty of Graduate Studies, and support from the School of Journalism and Communication.

A few members of my family were instrumental, both for their encouragement and because they provided the countless hours of childcare that made it work: My parents, Heather and Bernie Cardin, and my parents-in-law, Margaret Currie and Phil Feuerstack. Thank you all for your love and support.

Thank you to my closest friends, for their encouragement in my toughest moments, and the richness of their friendship: Muriel Rowe, Sarah Picard, Daniela Mastrocola, Maya Cardin.

Thank you so much to my children, Leo and Jasper. Becoming their mother, as I was working on this degree, brought me so many important insights. They are my biggest inspiration and my greatest joy.

This work was only possible because of my husband, Jal Feuerstack. He is the most supportive partner I could imagine and my biggest cheerleader. I'm grateful every day that I am privileged to be with him.

Table of Contents

ABSTRACT	II
ACKNOWLEDGEMENTS	IV
TABLE OF CONTENTS.....	VI
LIST OF ILLUSTRATIONS	IX
LIST OF APPENDICES	X
THE BIOPOLITICS OF PRENATAL HEALTH: INTRODUCTION	1
PRENATAL CARE AND SELF-REGULATION	3
EXPERIENCES OF PRENATAL TESTING AND ATTITUDES ABOUT DISABILITY.....	5
PREGNANT PEOPLE, WOMEN, MOTHERS	7
FETUS OR BABY	10
PERSON-FIRST LANGUAGE	11
THEORETICAL ORIENTATION.....	11
RESEARCH QUESTIONS.....	12
AGENCY WITHIN A BIOPOLITICAL CONTEXT.....	12
ROADMAP	14
CHAPTER 1 PREGNANCY AND HEALTH: FOUCAULDIAN THEORIES AND BIOMEDICALIZATION	17
BIOPOWER, DISCIPLINARY POWER, BIOPOLITICS AND GOVERNMENTALITY	17
MEDICAL AUTHORITY IN PREGNANCY CARE.....	19
GOVERNMENTALITY, BIOMEDICALIZATION AND RISK.....	23
ULTRASOUND: VISUAL KNOWLEDGE AND SURVEILLANCE	31
ABNORMALITY AND DISABILITY (THE HUMAN MONSTER).....	35
DEFINING DISABILITY, ILLNESS, HEALTH.....	41
BACKGROUND ON PRENATAL TESTING TECHNOLOGIES.....	44
CHAPTER 2: RESEARCH METHODS: A MULTIMODAL APPROACH.....	47
RESEARCH QUESTIONS.....	47
PHASE 1 METHOD: ONLINE COMMENTS	48
<i>Foucauldian and Feminist Discourse Analysis</i>	48
<i>Online Research</i>	50
<i>Benefits and Limitations</i>	51
<i>Themes</i>	52
Medical Authority and Prenatal Testing Results.....	52
Criticism of Eugenics.....	53
Anti-abortion Advocacy.....	53
<i>Ethics</i>	54
PHASE 2 METHOD: INTERVIEWS	56
<i>Feminist Interviewing</i>	56
<i>Researcher Subject Position</i>	59
Pregnant Embodiment.....	62
Decision-Making and Trauma.....	63
Ableism.....	66
<i>Recruitment and Ethics</i>	68
<i>Limitations</i>	73
<i>Interviewing Methods and COVID-19</i>	74

CHAPTER 3: THE SEARCH FOR SUPPORT AND COUNTERING EUGENICS: ONLINE ENGAGEMENTS WITH PRENATAL TESTING	76
COPING WITH PRENATAL TESTING: FORUM POSTS.....	76
<i>Seeking reassurance: Dealing with fear and anxiety</i>	78
<i>A New Hope: Non-Invasive Prenatal Testing (NIPT)</i>	85
<i>Prayer and Judgement: How Religious Beliefs Surface in Prenatal Testing Discussions</i>	91
<i>Defining “Normal”</i>	95
<i>Engagement with Medical Authority</i>	98
<i>Considering and Justifying Termination</i>	102
<i>Visual Knowledge/ Intuition</i>	104
<i>Direct Engagements with Ableism</i>	107
PRENATAL TESTING ADVOCACY: TWITTER.....	111
<i>Medical Authority and Prenatal Testing Results</i>	113
<i>Criticisms of Eugenics</i>	116
<i>Anti-Abortion Advocacy</i>	120
FINDINGS IN BRIEF	124
CHAPTER 4: INTERVIEWS, PART 1: THE IMPERATIVE TO FETAL HEALTH	127
TEN FINGERS, TEN TOES: “AS LONG AS IT’S HEALTHY” AND THE CONFLATION OF HEALTH AND DISABILITY.....	127
CHAPTER ROADMAP	136
PARTICIPANT DEMOGRAPHICS	137
DISABILITY, HEALTH, AND FEELINGS ABOUT TERMINATION.....	141
<i>Attitudes about Disability</i>	141
<i>Anxiety during Prenatal Testing and Feelings about Termination</i>	148
Grace.....	152
Julia.	153
Sadie.....	154
DISABILITY AND TERMINATION: VIEWS OF HEALTHCARE PROVIDERS	155
MEDICAL AUTHORITY AND RESPONSES TO IT	159
MEDICAL ERROR.....	162
Lisa.	163
TO TEST OR NOT TO TEST?.....	166
ECONOMIC INCENTIVES	167
FEAR OF MISCARRIAGE	168
ADVANCED MATERNAL AGE	170
ROUTINE EXPECTATIONS	171
POSITIVES OF DISABILITY	174
FINDINGS IN BRIEF	178
CHAPTER 5: INTERVIEWS, PART 2: COMMUNICATING PREGNANCY AND SHAPING EXPERIENCE.....	181
INTRODUCTION AND CHAPTER ROADMAP	181
COMMUNICATION ABOUT TESTS	182
SOURCES OF INFORMATION	189
HIGHLY INFORMED PARTICIPANTS	189
USE OF ONLINE FORUMS, WEBSITES, AND PREGNANCY BOOKS	191
INCONSISTENT HEALTHCARE PROVIDERS.....	195
EXPERIENCES OF PREGNANCY	198
TENTATIVE PREGNANCY	199
PRESSURES ON BEHAVIOUR.....	203
OTHER DISCURSIVE SITES	209
VISUAL KNOWLEDGE	213
FINDINGS IN BRIEF	217

CHAPTER 6: MOTHERHOOD AND QUALITY OF LIFE: EXPLAINING THE IMPERATIVE TO TEST	220
QUALITY OF LIFE AND QUALITY OF MOTHERHOOD	221
BIOPOWER, GOVERNMENTALITY AND GENDER NORMS AROUND MOTHERHOOD	223
THE SOCIAL MODEL OF DISABILITY VS. IMPAIRMENT AND PRENATAL TESTING.....	231
NEW TECHNOLOGIES, MEDICALIZATION, AND PREGNANT EXPERIENCE	234
VIEWS ABOUT DISABILITY, LANGUAGE, AND PRENATAL TESTING RESULTS	241
A FINAL WORD ON “QUALITY OF LIFE”	248
REFERENCES.....	249
ILLUSTRATIONS.....	269
FIGURE 1.....	269
FIGURE 2.....	270
APPENDIX: INTERVIEW QUESTIONS	271

List of Illustrations

Figure 1. Panorama advertisement

Figure 2. Harmony advertisement

List of Appendices

1. Interview Question List

The Biopolitics of Prenatal Health: Introduction

The widespread phrase “as long as it’s healthy…” is referenced by Nirmala Erevelles in her discussion of the cultural experience of pregnancy and fetal life. She argues that our mediatized representations of pregnancy:

include pregnancy tests, prenatal classes, moms-to-be parking spaces, ultrasounds, baby showers, and birth announcements. In each of these textual representations of burgeoning embodiment, the textured life of disability is consistently represented as lack, as manifested in the oft-quoted exclamation, “All I want is that my baby be healthy!”

(2011a, p. 37)

The importance placed on a certain restricted definition of a healthy and able fetus is culturally specific, socially produced, and maintained through discourse. It is also completely taken for granted (of course, all we want is healthy babies!). For instance, Mitchell and Georges (2000) report that medical practitioners such as ultrasound technicians sometimes tell parents to concern themselves with the health of their fetus (rather than its sex); this focus is certainly reinforced in ultrasound rooms, which often feature signs explaining that ultrasounds are only conducted for health testing purposes.

While the professed goal of producing ‘healthy’ babies is hard to argue with, the way we define ‘healthy’ is not simple; it is grounded in ableism, biomedicalization, and the framing of pregnancy as risky, requiring medical intervention (Gentile, 2013; Rapp, 2011; Wendell, 1989). Health and ability are often conflated, especially in the context of prenatal testing, and the concept of health for fetuses is mobilized in a way that implicates the pregnant person’s actions and behaviours, producing discourses of ‘self-care’ rendered much more complicated because the ‘self’ now includes a fetus, and creating a sense of maternal responsibility for outcomes. This

takes places notwithstanding the scientific evidence that shows very few connections between maternal behaviour and health or dis/ability outcomes (Ginzberg, 1987; Lupton, 2011; Sawicki, 1991).

The concept of health for individual fetuses is deeply interconnected with broader notions of population health, in a way that implicates individual decision-making in biopolitical discourses of disability as a danger to the health of the population (Sanger, 2007). This concern for a healthy imagined community materializes in many ways, as discussed by Greene:

An economic discourse begins to merge with a medical discourse that fears the pathogenic value of procreation. Finally, a ‘political socialization’ that calls for couples to be responsible to the social body by activating the principle of utility intersects an economic and medical discourse in their reproductive decisions. (1999, p. 31)

This socialization of responsibility towards the health of the social body manifests in discourses that “unwanted” babies “undermine the possibilities for a healthy and just society” (Greene, 1999, p. 146); disabled children, whose identities often intersect with racialization and/or poverty, are framed as burdens upon society (Barker, 1998), that defy capitalistic goals of ‘productive’ citizens who contribute to the economy (Fritsch, 2015; Magnet & Watson, 2017). These discourses are rampant despite some pregnant people and parents who question these norms; they choose to opt out of prenatal testing for many reasons, or they choose not to terminate their pregnancies in spite of ‘undesirable’ testing outcomes (Berube, 2018; Rapp, 2011; Saetnan, 2000).

Prenatal Care and Self-Regulation

In general, women are inordinately subjected to judgements centred on their care for the self and for others.¹ In pregnancy, these judgements are compounded with discourses of risk and the perceived authority of medical institutions to shape the way pregnant people experience healthcare and prenatal screening, potentially creating feelings of uncertainty and vulnerability. Furthermore, discourses that produce disability as abnormal and undesirable influence decisions people make as they navigate their pregnancy care and prenatal testing. Ableism operates, whether covertly or more implicitly, through medical professionals and institutions responsible for pregnancy care, which reinforces the discourse of disability as abnormal and undesirable (Erevelles, 2011a; Fritsch, 2015; Garland-Thomson, 2012; Daniel Goodley & Runswick-Cole, 2016; Wendell, 1989). These discourses play a critical role in influencing the decisions pregnant people make about whether to undergo prenatal testing, what tests to undergo, and how to respond to ‘abnormal’ results. My contention is that whether or not the pregnant person has disability at the forefront of their thoughts, and whether their test results are considered ‘abnormal’ or not, the widespread and pervasive operation of ableist discourses in conjunction with prenatal testing is likely to colour and influence that person’s experience of pregnancy. In other words, ableist discourses function as a mode of discipline, making people feel they ‘must’ test their fetuses. While there are previous studies that have explored the emotional impact of prenatal testing (Browner & Preloran, 2000; Clement, Wilson, & Sikorski, 1998; Kvande, 2000; L. M. Mitchell & Georges, 2000; Morgan, 2000; Rapp, 1999; Saetnan, 2000; Williams et al., 2005), showing that women felt either a sense of relief or a sense of anxiety during the process,

¹ As I will discuss further on, not all pregnant people are women—but many are, and pregnancy is deeply associated with womanhood, in a way that makes the discourses to which women are particularly subject very relevant to the experience of pregnancy. By women here, I refer to all people who identify as women.

there is a significant gap in the literature in terms of demonstrating the nuances of the disciplinary function of these norms, which is where this study makes its intervention.

While previous research has often been focused on the use of particular technologies, this research considers the experiences of pregnant people grappling with prenatal testing technologies as part of a Foucauldian framework, concerned with how these technologies operate biopolitically, connect to the production of knowledge and discourse, and contribute to power relations. This theoretical framework is augmented by an intersectional feminist approach which considers the effects of specific power structures of gender, race, and class, and by social and affirmation models of Critical Disability scholarship (Crenshaw, 1995; Ells, 2003; K. Q. Hall, 2011; Hughes & Paterson, 2006; Macleod & Durrheim, 2002; D. Mitchell & Snyder, 2003; Oliver, 1996, 2013; Roberts, 2015; Shakespeare, 2006; Sobnosky, 2013; Swain & French, 2000; Wylie, Okruhlik, Thielen-Wilson, & Morton, 1989; Yuill, 2014). This research used a combination of interviews based in Ottawa, ON, through which I was able to glean a local, Canadian perspective, and analysis of comments in online sites such as pregnancy forums and Twitter, which offers an overview of the broader context. In this way, I sought a qualitative view of how prenatal testing for conditions characterized as disabilities affects the affective experience of pregnancy, and perpetuates broader discourses surrounding disability.

This dissertation sought to understand the connection between the pressure placed on the individual by the medicalized process of prenatal testing, and larger discourses of fetal “health” which reinforce able-bodiedness/ neurotypicality as compulsory (Kafer, 2003; McRuer, 2006). As several scholars (e.g. Tremain, 2006; Williams, 2006) have noted, what has often been missing from analyses of prenatal testing and the discourses of risk has been the operation of

power relations combined with the qualitative perspectives of the people being tested, which is what this research sought to address.

Experiences of Prenatal Testing and Attitudes about Disability

In this research, I look at how discourses of risk, self-care, health, and disability inform pregnant people’s decisions and experiences of prenatal testing. I also consider how these discourses operate at a wider, societal level to reinforce and construct ableism—as well as other forms of marginalization, as they intersect with ableism. These topics are informed by a Foucauldian theoretical framework that understands contemporary prenatal testing practices as constitutive of systems of biopower. They are also informed by feminist studies and Critical Disability Studies.

The first part of the research seeks to understand how pregnant people, often cisgender women, undergoing prenatal care and testing, experience disciplinary power, a targeted form of power exercised through medical institutional authority. The second part looks at the biopolitics of prenatal testing. How do discourses about disabled people dehumanize and devalue them? In other words, I am asking how discourses contribute to what Jay Dolmage refers to as ‘disablism’: “the differential or unequal treatment of people because of actual or presumed disabilities” (2014, pp. 17–18). By contrast, Dolmage argues that ‘ableism’ functions in a way which I would describe as biopolitical, in that it “positively values and makes able-bodiedness compulsory” (2014, p. 17). This project asks how these discourses of disablism and ableism create a sociocultural environment that serves to perpetuate, and perhaps even encourage and promote, the termination of fetuses which might be born disabled or ill.² In the US, 67 per cent or more of

² Illness and disability are not the same, but are often conflated, and there can be overlap between them. Disability is generally defined further in Chapter 1, but tends to be constituted as physical impairments or neurodivergence which impedes the person’s ability to function ‘normally’ in society (whether that is

fetuses diagnosed with Down syndrome are aborted; in Canada, there are no studies but the numbers are estimated higher (Kaposy, 2018). How do discourses regarding disability contribute to these numbers?

Biopolitical discourses tend to normalize the idea of disability as unwanted, to a point where it can be difficult to understand why we might take issue with it at all. One reason is that the dichotomy of health vs. illness/disability, as defined by the discipline of medicine, is an extreme oversimplification of what is increasingly being recognized as a spectrum of difference (Fritsch, 2015; Tremain, 2006). Our knowledge of disability and illness has been produced through disciplinary power. We may ask, what is wrong with desiring to bear children who are healthy and able? But the medical definition of healthy and able once excluded queer people, who were seen by doctors as suffering from a mental illness (A. E. Clarke et al., 2003). It often still excludes autistic people, who are now increasingly being recognized as neurodivergent, part of a broad spectrum of neurodiversity, rather than disordered. In other words, it is only when we define brain function through a non-autistic (allistic) lens that neurological difference becomes a mental disorder (Maguire, 2016). Critical Disability scholars such as Fritsch (2015), Garland-Thompson (2012) and McRuer (2006) argue that ability, for all individuals, is a spectrum of impairment and capacity, and ability is not the whole measure of an individual (Rapp, 2011). Even the hypothetical total eradication of congenital disability and illness through prenatal testing would not remove disability and illness, much of which is created through injury,

more due to the impairment or the lack of social infrastructure depends on who you ask) (Garland-Thompson, 2012; Oliver, 2013). Illness too can be complex to define, since there are both chronic and non-chronic illnesses, and because, as Clarke argues, the reach of biomedicine into ever more areas of life has tended to pathologize many forms of difference as illness. When it comes to prenatal testing, often there is a strong interest in avoiding both disability and illnesses that would be seen as more serious—for example, heart conditions which might not be disabling, but which might require extensive surgeries and/or medical interventions.

environment, or even ageing—and how much would be lost? While we can medically intervene in disability and in illness, in many cases we cannot remove disabilities and illnesses from the people of whom they are a feature; people who contribute valuable perspectives to the world (Garland-Thomson, 2012; Sinclair, 2013). It is also important to remember in this context that contrary to our overwhelming discourses that health and ability are normal, and disability and illness are aberrations, in fact nearly everyone in the world will experience disability and illness over the course of their lifetime.

The medical model that promotes termination of genetic risk, rather than reduction of discrimination, is thus deeply flawed (Roberts, 2015). Moreover, by placing responsibility on pregnant people, and most often mothers, to produce ever more perfectly conforming children, according to a certain definition of perfection that is invariably white, middle or upper class, able, straight and cisgendered, we “divert attention away from state responsibility and the need for social change” (Roberts, 2015, p. 171). In other words, when the world’s physical and social architecture are narrowly built to only accommodate individuals with certain traits perceived as valuable, we will always find fault with some people. What we need is systemic change aimed at combatting ableism and all forms of intersecting racialized, gendered, and class-based prejudice, not a continual focus on genetic fitness as a requirement to inhabit the world.

Pregnant People, Women, Mothers

Before proceeding, a few brief notes on terminology, beginning with the term ‘pregnant people’ vs. ‘pregnant women.’ Pregnancy has a gendered history and pregnancy research is focused on bodies. I view sex and gender as separate aspects of identity: Where sex is assigned at birth based on the physical body in which one is born (although as Dreger & Herndon [2009] point out, this is vastly oversimplified by society), gender is a socially constructed part of

identity (Butler, 1993). I consider socially constructed binary gender roles to be limiting and constrictive for most people, but especially for transgender people, who do not identify with the gender assigned to them on the basis of their sex. Some who identify and present as men or non-binary have a uterus, ovaries, and vagina, and thus sometimes get pregnant. For the purposes of this work, I sought experiences of pregnancy, regardless of the gender of the participant. I was concerned with embodied and cultural experiences, and therefore throughout this dissertation, I have taken the approach of using the inclusive term ‘pregnant people.’ My research was open to all experiences of prenatal testing, including those occurring to women, trans men and non-binary people. This is certainly not to suggest that trans or non-binary people would experience pregnancy in the same way as cisgender women; of course, the extreme normalization of gender in society at large, and in pregnancy as well, has been shown to have a significant impact on the embodied and cultural experiences of pregnant people who are not cisgender women (Charter, Ussher, Perz, & Robinson, 2018; Surkan, 2015).³ In this study, no participants identified as transgender or non-binary.

I do also want to highlight the importance of gender to pregnancy care, which has been extraordinarily impacted by the patriarchal history of obstetrics and gynecology (Browner & Press, 2017; A. E. Clarke et al., 2003; Dubriwny & Ramadurai, 2013; Parry, 2008; Paterson, 2011; Shaw, 2013; Sobnosky, 2013; Vedam et al., 2012; Weir, 1996; Williams, 2006; Worman-Ross & Mix, 2013). As I will elaborate further, the field of medical pregnancy care was developed as an exclusively male, cisgender, patriarchal disciplinary body that privileged certain

³ Previous research suggests that trans men receive even less support than cisgender women during pregnancy, and that trans men often face not only psychological difficulty related to the growing pregnancy, but also added gender dysphoria from stopping testosterone, which cannot be taken while pregnant (Charter et al., 2018). The experience of pregnancy for trans and non-binary people is clearly an important area for further research.

kinds of androcentric knowledge at the expense of embodied knowledge, and pregnant people, very often cisgender women, are still dealing with the effects of this today (Barker, 1998). Moreover, pregnancy research and care are associated with cisgender women, and therefore have been historically under-funded, under-researched and poorly understood (Barker, 1998). Therefore, while I use the term ‘pregnant people’ in recognition that trans men, those misgendered as women, and non-binary individuals are among the people who get pregnant (and of course trans and non-binary people also experience patriarchal biopower), I think it is important to note the gendered discrimination cisgender women have experienced through pregnancy and as a result of doing most of the embodied labour of creating babies.

Moreover, regarding the term ‘mother’: I want to recognize that not all people who create babies in their bodies are mothers, and many mothers do not experience pregnancy (trans mothers, adoptive mothers, stepmothers, foster mothers, etc.); nonetheless motherhood and pregnancy are linked.⁴ Motherhood is a complex site of cultural significance and oppression. To leave out the term ‘mother’ from my research could potentially erase the labour and marginalization of motherhood; all references to mothers in my work should be read as recognition of this context.⁵

⁴ A recent article in the Guardian notes the UK’s first court ruling that a transgender man can not be considered a “father,” since the work of pregnancy and childbirth constitutes motherhood (Booth, 2019). I would categorically reject this notion and welcome an expanded definition of fatherhood which can include pregnancy and birth. Many mothers do not ever give birth. Many people give birth and do not therefore become mothers. I am not arguing that pregnancy constitutes motherhood, only that they are often linked, and I do not want to discount the immense labour of pregnancy and childbirth, which is mostly associated with the term mother.

⁵ My use of this word is not without pause. For many women, including myself, the idea of “motherhood” is an important aspect of identity. It is also a word that is used to frame the specific parenting role we play, often in ways that oppress us. It centers us as uniquely/primarily responsible for children and puts more expectations on our shoulders. The connotations of the word mother are very different than those for the word father. While recognizing the importance of motherhood as a social construct, I do not wish to perpetuate motherhood ideals that reproduce gender inequality, or that define womanhood through oppression.

Fetus or Baby

The terminology we use to refer to fetuses and babies is loaded, and therefore I wish to speak briefly to my own use throughout. Anti-abortion advocates often use the word “baby” (or worse, “preborn baby”) to refer to fetuses, frequently in ways that are coercive or which ignore the feelings of the pregnant person about the fetus. As I explore in Chapter 1, this terminology is used in tandem with descriptions of fetuses via ultrasounds that treat fetuses as fully-grown babies, with intent to influence the pregnant person’s feelings about the pregnancy (Hartouni, 1997). Anti-abortion advocates use imagery of fetuses near term or born infants to argue against abortion, intentionally conflating fully-grown babies with new embryos to obscure the reality that most abortions occur in the first months of pregnancy when the embryo still looks more like a tadpole than a human. Throughout this dissertation, therefore, I use the word “fetus” for the life in utero, as an umbrella term which covers other stages of fetal development such as zygotes or embryos. I do not use the word baby unless referring to a human that is born, unless quoting. However, this should not be read as an imposition of my views regarding fetal/child development on anyone else’s pregnancy. Many pregnant people, myself included, view(ed) their gestating fetus as a baby already, and this affective relationship is important. For these pregnant people, miscarrying a fetus is a significant emotional loss. The word “fetus” can feel cold for pregnant people in that situation, who feel they have lost a baby. Words matter and need to match the situation; as a researcher, it is important to me to use the word fetus, to be accurate, and because I do not wish to assume an affective feeling about a pregnancy where it is unwelcome. As a parent, I felt quite differently about my specific situation, due to my own privileged circumstances of wanted pregnancies, and of course others may feel that way as well.

Person-First Language

There is some debate within disabled communities about the correct way to refer to disabled people. This terminology has undergone historical changes, in part because the words used were often imposed from outside of the communities, and were used pejoratively. Some people prefer the use of person-first language, e.g. “people with disabilities”, as opposed to identity-first language, e.g. “disabled people”. But increasingly, many disabled communities reject person-first language, arguing that their disabilities are essential to their identities broader social identity categories, and also, importantly, not an insult (Maguire, 2016; Sinclair, 2013). Following this argument and predominant preferences, I do not use person-first language out of respect for those who recognize disability as an integral part of their identities (Swain & French, 2000) or who wish to signal the disabling effects of society (Oliver, 1996). I do recognize that this may not be everyone’s preference, and certainly upon learning any individual’s preference I would refer to them as they wished.

Theoretical Orientation

This dissertation is grounded in Foucauldian theories of power, feminist theory, and Critical Disability Studies. As I will explain further in a more complete overview in Chapter 2, Foucault’s explanation of modern ‘biopower’ provides a logical framework through which to understand the exercise of power through eugenic control of reproduction. Foucault argues that control of reproduction was at the heart of economic and political power and therefore his theories provide a useful way to consider the parallels between contemporary prenatal testing and historical eugenic policies (1990). However, Foucauldian theory also has two significant drawbacks in terms of this research. One is a failure to adequately recognize the gendered nature of power relations (Sawicki, 1991). The other is a general failure to recognize the *specific* ways

in which concepts such as heterosexism, ableism/disablism and racism have been deployed to dehumanize people and construct them as unworthy. In his posthumously-published course lecture, *Society Must Be Defended* (2005), Foucault defined “racism” in a broad way, drawing from social Darwinism, as the biopolitical project of creating an idealized master ‘race’ of humans. While there are certainly important parallels between the biological categorization of races and ableism, racism (in the generally understood sense of hatred or fear based on race) does not function in exactly the same way as ableism, homophobia, sexism or other forms of discrimination and oppression. Feminist theory and Critical Disability Studies provide an important counterpart, therefore, to Foucault’s work, through their theorizing of the specific ways power functions to normalize maleness, gender norms, ability, and health. I will expand upon this in Chapter 1.

Research Questions

The research questions will also be outlined in more detail in Chapter 2, but in brief, the research questions are posed as per the two interconnected foci of the project outlined above:

Experiences of prenatal testing and attitudes about disability.

- 1) How does the medicalized process of prenatal testing instill the pregnant person with a sense of responsibility (to the fetus/baby, partner, family, community, or population health)?
- 2) How do pregnant people negotiate with the implicit marginalization of disability in the discourses surrounding prenatal testing?

Agency within a Biopolitical Context

Throughout this work, there is a clear tension between two equally important ideas: That pregnant people are best placed to make their own decisions as regards their pregnancies and

their fetuses, and that these decisions are not made in isolation, but are deeply affected by and even constituted through discourses.⁶ The discourse of risk, which will be further explored in Chapter 1, is particularly significant here; for one, pregnancy is often culturally framed as risky, the chances of having disabled children are framed as a ‘risk,’ and one can also argue that discourses produce a sense of a ‘risk’ of being stigmatized or having a lessened quality of life through becoming the parent of a disabled child (Cardin, 2020b; Hacking, 1991; Yuill, 2014).

The first point, regarding the agency of pregnant people, is significant because of the patriarchal context in which pregnant people have often been, and continue to be, stripped of these decisions, which has often been experienced as violence and trauma. Pregnant people in these circumstances have fought for the right to make their own decisions for their own bodies and pregnancies, and have experienced these decisions as a form of empowerment, including the ones to make use of prenatal testing technologies and to terminate their pregnancies if they so choose. At the same time, we do need to recognize the extent to which decisions about pregnancy are made in an ableist context, often deeply influenced by discourse and by medicalization, to the point where the concept of individual decision-making and choice can themselves be read as deeply problematic. While I am not sure if this can be fully reconciled, I come back to this tension throughout this dissertation, and I uphold the ideal of pregnant people’s agency and choice, even as it is often undermined by the effects of wider ableist discourses and medicalization, which are not only influential but often coercive.

⁶ Foucault argues that we must think of discourse as power and knowledge joined together; in other words, not only that which is said or written but also the institutional context in which it is produced (1990).

Roadmap

In Chapter 1, I provide an overview of the ways I am deploying Foucauldian theory. I begin by defining Foucauldian terminology that will appear throughout the dissertation: Biopower, disciplinary power, governmentality, biopolitics. I offer a review of the previous literature in this area including feminist analysis of the medicalization of pregnancy and marginalization of disabled people. I discuss the development of ultrasound technologies, in the context of patriarchal privileging of observational knowledge over embodied knowledge, and I discuss the construction of the pregnant ‘self’ and the fetal ‘self’ in the context of disability. I also provide background on prenatal testing technologies, especially in Ontario, where a portion of this research is located.

In Chapter 2, I outline the methods used in the dissertation; a combination of 18 semi-structured interviews with pregnant and recently pregnant people, and Foucauldian discourse analysis of participation in online discussions related to prenatal testing. I discuss the strengths and limitations of these methods, incorporating feminist research methodologies, discuss the ethical challenges in interviewing and online research, and provide a broader overview of Foucauldian discourse analysis.

In Chapter 3, I focus on my findings from a discourse analysis of posts about pregnancy and testing in online discussion forums and Twitter. These findings provide a broad overview of some of the ways pregnant people are experiencing prenatal testing results and negotiating with medical authority. This chapter also demonstrates the anti-eugenic activism that is occurring online, particularly from autistic people and communities. Chapters 4 and 5 outline my findings from primary research with 18 pregnant or recently pregnant people from Ottawa, Canada. Chapter 4 focuses on their experiences with prenatal tests and results, their dealings with medical

professionals, and their attitudes and fears about disability. Chapter 5 argues for shifts in the communication around both prenatal testing and pregnancy at large, showing how the governmentality in pregnancy experience more broadly affects prenatal testing specifically. Throughout these findings chapters, I demonstrate the interconnection between discourses of disability and decision-making about testing and termination. I show how the institutional pressures and widespread and deeply ingrained social attitudes about prenatal testing in my research are underpinned by discourses of disability in society at large.

Finally, in Chapter 6, I offer a discussion of these findings and concluding remarks. Among these, I argue that disability is composed of both physical impairment, and, as argued by the social model of disability, discursive constructions of what it means to be disabled (Oliver, 2013), and that both aspects influence decision-making for fetuses diagnosed as disabled. However, I also argue that the social model of disability, combined with medical disciplinarity and adherence to routine, are more responsible for the current ubiquity of testing than are fears of impairment. I argue that recent advances in prenatal testing technologies are having significant impacts on pregnancy experiences. I consider the role of technological advances in bolstering and reinforcing medical authority, through the power/knowledge dyad drawn from Foucault (1980). I argue that pregnancy care has not only undergone an increase in medicalization, even as some pregnant people are turning towards midwifery care and home births, but that the language of “risk” has become more pervasive, and is accompanied by a routinization of technology, an abandonment of embodied knowledge, and an increasing disregard for birthing experience or agency in pregnancy. In all this, the pregnant person’s experience is often minimized, leading to further entrenchment of obstetrical violence and trauma. Negative

experiences of pregnancy and motherhood are part of the collateral damage of biopolitical normalization; they are an inherent feature of ableist discourses, not a by-product.

Chapter 1

Pregnancy and Health: Foucauldian Theories and Biomedicalization

Biopower, Disciplinary Power, Biopolitics and Governmentality

In thinking about ‘health’ for pregnant people and fetuses, both within the field of medicine and through ‘common knowledge’ discourses, I begin with an overview of some of Foucault’s ideas surrounding power. As stated in the introduction, modern biopower provides us with an important way to consider the operation of power around disability, as well as how decisions about disability are individualized. We can thus understand prenatal testing technologies as biopolitical tools, constitutive of biopower. In Chapter 2, I will also cover more of the Foucauldian approach to thinking about discourse, as it applies in the context of Foucauldian discourse analysis as a method.

Foucault historicized modalities of power developing in Western liberal societies in recent modern history. He characterized power prior to the eighteenth century as emanating top-down, from a sovereign (e.g. the monarch), whose power over life and death was absolute; he described it as “the right to *take* life or *let* live” (1990, p. 136). In other words, the sovereign had the right to execute any subject without justification, and those who were not executed were being passively allowed to live. Foucault described a slow shift in which this power is transformed — modern “biopower” becomes increasingly diffuse, no longer concentrated in a central authority, but produced and perpetuated through discourse. He saw biopower as a productive mode of power largely centred on ideas of individual choice. Rather than the sovereign’s active killing or passive allowing of life, power now actively fosters life or passively permits death to occur: “The ancient right to take life or let live was replaced by a power to foster life or disallow it to the point of death” (1990, p. 138). Death is ostensibly merely a by-

product of not fostering life, or of neglect; examples include failure to put in place protections against environmental pollution, or making the necessities of life or health care inaccessible. To study biopower is to critically examine the ways power fosters life, produces it, conserves it — operating, visibly, according to a mode of producing vitality. It is also to make note of where power takes on an appearance of fostering life, while simultaneously disallowing life to the point of death. While naturalized, there is always a dark side to biopower — there are always the lives deemed unworthy, individual lives neglected and even disallowed in the service of “population” health (Foucault, 2005).⁷

Biopower has two “poles” (Foucault, 1990, pp. 138–139): The first, disciplinary power, is centered on the individual body as a machine. The focus of this dissertation is prenatal health, so I am primarily interested in the emergence of disciplinary power through medicine. Medical authority is productive of knowledge and discourses, which have a significant impact on individual behaviour; ultimately, power is enforced through self-regulation: “Self-policing frequently entails harsh and debilitating ways of relating to the self and keeps individuals tied to prescribed identities. It effectively means that individuals live their lives as though under constant observation” (O’Grady, 2004, p. 91). The knowledge produced by medicine influences individual behaviour both through the authority of doctors and medical institutions and through the infiltration of these discourses into ‘common’ knowledge or practice (2004).

⁷ Simone Browne provides clear examples of how what Foucault termed “to disallow [life] to the point of death,” has, for racialized people, often taken the form of extreme violence (2015). For the many people in groups that are dehumanized and devalued, the phrase “disallow life to the point of death” may seem like quite incorrect and even obtuse terminology. My point in calling these deaths ‘passive’ is not to absolve them. It is to highlight that biopower must retain the appearance of fostering life, and therefore must justify death through dehumanizing discourses. Under sovereign power, there was no such need; sovereign power could take life at will.

The second pole, biopolitics, is focused on the “species body,” or populations (Foucault, 1991, p. 139). It concerns itself with “propagation, births and mortality, the level of health, life expectancy and longevity” (1991, p. 139). Foucault writes, “Hence there was an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations” (1991, p. 140). Savage argues that as public health has become an essential tool of power, “the elimination of illness through state surveillance and state control of the individual could be viewed not only as a necessity, but also as humane” (Savage, 2007, p. 418); I argue that this discourse extends to provide justification for not only the elimination of illness but elimination of people defined as ‘ill.’ Prenatal testing functions as a biopolitical technique because it allows for the collection of data, the identification of ‘risk’, and the classification of maternal and fetal life into categories of normal and abnormal.

Medical Authority in Pregnancy Care

Prenatal testing technologies operate not only as a method for finding out information about individual fetuses but as a broader mode of knowledge production. The increasingly complex ability to photograph and analyze fetal life has led to incredibly minute classifications of what a fetus ‘should’ look like.⁸ These are based on averages as well as what is considered to be normal or abnormal about people born with or without the conditions tested for in fetuses. The invention and use of these technologies, which follow cultural norms and values, has been a significant component in the production of medical authority for female-sexed reproductive health, and the gradual medicalization of pregnancy in North America and beyond (Barker, 1998; A. E. Clarke et al., 2003; Shaw, 2013).

⁸ Indeed, prenatal testing technologies have been refined since their invention and as more people are tested, we have an ever more complex understanding of the human genome.

It is very difficult to question the cultural authority of prenatal technologies to produce knowledge and norms, because they have been strongly associated with the elimination of maternal and infant mortality and morbidity. Therefore, there is a sense that their existence as knowledge producers is justified, no matter what drawbacks or various uses they may have. This association to reduced mortality is correct to some extent and goes a long way to explain the collective hold prenatal testing has developed over our cultural psyche. As Foucault argues, power is productive of knowledge; he sees power as a primarily productive, not a repressive force (A. Clarke, 1998; Foucault, 1980; Macleod & Durrheim, 2002; Sawicki, 1991). Therefore, by producing knowledge that has led to decreased maternal and infant mortality rates, the medical disciplines have cemented this common knowledge idea of medicalization as responsible for healthy, living mothers and babies (Foucault, 1990, 2005) — this has created a powerful allure to medicalization.

There is, therefore, a sense of both morality and responsibility for outcomes attached to the pregnant person; this is both externally imposed and self-imposed. Under these conditions, prenatal testing has become a new imperative:

Being screened is a duty; evasion is tagged as irresponsible behaviour, a moral dereliction... If women are not morally vigilant, they may fall from grace and slip from low risk to high risk. If a pregnancy ends with a less-than-desired birth experience... it is hard to imagine a woman who could not go back over that daunting list and find at least some areas in which she should have done more, could have tried harder... (Williams, 2006, p. 16)

Whilst this self-responsibilization is understandable within a context in which social surveillance and judgement of pregnant people's actions is ubiquitous, it is not backed by evidence of better

outcomes. In fact, many scholars argue that the fall in maternal and infant mortality actually precedes widespread prenatal care, which began to gain significant traction in industrialized countries such as the U.S. and Canada only in the 1940s. Present day low mortality rates in much of the world are more attributable to the discovery of bacteria and the widespread use of antiseptic technologies (Barker, 1998). Barker argues that the cultural authority of medicine in the field of pregnancy care has less to do with its direct successes and more to do with the reconceptualization of the phenomenon of pregnancy as a ‘medical’ concept and the widespread acceptance of that by the public (1998).⁹ The rapid advancing of prenatal technologies, especially since about the 1980s, has further contributed to the discourse of medicalized pregnancy as safer, and contributed to the perception of the hospital as the safest environment in which to give birth, despite the fact that the hospital also carries risks, such as a higher risk of infection compared to births in the home (Abel & Browner, 1998). The common discourse that birth should take place in the hospital ‘just in case,’ demonstrates the ongoing view of pregnancy as a risky endeavour, potentially requiring medical intervention (which, indeed, it sometimes is) (Cardin, 2020b). Furthermore, our image of a healthy and safe pregnancy has been significantly impacted by white, middle-class assumptions and agendas; Barker points out that there are “attempts to limit and control pregnant women through presumably objective, universal criteria that best ensure a healthy pregnancy outcome,” but that “through these criteria a rigid composite of Anglo, bourgeois mother as universal ‘woman’ is advanced” (1998, p. 1072). For instance, Barker cites *Prenatal Care*, an American government leaflet from the early twentieth century,

⁹ I do not want to discount the importance of medicine or prenatal care, which save lives. Pregnant people still often die in childbirth around the world due to lack of access to knowledgeable healthcare practitioners, blood products, medicines, clean facilities, and clean water, among other necessities. However, rates of childbirth mortality decreased dramatically with the discovery of germs, as the leading cause of death among pregnant people used to be sepsis (Roser & Ritchie, 2013).

which advocated that pregnant women spend two hours a day in the fresh air, but do no necessary labour. (In other words, pregnant women should do only optional work like tending their gardens; they should not be on their feet for 8 hours doing paid work. This was an option that would clearly not be available to working class mothers). More recently, Jette points out that exercise was long considered a risk factor for congenital birth defects, and until 1980, physicians were still accepting as a given, because of their belief that it diverted oxygen from the fetus to the mother's muscles (2011, pp. 299–300). All of the guidelines were in place at times when exercise was associated with poverty and marginalization—working women were those unable to 'rest.' However, modern guidelines advocate (some) exercise for pregnant people, at a time when the medical community is very concerned about an 'obesity epidemic,' and high weights are now more prevalent among marginalized communities. As Jette states, "the active pregnant body remains bound up in relations of power" (2011, p. 309).

In this context, 'opting out' of hospital birth, any aspect of prenatal care, or even prenatal testing now means contending with social pressures from friends, family, colleagues, or others who see medicalization as necessary, and also coping with internalized pressures to do what is best for oneself and especially, for one's child. The risk of negative outcomes from refusing a test or from choosing home birth is often inflated, yet social discourses can still produce an inner voice of "responsibilization" (Rose, 2007, p. 4) that cause a pregnant woman to ask, 'What if?' and potentially prevent the exercise of non-medical options (BORN Ontario: Better Outcomes Registry Network, 2016).

It is worth noting, however, that risk avoidance is to an extent a phenomenon of class; Lupton's studies indicate that working class women are less risk-avoidant, perhaps due to socioeconomic disadvantage, and that white, middle-class women are more likely to test and to

terminate if they receive ‘abnormal’ results (2011). Rapp has also demonstrated a connection between family size and fear of disability; higher-income, professional, often white families, tend to have fewer children compared to lower-income, often racialized families (1999). Rapp argues that in families where children are scarce, a ‘high-risk’ diagnosis sounds “large and present,” whereas “the same number may sound distant and small for a low-income mother of four” (1999, p. 70). While this research did not survey a significant enough sample to determine such correlations, I included some demographic questions in order to observe whether these variables had an effect for the people I interviewed, and I looked for demographic markers in the online research. This research did skew somewhat towards privileged populations, but the only demographic marker which I noticed aligning with greater comfort with a “high-risk” diagnosis was previous experiences of disability. There were some pregnant people in this study who refused to adhere to medical recommendations and felt a sense of agency because of it, as well as some who felt they had failed to adequately comply, and some who were treated as non-compliant by their doctors. I observed that participants’ feelings about this were less connected to their demographic position, and more connected to their pregnancy outcomes. Perceived positive outcomes tended to produce feelings that non-compliance with medical authority was empowering, whereas perceived negative outcomes tended to produce self-blame.

Governmentality, Biomedicalization and Risk

There is significant previous research on the operation of governmentality in pregnancy (e.g., Lupton, 2011; Weir, 1996). However, prenatal testing specifically has become a type of cultural imperative—an act which pregnant people are normatively expected to do—which is an important avenue for further research. Governmentality, as many pregnancy researchers have already suggested, operates on pregnant people not as a requirement that they engage in or avoid

certain behaviours, or indeed even as overt pressure to do so, but as the accumulated effect of years of discourses of risk, responsibility, and the role of mothers. Years of media that suggest the importance of mothers behaving in certain ways, years of cultural expectations, and years of hearing about biological clocks for female reproduction significantly influence our attitudes. This is also not to discount coercive statements made by partners, family, friends, and medical professionals—the operation of governmentality is both subtle and overt. “Governmentality rests on a dispersed form of power that emerges through all aspects of social life and is enforced through self-governance” (Barcelos, 2014, p. 477). This self-governance was perhaps best explained by Foucault in the following excerpt from *Security, Territory, Population*, where he describes governmentality as the “conduct of conduct”: “Conduct... is equally the manner in which one conducts oneself, the manner in which one lets oneself be conducted, the manner in which one is conducted, and finally, in which one finds oneself behaving under the effect of a conduct...” (Foucault, 2007b, p. 193). In a sense, these words diminish the agency behind individual conduct—we are, in fact, “conducted”—by forces outside of ourselves and by discourse (Murray, 2016). We choose, but those choices are influenced, at a very deep level, with our very sense of identity wrapped up in our choices. The term governmentality is about the way our selfhood, and our behaviour (our choices), are governed, by the many discourses to which we are exposed and in which we are, ourselves, also complicit. We hear, internalize and further perpetuate the messages that pregnancy is risky, that to be a parent of a child with a disability is a difficult life that (potential) parents are responsible for avoiding at all cost, the fears that our child will not be ‘normal,’ and that to be normal matters, as to be otherwise burdens both individuals and society at large. In health, especially, messages of self-care have become pervasive through what Clarke et al. (2003) refer to as “biomedicalization,” or the reach of

medicine into everyday lives. Pregnancy intensifies a biomedicalized morality of self-care that is already pervasive:

I am subject to medico-moral judgement if I fail to exercise “due care,” if I neglect my self, if I do not live up to a level of self-care that is sanctioned by medical authorities, public health and occupations safety standards, family, friends, and concerned passers-by, who, with a glance, condemn me in my knowledge that this cigarette or cocktail is bad for me and violates life itself. (Murray, 2007, p. 5)

This “violation of life” through unregulated behaviour is that much truer and more applicable in the case of pregnancy, where one is now not only responsible for “self-care” but also for care of the fetus. As Bordo further notes, there is a highly gendered component to these discourses of care:

Yet at the same time as supererogatory levels of care are demanded of the pregnant woman, neither the father nor the state nor private industry is held responsible for any of the harms they may be inflicting on developing fetuses, nor are they required to contribute to their care. Fathers’ drug habits, smoking, alcoholism, reckless driving, and psychological and physical treatment of pregnant wives are part of the fetus’ “environment” too... but fathers are nonetheless off the hook, as is the health system that makes it so difficult for poor women to obtain adequate prenatal care and for addicted mothers to get help. (2004, p. 83)

Moreover, as Lupton (2011) argues, these pressures on pregnant people are pervasive, and can be damaging, since one logical outcome is that failure to appropriately modify one’s behaviour can result in self-blame, or blame by others, for negative outcomes, which I certainly saw in this research. Prenatal testing is thus available as a technology to help the mother mitigate her risk. In

this way, testing becomes no longer an option but a de facto requirement: “In reproductive technologies, in particular, patients and practitioners are bound up with the technologies in question, so a politics of ‘just say no’ is unconvincing” (Thompson, 2005, p. 180) This provides some of the essential background to the first of a series of more detailed research questions which will be outlined in Chapter 2, which asks why people choose to undergo, or indeed not to undergo, certain prenatal tests, and how they then experience this. As Lupton argues, pregnant people are socially expected to engage in risk-averse behaviours (2011). Lupton points out that there are strict expectations of conduct during pregnancy around food, drugs including alcohol, smoking, exercise, work, and age, among other areas (2011), and I argue that testing has taken on a similar veneer of being ‘correct’ behaviour. Therefore, in this context, are people inclined to refuse? Do they? Do they accept some tests and refuse others? Once accepted, do they feel they had sufficient information? How do they experience testing, once accepted? These are some of the questions this research proposes to address, which are listed more fully in Chapter 2.

There are several instances in previous academic literature which have addressed some of these questions; for instance, Rayna Rapp (1999) has done seminal work on women’s experiences of amniocentesis in the U.S., and there have been important studies on women’s experience of ultrasound (e.g., Browner & Preloran, 2000; Clement et al., 1998; Daniel Goodley & Runswick-Cole, 2016; Kvande, 2000; L. M. Mitchell & Georges, 2000; Morgan, 2000; Saetnan, 2000; Williams et al., 2005). Most works in this area are now relatively dated, few have a Canadian perspective, and few have a centralized focus on the role of disability discourse in informing pregnant people’s decision-making. Therefore, this research contributes by building on previous studies, and updating their findings, especially in light of recent advances in prenatal testing technology such as Non-invasive Prenatal Testing (NIPT). By conducting interviews with

people primarily in the Ottawa area, this research also contributes a Canadian perspective which is not commonly found in previous studies, and which differs somewhat due to our unique position of having socialized healthcare, like many of the countries which have been studied,¹⁰ but also a culture that is more interwoven with the U.S. than many European countries. This has an impact on participant experience in several ways: For instance, many European countries have much stronger traditions of midwifery, home birth, and client choice-based birth care. Canada, like the U.S., has very high C-section rates and low breastfeeding rates, due to insufficient lactation supports and much poorer parental leave policies compared to many European countries. (Canada is doing much better than the U.S. on this latter point, but our policies are much less generous than, for example, Scandinavian countries.)

Another significant factor to participant experience of prenatal testing is legalization of abortion. Canada has a history of legal abortion that is similar to the U.S. (abortion was made legal in the U.S. as a result of *Roe v. Wade* in 1973, and in Canada through *Morgentaler v. The Queen* in 1988). Many European countries had similar timelines for legalization—between the 1960s and 1970s, with a few notable exceptions, such as Ireland, which legalized abortion in 2018. It is worth noting that abortion laws in all these countries generally did not change in one fell swoop—usually, prior to a general legalization of abortion, there were smaller steps toward it, in which some abortions were made legal (instances of rape, danger to the life of the pregnant person, etc.). In most cases, abortion due to fetal abnormalities has been legal much longer than general abortion, although often this has been quite specific. For example, Ireland has provisions for fatal fetal abnormality, but conditions such as Down syndrome were not included in this. These differences in legalization have had a significant impact on the rates of disability in the

¹⁰ E.g., Norway (Kvande, 2000); Greece (Mitchell & Georges, 2000)

general population—for example, in Ireland, there is a 1 in 546 rate of Down syndrome (Irish Health, 2006). In Canada, the rate is 1 in 781 (“Down syndrome facts and frequently asked questions,” n.d.). So we see legalization has a significant correlation with bringing down the total number of babies born with prenatally diagnosable conditions, and therefore more than likely impacts the experience of prenatal testing. Participants in this study also experienced issues specific to Canada; for instance, Canada generally has a universal healthcare system in which most prenatal testing is covered by taxes, but the new Non-invasive Prenatal Testing (NIPT) is only covered for pregnant people who are over 40, have a positive Integrated Prenatal Screening (IPS) result, or have a family history of birth abnormalities. This meant that the new medical and cultural pressures to do this test are resulting in out-of-pocket expenditures for many Canadians. Another example of Canada-specific experience is cultural: For instance, a participant spoke to the importance of avoiding any alcohol in pregnancy as being as much based around Canadian cultural expectations as it was on medical evidence. I speak to these experiences further in Chapters 4 and 5.

In addition to lacking Canadian perspective, most previous studies have been delimited through a focus on one specific technology, such as ultrasound or amniocentesis. In this research, I look rather at the whole picture of pregnant peoples’ use of prenatal testing, and have delimited instead through a focus on discourses of disability. This provides a contribution to disability studies, which is significant in light of the Canadian focus of the research and Canada’s history of eugenic practices against disabled people, on which I will elaborate further in this chapter.

As Weir (2006) points out, the discourse of risk during pregnancy is so effective in engendering self-regulation because, of course, pregnancy can result in unwelcome and even tragic outcomes. However, Critical Disability scholars and activists have problematized medical

and deficit models and the very idea that disabled children constitute an adverse outcome, arguing that the definitions of ability and disability have been normalized in an ableist context (Erevelles, 2011a; Garland-Thomson, 2012; McRuer, 2006), and that society and its infrastructures have been designed in such a way that they are often what disables people (Oliver, 1996; Shakespeare, 2006; Titchkosky, 2011).¹¹ Roberts argues that the medical model of pregnancy care contributes to strict discursive divisions between ability and disability, reinforcing categories of normality and abnormality:

Widespread prenatal testing has already generated greater surveillance of pregnant women and assigned them primary responsibility for making the “right” genetic decisions. It is also often expected that they will opt for abortion to select against any disabling traits identified by genetic testing. Many obstetricians provide these tests without much explanation or deliberation because they consider such screenings to be a normal part of treating their pregnant patients. (Roberts, 2015, p. 176)

This widespread acceptance of testing has a strong connection to its association with the modern reduction in maternal and infant mortality and morbidity in the developed world. Death, disability and illness were previously an integral and accepted part of pregnancy, and they remain so in many parts of the world. However, as there is now less probability of death and disability in Western industrialized countries (often couched in terms of risks), they have also become pervasive discourses, which stigmatize people with disabilities and illnesses and place pregnant people in the position of trying to mitigate the smallest of risks.

¹¹ Following criticisms that the social model of disability does not do enough to acknowledge issues such as pain, isolation and physical impairment, it has been updated to reflect the lived experiences of those living with painful or disability or chronic medical conditions (Magnet & Watson, 2017; Oliver, 2013; Swain & French, 2000).

Risk forms a central component of discourses of disability; it perpetuates fear of disability. ‘Reducing’ means eradicating disability at the population level; this is why it is a biopolitical goal. It is also, as Rapp argues, a tool that aids in the project of “stratified reproduction”: A biopolitical eugenics project in which “the reproductive aspirations, practices, and outcomes of one group of people are valorized, while the parenthood of another is despised or unsupported” (2011, p. 703). In practice, stratified reproduction often occurs through intersections of marginalization; assisted reproductive technologies are very expensive, which makes them more available not only to those with higher incomes but also to white people, since racialized people are more likely to be poor (Erevelles, 2011a; Rapp, 2011). Disability also intersects with racialization and poverty; people of colour are more likely to have learning disabilities (although they may have reduced access to diagnosis), people with disabilities are more likely to be poor, and people who are racialized and/or poor are more likely to have barriers to accessing medical care (Erevelles, 2011a). Risk assessment is “a moral technology used as a means of identifying specific targets of surveillance and punishment” (Lupton cited in Barcelos, 2014, p. 481). Prenatal testing is expensive and time-consuming; therefore, it is only a valuable proposition if those whose results are ‘abnormal’ mitigate their risk through appropriate behavioural self-regulation. Clearly, termination is among what Barcelos terms the “rational, individual” behaviours these high-risk individuals can perform¹² (2014, p. 481).

¹² In a sense, abortion based on undesirable prenatal test results also does not seem ‘passive’; it does not seem like merely “disallowing life to the point of death,” but active killing, especially in light of polemics surrounding abortion. However, from a biopolitical perspective, these terminations do not occur as a requirement of an overarching sovereign body but individually, at the behest of the mothers. Therefore, these terminations are at least somewhat made possible through the operation of discourses that ‘dehumanize’ these fetuses (at least in comparison with the ‘normal,’ ‘healthy’ fetus.) Therefore, these terminations operate biopolitically.

Under a risk management structure, Rose argues, it is more than people with disabilities who are allowed to die: “Modern biopolitics goes beyond trying to classify and eliminate ‘defective’ people and tries to identify those seen as at risk for being defective” (Rose, 2007, p. 70). Ultimately, this can create a coercive situation in which pregnant people are internalizing a sense of responsibility for fitness of populations, though it may be couched in language of fear for the suffering of the child. As Roberts points out, this argument is very effective:

The individual woman becomes the site of governance through self-regulation of genetic risk. The medical model of disability that promotes eugenic elimination of genetic risk instead of ending discrimination against disabled people supports state reliance on individuals to secure their own well-being through the use of genetic technologies. (Roberts, 2015, p. 171)

Whether the termination of pregnancies based on fear of disability is intended or not by the people involved in testing and genetic screening, it is a probable effect of continual risk discourses which implicitly incite the pregnant person to mitigate their own risk—by having their children younger, by testing, and potentially, by terminating.

Ultrasound: Visual Knowledge and Surveillance

Risk goes hand in hand with surveillance; they work hand in hand to discipline bodies. Foucault argued that the surveillance of the body was key to establishing medical dominance (Draper, 2002) and empowers medical authority to establish both what is worthy of surveillance and a monopoly of interpretation of meaning.

Ultrasound was first used by obstetric medicine in the 1950s-1960s, and initially only when physicians suspected ‘abnormalities.’ Initially, ultrasounds were only visible to the technicians or physicians. When a second screen was added so pregnant people and their partners

could see the fetal images, everything changed. Ultrasound became normalized, a part of the “Western pregnancy ritual” (Draper, 2002, p. 778). Ultrasonography has become the “icon signifying pregnancy” (Clement et al., 1998, p. 13). The ultrasound scan also took on special significance for fathers, helping them participate more actively in their partners’ pregnancies, adding to the cultural significance of the technology. In this sense, it “holds a dual meaning, as the skilled cultural practice of medicine generates one image and the skilled cultural practice of the parents produces another” (Draper, 2002, p. 791). Draper reports that for many parents, the desire for ultrasound is produced as much by the desire for fathers to participate more fully, and a visual culture anxious for those first ‘photos’ of the baby, as it is for diagnostic purposes, or to rule out potential ‘problems.’ In fact, Draper argues that other forms of diagnosis such as amniocentesis are more widely understood as diagnostic techniques, underlining the social function of ultrasound (2002).

What this may lead to, in part, is a deep privileging of the knowledge acquired through such techniques, often at the expense of felt and embodied knowledge. Many women report not feeling their pregnancies were “real” until after the ultrasound (Saetan, 2000, p. 340). As Barad argues, ultrasound creates our “reality” in a way that has discursive and material consequences: For instance, the discursive decision, by way of ultrasonic technology, that defines a fetus as a ‘girl’ has led to masses of terminations in India (Barad, 1998). The discourses that girls are less valuable, more expensive, or less able to support the family financially are certainly key to this issue, but the ultrasound enables us to classify these fetuses as ‘girls’ before they are ever born; the ultrasound is thus an instrument of biopolitics.

Moreover, as pregnant people become more reliant on the observational knowledge produced by ultrasound, it may even lead to a loss in their own observations of embodied

sensations or intuition (Draper, 2002; Lupton, 2011). While many doctors and midwives ask pregnant people to observe, for example, when something ‘doesn’t feel right,’ they may lose the connection to this embodied knowledge through overreliance on the visual.¹³ This is not only a widespread loss in cultural terms, but in the potential for scientific knowledge production. There are many limits to the knowledge that can be produced through ultrasound: For instance, when dating ultrasounds are wrong this can lead to potentially unnecessary labour interventions (Browner & Preloran, 2000). Ultrasound imaging also takes training to interpret, and the pregnant person and their partner are normally reliant on the interpretation of the technician or physician to understand the images. These interpretations can include biases: for instance, Mitchell and Georges (2000) observed cultural differences between descriptions of the fetus; in Canada, technicians frequently personified the fetus; in Greece, ultrasounds were much more

¹³ A digression that I think is worth making: In the feminist literature of pregnancy, the increasing critiques of biomedicalization, and the turn toward midwifery and home birthing in the late 1960s and 1970s (Cardin, 2020a; Keating & Fleming, 2009; Parizeau, 2007; Parry, 2008; Shaw, 2013; Umansky, 1996; Worman-Ross & Mix, 2013), there is significant emphasis on these various forms of knowledge, including spiritual, embodied, intuitive and other knowledges which tend to be displaced by the visual and technological. As a researcher but prior to becoming a parent myself, I did not have a really clear sense of what types of data were produced by these ways of knowing, and saw them as something a bit esoteric and vague, in contrast to my sense of the hospital/ medical knowledge as producing clear and documentable data. This may be true in some cases, but I have a much better idea now, after my own embodied experiences of pregnancy, of both the kinds of knowledge that are possible through embodied observation as well as the many limits to ultrasound and other prenatal technologies. For instance, many pregnant people document their menstrual cycles using apps on their mobile phones; they document data points such as the day they get their period, heaviness of flow, and the use of ovulation test strips. These data points are probably not particularly subject to memory lapse, and yet my experience is that medicine continues to treat women’s self-reporting as highly error-prone in terms of dating pregnancy, while failing to account for the error margins of their own technology (which often produce wrong gestational ages, wrong estimated birth weights, etc.). I would also note that medicine does use pregnant people’s self-reporting in situations where technological monitoring would be prohibitively expensive or inconvenient—for example, pregnant people are asked to do “kick counts” in late pregnancy, rather than outfitting every pregnant person with continuous wireless external fetal heart monitors. In other words, embodied knowledge is widely used and its uses are acknowledged by medicine when the need is clear; it is also immediately discounted when there is any discrepancy between knowledge acquisition from the pregnant person or the medical institution. I believe this power imbalance can lead to very complex feelings and resentment from the pregnant person whose knowledge and participation are acknowledged, but only up to a point.

diagnostic. Ultrasound also has a history of intentional coercive use, including its use in deliberate attempts to prevent mothers from choosing termination (Bailey, 2010; Hartouni, 1997; L. M. Mitchell & Georges, 2000; Upadhyay et al., 2017).

I am certainly not suggesting that ultrasound or other prenatal testing be abandoned. Ultrasound is a useful form of knowledge acquisition, especially in tandem with other methods. But the valorization of this form of learning about the pregnant body over embodiment is grounded in misogyny. It is grounded in a patriarchal obstetrical viewpoint that emphasized what the doctor could observe over what the pregnant person could observe (Draper, 2002; Ginzberg, 1987; Saetnan, 2000; Williams, 2006; Williams et al., 2005). From a less hierarchical viewpoint, a doctor has an opportunity to use their knowledge to help the pregnant person interpret the knowledge acquired through embodiment.

The visual element of ultrasound has been an important aspect of this research. I sought to discover whether pregnant people had a sense of the ultrasound as a technology used for surveillance. How did this affect their experience of it, or their decisions to use it? How did it contribute to their knowledge of their pregnancies, or their trust of their bodies? How did it impact their relationship to the fetus? This latter question was especially important in terms of considering the way the ‘self’ is changed and identity affected by pregnancy. Literature has shown that pregnant people await diagnosis in order to define the fetus; they wait to consider it a ‘baby’ until its status as ‘healthy’ is certain (referred to as ‘tentative pregnancy’) (Draper, 2002; Lupton, 1999). Therefore, I sought to determine from participants how their impression of the fetal self was impacted by prenatal testing technology, and what impact, if any, did diagnosis have on their decisions regarding terminating or continuing pregnancies? Last but not least, how

did their impressions of disability impact their decisions? What was the impact of discourses of disability operating within medical institutions or within the sources of information they sought?

Abnormality and Disability (The Human Monster)

How we consider the fetus is central to our decisions to test and terminate, and therefore I explore some of the major relevant arguments for conserving disability, considering dis/ability along a spectrum, separating disability and impairment, and considering the social construction versus the materiality of disability. Critical Disability Studies also informs the points of tension, mentioned above in my research question, between individualizing and massifying discourses (that is, discourses of population health).

This intersection seemed to put the interests of two specific groups—pregnant people and disabled people—into direct opposition. On one hand, we have the ethics of termination and the importance for pregnant people of the right to make their own decisions regarding family planning and pregnancy. On the other, we have a history of eugenics and devaluation of disabled people, and the potential for eradication, through selective termination, of certain forms of difference. Mills writes that the individual decisions made by women with regards to their own pregnancies are affected by ableist discourse:

Such individual decisions ... are given a certain coherence and reasonableness through the operation of background conditions of ableism. This is not to say that individual decisions are simply reducible to these background conditions, or to suggest that such conditions wholly determine the morality of possible courses of action. (2001, p. 74)

Not only do such decisions stem to some extent from ableist discourse, they cannot help but contribute to its reproduction.

I would argue that this seeming opposition between these two groups is neither a true contradiction nor is it irreconcilable.¹⁴ Grounding my research in a standpoint of intersectionality, I consider disability to be a feminist issue, for many reasons (Wendell, 1989), including the fact that women are more likely than men to be disabled. Many of the arguments made by feminist scholars, civil rights activists and queer theorists¹⁵ paved the way for Critical Disability Studies, including Wendell’s assessment that the physical and social architecture of the world assumes male sex and ability, in ways that can render both female sex and disability as impairment (1989). People assigned female at birth can benefit from the work that has been done by disability activists or theorists to denormalize the structure of the “mythical norm” social environment (Lorde, 1984); one designed for the white, straight, able cisgender male. Notwithstanding the broad range of disability and the varied experiences of people with disabilities, disability activists have pushed for disability to be viewed as another type of difference, without negative deficit-based overtones (McRuer, 2006; Swain & French, 2000). This is done while still acknowledging the pain and lack of social supports often experienced by disabled people and other marginalized communities, and the labour involved in creating communities of care—not without great struggle (Piepzna-Samarisinha, 2018). Feminist and queer disability studies also emphasizes a denaturalization of the hierarchies of embodiment in which bodies assigned female at birth are worth less than those assigned male, and people

¹⁴ Kaposy (2018) provides an interesting example of this: In his *New York Times* op-ed, he details how his wife’s prenatal testing revealed that their son would be born with Down syndrome, and his wife’s choice to continue the pregnancy. I raise this example not as an “ideal” situation (this, to me, is subjective, and I would argue each pregnant person is best placed to decide what their own ideal outcome is), but to demonstrate that choice does not have to be at odds with disruption and destigmatization of disability. This may take many forms.

¹⁵ Socialist feminists of colour were at the forefront of activism for reproductive rights, abortion, and fighting violence against women, and were concerned with concepts of intersectionality before the term gained widespread use in the 1990s (Taylor, 2017).

considered to have impairments (e.g. disabled, trans, elderly, fat) are worth less than those whose bodies are coded as normal (Clare, 1999; Garland-Thomson, 2005; Daniel Goodley & Runswick-Cole, 2016; Kafer, 2003; Tremain, 2005, 2006). Moreover, Kim Hall argues both female sexed and disabled bodies have been historically defined as lack; the female body in relation to male is Othered in a way that produces *woman* as a “handicap” (K. Q. Hall, 2011, p. 3). She suggests therefore that the “feminist disability studies” lens goes beyond feminism or disability, constituting a way of thinking about embodiment. Feminist disability studies troubles the notions of which bodies are framed as abnormal; it troubles defining any body in relation to a norm (K. Q. Hall, 2011). Garland-Thompson adds that the study of disability in a feminist context furthers our critical understanding of cultural contexts, not only for people with disabilities, but for everyone. She calls for a “universalizing view” to replace a “minoritizing view,” in other words, using the experience of disability to enrich all our experiences of embodiment (2011, pp. 16–17). Furthermore, in her chapter “Queer Breasted Experience,” Hall expands on her previous view of feminist disability studies, which can also encourage us to remember the diversity of both bodies and genders (Hall, 2009). I find this especially useful in terms of remembering that trans identity has also historically been either viewed as lack or erased, with many trans men or non-binary people misgendered as women by their healthcare providers, and therefore experiencing an additional level of violence on top of the misogyny present in patriarchally founded health care institutions.

Further to the point that feminist disability studies permits us to consider many people’s diverse experiences differently, Garland-Thompson (2012) argues that part of the case for conserving disability is fighting eugenics logic that the world would be improved if disability were eliminated. She points out that disability, when considered as a spectrum rather than a

dichotomy between able and disabled, is a natural and expected part of everyone's lives. People experience impairments that are disabling in all sorts of ways—for instance, age, pregnancy, illness, and broken limbs. What, therefore, sets apart certain conditions and makes them disabilities that need to be eliminated according to these social logics? Garland-Thompson argues that the chief difference is social convention. For her, as with many Critical Disability scholars, prenatal testing constitutes a new and more socially acceptable method of eugenics; in which we are “controlling the composition of a particular citizenry” (2012, p. 351). In this dissertation, I sought to understand how the discourses of disabled children as risky, catastrophic or unwanted are implicitly understood or internalized, shaping the individual decisions pregnant people make to test or to terminate.

One of the important aspects of biopolitical discourses is that they are not a directed, overt eugenics project as with other historical projects. While this certainly includes Nazism, in which genocide was committed against people with intellectual and physical disabilities, it is important to recognize that there were projects spearheaded by Canada, the U.S., and many European countries aimed at eradication of people with disabilities. In these countries, which Mitchell and Snyder term the “eugenic Atlantic” (2003), eugenic activities were practiced against many groups of people, including disabled people, racialized people, Indigenous peoples, and lesbians and gay men. The crimes committed against these people included forced sterilizations, confinement practices, the denial of education, the invention of ‘intelligence testing’ to classify them, and the passage of restrictive laws that prohibited their marriage, immigration, work, and other forms of inclusion in society (Gibson, 2015; Maguire, 2016; D. Mitchell & Snyder, 2003; Pegoraro, 2015; Savage, 2007). Eugenics is explicitly biopolitical; it is a direct classification of those worthy to reproduce, and those unworthy to do so, followed by

acts of the state to promote or limit reproduction. Foucault directly identified eugenics as one of the great innovations of biopolitics in the twentieth century, and stated that it was used to foster the reproduction of the ruling classes (1990). Many scholars argue that contemporary prenatal testing and termination, which occurs, in the Global North, ostensibly at the behest of the pregnant person, has important parallels to these historical practices of testing, classification, separation, and eradication (Magnet, 2013; Rabinow & Rose, 2006; Rose, 2007; Sanger, 2007). While these are no longer state-mandated or sponsored projects, this project sought to understand the discursive environment that makes these terminations possible.

The research, in this section, considers one localized aspect, therefore, of the philosophy of termination. It does not reach into the broader ethics of abortion but looks at one specific instance of people terminating pregnancies because of the presence of a prenatal diagnosis of disability or impairment.¹⁶ What, therefore, is the specific discourse surrounding the disabled fetus that changes a wanted pregnancy into an unwanted one?

Here I plan to employ Foucault's notion of abnormality vis-à-vis the "human monster" (2007a, pp. 55–57). Foucault argued that until the 18th century, and the change towards biopower, the domain of abnormality had three elements (which remain under biopower, but become blurred and overlap with one another) (Foucault, 2007a). These three were the human

¹⁶ I think it worth briefly stating my own point of view with regard to abortion rights/ termination, because this issue remains so controversial and every researcher carries their own bias. I note that the following is my opinion, not the argument of this dissertation; I include it only because it may be relevant in terms of the way I have conducted, presented and analyzed the research in this dissertation.

I personally view abortion as a necessary part of health care for people who can get pregnant. I think abortion should be legal, safe, accessible, and free at any point in a pregnancy. As I have made clear elsewhere, I think pregnant people are the best people to make decisions for their own bodies and their own circumstances, not only with regard to termination but the many decisions that need to be made over the course of a pregnancy. I am against coercive practices such as forcing pregnant people to discuss their pregnancies with therapists, or to have ultrasounds in order to access termination. My own beliefs in this respect thus certainly impact my research.

monster, the individual to be corrected, and the masturbator. Of these, the latter was most common, and in the 18th century, he argues, nearly every ailment was blamed on masturbation. The second most common was the individual to be corrected, through the disciplines — schools, psychiatry, the institution of the family, etc. He argued that we assume this individual's abnormality is corrigible, though the disciplines have so far failed to correct it. The final and least common element is the human monster; its existence is a violation of social law and it provokes violence, medical care, or pity. In *Abnormal*, university lectures by Foucault from 1975 which were published posthumously, he separated disability from monstrosity; he argued that disability was not equivalent to monstrosity because it is codified in law. Foucault, therefore, would more aptly describe disabled people under the discursive category of the individual to be corrected—by disciplines such as medicine, courts or education. He does, as mentioned, also note that the categories begin to overlap under biopower, and I argue that there is a large extent to which disability is now discursively represented as monstrous and frequently represented that way in popular culture (Darke, 1998;1994), and this discourse of the monstrous is necessary for the construction of disabled lives as not valuable or not worthwhile.

Furthermore, there is a discursive separation that occurs between the unborn and the born which cannot be overlooked—in fact, disability in a fetus, according to Foucault, constitutes a socially unacceptable mixture of life and death—the disabled fetus is codified in part, as already dead: “It is a mixture of life and death: the fetus born with a morphology that means it will not be able to live but that nonetheless survives for some minutes or days is a monster” (2007a, p. 63). While in this quote he speaks only of terminal disability, I think we can extend this idea to disability more generally as it connects back to the idea of ‘morbidity’, a word that is always spoken of in conjunction with mortality. For fetuses, mortality and morbidity are often conflated

and form the same statistics; in short, they are considered part and parcel of the same outcome. By asking the question of how society thinks about morbidity or disability of fetuses, and how this links to pregnant people's decisions regarding it, this dissertation will explore how and when individual people decide to keep or terminate their fetuses, and how this connects to the larger biopolitical question of which types of life we, as a society, deem expendable. While I am not suggesting that individual terminations are intended as eugenic, we certainly base our conceptual visions of the disabled fetus on people who are alive among us, and therefore discourses of disability impact decisions surrounding fetal life.

Defining Disability, Illness, Health

I turn to definitions of dis/ability and health at this juncture because of the complexity of such definitions. While the definition of each term is certainly dependent on who is defining it, we can say that disability is generally defined as a physical or mental impairment that affects one's ability to live in society. For instance, take this definition from Disabled People's International, which defines 'impairment' as a "functional limitation in the individual caused by physical, mental or sensory impairment" and 'disability' as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Oliver, 1996, n.p.). This definition has two notable aspects: 1) impairment and 2) society. For many critical disability scholars, it is important to note this social model of disability, which argues that it is often society's refusal to accept or accommodate the impairment that causes that impairment to be disabling. In other words, society disables, rather than the body (Mills, 2001). The social model of disability has been criticized for failure to acknowledge impairment, the material felt experience of disability, and pain, as parts of the everyday lives of people living with disability and illness (Hughes & Paterson, 2006; Oliver,

2013). This is a significant point; Nirmala Erevelles further complicates the social model of disability, arguing that disability cannot be universally celebrated if it is “acquired under the oppressive conditions of poverty, economic exploitation, police brutality, neocolonial violence, and lack of access to adequate health care and education” (2011b, p. 119). However, Oliver notes that the social model of disability does not deny the existence of impairment or the material experience of living in one’s body; he argues disability is about both embodiment and culture (Oliver, 2013).

The question of what constitutes disability thus exists at the confluence of critical debates on materiality and constructivism: To what extent is disability a physical or intellectual impairment, determined by the body (Garland-Thomson, 2012; McRuer, 2006; Tremain, 2006)? To what extent is it a sociological category (Butler, 1993; Fritsch, 2015)? Furthermore, the category ‘disabled’ is diverse and heterogeneous, and includes both those who self-identify as disabled, and those who society identifies as disabled, but who would prefer to be seen as neurodivergent (Maguire, 2016), as well as those with non-visible disabilities, who are not always recognized by society. Even the idea of identifying in these latter ways continues to define disability in reference to an able norm.

All bodies exist in the assemblage of materiality and discourse. The difficulty we encounter in trying to define disability is the inevitable framing of it in reference to ‘normality’; as Goodley and Runswick-Cole argue, in defining disability we inevitably revert to defining a “human” norm, and then set up disabled and human as antitheses (2014, p. 5). To be disabled, however, as Goodley and Runswick-Cole is not to be nonhuman, and the pervasive normalizing of ability is a false construct that ignores how often bodies are broken, repaired, sore, ill, pregnant, ageing, or otherwise rendered Other (Daniel Goodley & Runswick-Cole, 2016; Puar,

2009; Titchkosky, 2011). Disability and illness are not only viewed as Other, but as temporary and imperfect, less than whole—a liminal or transient state that is waiting for better science, better technology; a cure. This constructs a vision of ‘health’ as wholeness (which is itself a construct), as the ideal state for human bodies, that belies accuracy and naturalizes certain (able) versions of bodies. As Titchkosky points out, what is framed as able vs. disabled has to do with how spaces are created for bodies. For instance, classrooms need tables tall enough to accommodate wheelchairs in order to be accessible to wheelchair users. However, they need chairs in order to accommodate non-wheelchair users, something the wheelchair users do not need. Yet we view non wheelchair users (bi-ambulatory) as “able” bodies that do not need accessibility in this context. Through what we decide is a normative requirement, and what we decide is an accessibility accommodation, we normalize some bodies and create some bodies as the Other (Titchkosky, 2011).

In this dissertation, I seek to discard the biopolitical value that some bodies are more correct or desirable than others, a task which at times requires identifying my own ableism. A further criticism, for me, of the social model of disability is that while it correctly notes that the “burden” of disability is created by social constructs, it does not do enough to challenge the notion of disabled identity *as a burden*. As Swain and French (2000) note, both disabled and able people experience pain and suffer. It is only what they call a “tragedy” model of disability, seen from an able standpoint, that determines that the pain of disabled people outweighs their positive experiences. In making this argument with regards to fetuses, the discourse is often that termination of fetuses with chromosomal abnormalities or birth defects prevents suffering (Saxton, 2006). This may be true, and for some parents, this may be an important truth that weighs heavily in making their decision. I do not presume to know better than any individual

what is right for them in their particular circumstances. However, Critical Disability scholars such as Saxton (2006) have argued that a significant part of the suffering of people with disabilities is due to social stigma, rather than the physical impairment itself (of course, stigma avoidance has been shown by researchers such as Rapp (1999) to be a significant reason behind terminations). Moreover, we tend to focus uniquely on the suffering of people with disabilities, forgetting that suffering is part of the human condition (Swain & French, 2000). The desire to avoid suffering for ourselves and our children is natural, but disability researchers such as Swain and French (2000) remind us that all humans suffer, and the idea that people with disabilities suffer out of proportion with what is an accepted ‘norm’ for human suffering is a discursive construct. For most, we hope that the joy we will experience in our lives will outweigh the suffering. It is very difficult to know in advance for whom that will happen. When it comes to fetuses, we have a deeply held cultural discourse that the chances of joy outweighing suffering are tied to perfect health; the affirmative model of disability seeks to interrupt this discourse (Swain & French, 2000).

Backgrounder on Prenatal Testing Technologies

Before proceeding to my proposed methodology, I offer the following background as a way to situate the technological and social experience of prenatal testing for the reader. In Ontario, all pregnant people are offered a test, which can usually be refused, called Integrated Prenatal Screening (IPS), which includes nuchal translucency ultrasound (BORN Ontario: Better Outcomes Registry Network, 2016). This test, conducted between 11 and 13 weeks of pregnancy, combines ultrasound with a blood test to offer a screening for the risk of chromosomal ‘disorders,’ and birth ‘defects’ such as skeletal or cardiac ‘anomalies.’ The test measures the nuchal fold, a fluid-filled area at the back of the neck, with a thicker measure

considered a ‘soft’ (or inconclusive) indicator of abnormalities. If the nuchal translucency ultrasound is ‘positive’ (read: abnormal), the parents are offered further testing. While statistics vary according to the source, this test turns up around 5 per cent false positives (Kim et al., 2006; Prenatal Screening Ontario, 2018). Further testing may include Non-Invasive Prenatal Testing (NIPT), a relatively new blood test, which works by testing fetal blood from a sample of the mother’s blood (it does not work for all pregnancies, for example, multiples). NIPT is also a screening, not a diagnosis, but the rate of false positives is much lower—the test is considered to be more than 99% accurate in looking for Trisomy 21, 13 and 18 (Down syndrome, Patau syndrome, Edwards syndrome) and sex chromosomes (missing or additional sex chromosomes can indicate conditions such as Jacob’s syndrome or Turner syndrome). The further testing options also include amniocentesis, Ultrasound II (a very complete anatomy scan of the fetus performed after 16 weeks), a fetal echo (an in-depth heart ultrasound), additional ultrasounds, and fetal MRIs. The level of testing that is undertaken will depend on the advice of doctors, genetic counsellors, the parents’ choices, and the results of each successive test. Any parents who undergo testing and receive positive results at any point will be referred to genetic counsellors, where they will learn in detail about all possible ‘abnormalities’ that could be revealed, ostensibly to prepare them for the potential results of further testing. There could be multiple sessions with genetic counsellors. These do include cautionary notes that medical knowledge is often incomplete — for instance, the doctors could find a missing, extra or mutated piece of genetic code, but not know what it means.

It is important to note for my online research, where the respondents may be geographically widespread, that the situation in Ontario sometimes differs from other health care jurisdictions in Canada, the U.S., or abroad. NIPT, for instance, was available in Europe and the

U.S. before it became available in Canada. In Canada, where health care is publicly funded, NIPT is offered free of charge only to mothers deemed ‘at risk,’ either because of previous positive tests, or because of other risk factors such as Advanced Maternal Age (defined in this context as age 40 or older, although often as 35, reinforcing the argument I have made elsewhere that this is an arbitrary designation [Cardin, 2020b].) For other parents, or parents in other geographical areas, this expensive test (usually about \$550 CAD) is an out-of-pocket payment, and thus inaccessible to many people.

As mentioned throughout this chapter, the use of prenatal testing technologies has become incredibly routine and normalized in the past generation, a normalization which can serve to mask its ultimate purpose of classifying and eradicating many conditions defined as genetic abnormalities. Discourses about disability and about responsible motherhood function in conjunction to create an environment in which pregnant people often feel an overwhelming imperative to be tested, and to base their decisions around continuing or terminating their pregnancies on the results of those tests. In the following chapter, I provide an overview of the methods chosen for this project, as well as some of the ethical and methodological considerations that arose in the course of this work.

Chapter 2:

Research Methods: A Multimodal Approach

Given the topic of prenatal health, and the grounding of this work in feminist disability studies and Foucauldian theory, I have chosen methods that are in keeping with these research traditions. In this chapter, I expand further on the use of interviews and online research as modes of feminist research, as well as the use and limitations of Foucauldian discourse analysis as a method for understanding relationships of power. Ultimately, the methods were chosen as anticipated best practices to answer the following research questions, which were crafted as a way to delve into the two aspects of prenatal testing mentioned above: Its effects on pregnant people's experiences, and its relationship to discourses of disability.

Research Questions

Before describing the methods in more detail, I return to the research questions, offering a more complete list. As stated previously, the research questions are broken down into two areas, the first pertaining to pregnant people's experiences with prenatal testing, and the second to their attitudes regarding disability.

First:

- How does the medicalized process of prenatal testing instill the pregnant person with a sense of responsibility (to the fetus/baby, partner, family, community, or population health)?
- How does a sense of responsibility link to broader concerns related to population health in different discursive sites?
- Do discussions online vary from more individualized sites?

Second:

- Do participants recognize the implicit marginalization of disability produced through prenatal testing?
- If so, do they have negotiated or oppositional readings of it?
- How does this process of prenatal testing produce or reinforce a sense of aversion to the marginality that is often associated with disability?
- Does the person's previous experience or subject position have an impact on how they feel about the potential for having a child with a disability?
- Does their previous experience or subject position impact how they feel about undergoing the tests?

These questions address an area that has previously been explored by research on prenatal testing, which has not adequately addressed the connection between individual decision-making and massifying discourses (Rose, 2007, p. 78; Weir, 2006). As Tremain notes, "This discourse of risk implicates [prenatal testing] practices and procedures in relations of power in ways that, for the most part, have not been critically interrogated" (2006, p. 37). Williams further argues that few studies in this area have directly sought the perspectives of pregnant people (2006). The two methods employed in the study sought these perspectives directly in different ways: Through analysis of online comments in user-led forums on pregnancy, and Twitter, and through semi-structured interviews. I have entitled these Phases 1 and 2, although they were conducted concurrently.

Phase 1 Method: Online Comments

Foucauldian and Feminist Discourse Analysis

Foucauldian discourse analysis is concerned with understanding power relations, and the ways they connect to the production of knowledge and discourse. Researchers employing this

method are seeking to uncover the ideas and knowledge that have become entrenched as ‘common sense.’ While there is no one set of guidelines to this type of discourse analysis, there are a number of approaches, including examination of the ways discourse has changed historically (Foucault, 1972) and to examine instances of resistance to these common knowledge discourses (Foucault, 1982). Foucault also suggests the identification of authority and its “rules and processes of appropriation of discourse,” (1972, p. 68), and attention to the economy of knowledge, as well as who benefits politically and economically from the normalization of certain ideas (1972, p. 68). Which discourses have taken on “truth” status (Cheek, 2004, p. 1143)?

These approaches are further enriched by Foucauldian feminist scholars who argue that biopower tends to overlook the specific power relations of gender (Deveaux, 1994), racialization (Browne, 2015), and disability (Maguire, 2016; Tremain, 2005). Sawicki argues that Foucault overlooks these imbalances of power: “he generally spoke of power as though it subjugated everyone equally” (1991, p. 49). Moreover, O’Grady argues that the consistent oppression of women and those with female-sexed bodies makes us more susceptible to governmentality; that repeatedly being treated as the ‘other’ in comparison to the male norm has an overall effect of making cis women¹⁷ more vulnerable to the coerciveness of discourse (2004). An intersectional, feminist approach to this research includes keeping top of mind the ways in which medical discourse is linked to and produced within patriarchy, and that medicalization is rooted in gendered power structures (Moore, 2010). This means special attention to the ways gender, race, class, heterosexism, ageism, and ableism manifest through these discourses of risk and

¹⁷ I am not sure how this argument applies to trans people. I think this discourse is highly gendered and therefore it is more the gender construction of womanhood that causes this responsabilization than the way we are sexed. I am sure trans people probably have experiences of this too but cannot comment on what they are; this would be an interesting area for research.

responsible motherhood. In this respect, I certainly noticed that previous experiences of disability, especially personal ones often produced a greater level of comfort with the idea of having a baby who was disabled. Moreover, those who reported positive feelings about disabled people, or imagined a positive future for them, often had other experiences of marginality in their lives, such as being queer and/or having queer family members. That said, everyone to whom I spoke felt some level of pressure to conform to motherhood norms, and these were also rampant through online comments.

Online Research

Through this method, I was looking to understand pregnant people's individual experiences in the context of wider debates about the uses of prenatal testing. Others writing in these disciplines, such as Maguire (2016), Morrow, Hawkins and Kern (2015), and Nind, Wiles, Bengry-Howell and Crow (2013), have used similar mixed methods which include some interviews, some online research and/or some critical discourse analysis of primary documents. This has allowed these researchers to both produce a deeper qualitative analysis and to reach data in comfortable and accessible settings in which it is being produced.

While I expand further on the choice of sites in Chapter 3, I will briefly outline this choice here. WhatToExpect.com and BabyCenter.com were chosen because they constitute first lines of inquiry for many pregnant people—many of the forums from these sites will come up in the first page of Google search results for queries such as “prenatal testing,” or “large nuchal fold” (which is the first screening result that indicates a “positive” Down syndrome test.) These websites have an international presence, with different versions in different countries, though I focused on the .com versions since these are largely the ones used in North America, which is also the location for my interviews. Finally, these websites also allow for reproduction of the

comments on the forums within their Terms of Service. I discuss this issue further in this chapter, under *Ethics*.

Comments from these sites were captured and coded using NVivo qualitative research software. I began by searching terms on these websites which might produce relevant forums, such as “prenatal testing,” or “Down syndrome.” These results were screenshotted and downloaded to NVivo, and then coded thematically. Themes emerged from the forums themselves, with many themes added based on topics frequently addressed. This approach ensures the themes are as participant-led as possible (Glaser & Strauss, 1967). Twitter was searched similarly, with Tweets both directly captured using NCapture (an add-on to NVivo), as well as screenshotted from the website directly, since NCapture will only find Tweets from the past 30 days. Tweets were then also coded thematically. Forum posts were selected from a relatively short period (October 2019), because these forums are very busy and even a short period produced hundreds of comments. Twitter posts were selected from a longer time period, beginning in October 2019 and going through to July 2020, since it took a longer time period to produce sufficient results. The exact number of analyzed Tweets is difficult to count due to some repetition through retweets, as well as some counted by NVivo, but discarded from analysis since they were advertisements; however, the total number fell between 500-1000.

Benefits and Limitations

The Q&A forums, hosted by websites such as WhatToexpect.com and BabyCenter.com, have several advantages as a site of analysis. Individuals start the forums, usually by posting a question in order to get feedback from others who have had similar experiences. Through the questions and answers, we can see some of the questions pregnant people have; these are questions they are turning to strangers to answer rather than medical professionals or friends. My initial searching showed that participants in these forums are often seeking validation from

others who have had similar experiences (What to Expect, 2017). Through their questions, and the answers provided by other users, we can see their emotional engagement with the prenatal testing issues they were dealing with, often as those issues were occurring.

The second phase of the online research was to conduct searches on Twitter for relevant themes. I used NVivo qualitative research software to directly capture data from Twitter, gathering all Tweets for the following search terms: ‘prenatal testing’, ‘nuchal translucency ultrasound’, and ‘amniocentesis’, from 2019/2020. Twitter functions differently than anonymous pregnancy forums: Users are generally not anonymous, but often have their personal identities associated with their Twitter handles. Therefore, my expectation was that these comments might serve a different function than the Q&A forums. I suspected they were less likely to provide insight into private experiences of engagement with prenatal testing, but more likely to show reaction to prenatal testing services and the more ‘activist’ side of negotiating prenatal testing. In other words, my hypothesis was that people Tweeting about prenatal testing are either very pleased with the process, pushing for systemic change, or perhaps looking to be heard.

Themes

Data collection was focused on three themes drawn from preliminary research, and germane to the research questions.

Medical Authority and Prenatal Testing Results.

This thematic area speaks to how the medicalized process of prenatal testing affects pregnant people’s experiences, and to the above section of the literature review regarding medical authority and how it reinforces discourses regarding disability. Through this theme, I sought pregnant people’s engagement with medical authority and disciplinary power. How did these interactions compare with intuition or the way the mother experiences or feels her

pregnancy? How did participants use these discussions to challenge predominant views of disabilities such as Down syndrome that are rampant within a medical context?

Criticism of Eugenics.

Through this theme, I looked specifically at Tweets from disabled people or their communities which challenge eugenic uses of prenatal testing and argue against its widespread adoption. This theme connected to the section in the literature review exploring the connection between histories of eugenics and contemporary prenatal testing.

Anti-abortion Advocacy.

This theme looked at anti-abortion advocacy, not in a broad way, but specifically at the intersection of prenatal testing and disability-specific abortion. This one carries over, in a sense, from the previous theme of anti-eugenic advocacy, because many of the anti-abortion advocates actually start from a place of criticizing eugenic uses of prenatal testing. The fear of eradication of disabled people does extend in some people's minds to a desire to revoke legal abortion, and this is important to document. In Chapter 1, I also addressed some of the coercive uses of ultrasound to prevent abortion (Berube, 2018; Hartouni, 1997). This theme also shows that some people are against ultrasound for the same reason, or use this argument as a rhetorical strategy to forward an anti-abortion agenda by sweeping both issues together. This theme thus offers a very clear demonstration that it is not the technology itself but the way it is used which is the issue. Through this theme, I explore the coercive uses of prenatal technologies, especially ultrasound, described in the literature review (e.g., Berube, 2018; Hartouni, 1997). This theme demonstrates the slippery slope from pointing out ableism in terms of the way we place value on people (everyone has value and should be born) to arguing an anti-abortion agenda; in other words,

disability advocates and anti-abortion advocates are sometimes making very similar arguments, although not necessarily with the same motives.

Ethics

I identified several ethical concerns with research involving participants in online forums. Among these, that because comments are taken out of context of the person, the research reinforces a strict divide between researcher and participant, and that because the participants are anonymous, their inclusion in the research is often done without their informed consent (boyd & Crawford, 2012; Morrow et al., 2015). There is no simple accepted guideline for research in online spaces, and ethics in this area remain under discussion (Morrow et al., 2015; Nind et al., 2013; Sugiura, Wiles, & Pope, 2017). This ethical concern became an affective one for me during the course of this research and highlighted for me that there is a strong link between ethics and affect (for instance, see Seigworth & Gregg, 2010). Reading the user comments without much context for the commenter's lives beyond those comments produced a strong affective response (without getting into too much detail which is covered in Chapter 3, one example was comments arguing that people with Down syndrome could not live good lives). Once I began the second research phase of participant interviews, I began to realize that I was much better able to cope, emotionally, with what I was hearing from interview participants, because the breadth of the interview gave me context. I could hear in their voices that their feelings were complicated, and often arose from how difficult their experiences had been. Coming back to the online phase later, to complete the analysis and begin editing the chapter, I realized this and found myself much less enraged by the comments I was analyzing. I offer this experience to highlight that emotional response does not necessarily reduce the effectiveness of the researcher as might be argued by the tradition of positivist research; in fact, having an

emotional response to reading ableist discourse seems a natural response for a researcher who cares about disability social justice. This affective response does, however, produce bias. I was certainly biased as I read those comments because they made me angry, and they produced grief. I think I am well aware of that bias, and I think it is important for me to be open about it here; and that understanding my affective process can be potentially useful for the reader heading into Chapter 3.

Another ethical issue for online research that I wish to address is the use of comments outside of their intended purpose. Quite beyond the Terms of Service provided by the sites I propose to use, such as Whattoexpect.com, or Twitter (Twitter, 2018; WhatToExpect.com, 2017), both of which warn the user that their content could be seen and used by other internet users, it is probably safe to assume most users do not expect to have their comments reproduced, out of context, and in a different form that is searchable (boyd & Crawford, 2012). This does not necessarily mean all participants would object to such usage. However, in many forums there is no way to ask the participant directly (their screen names are not connected to an account that could be contacted) or without influencing the content that is posted (for example, by declaring one's presence). In the case of online pregnancy forums, the participants' comments are publicly available without a login, and the participant is also protected by their anonymity to the researcher. I argue that the collection and analysis of these user responses has the potential to further our understanding of how pregnant people experience prenatal testing; acquiring this knowledge base is a first step to improving the process of informing people, making sure they feel comfortable exercising choices, and improving our conversations within the health care system, and more broadly, about prenatal diagnoses of disability. Moreover, electing not to use these types of participant-generated comments because of the potential ethical concerns risks

privileging ‘official’ or institutional voices in medical care. There is a strong potential benefit of the research, in terms of reducing the stressful environment of prenatal testing that has sent these people seeking help in online forums in the first place.

In my application to the Carleton University Research Ethics Board, I proposed to leave out the forum user’s ‘handle,’ which makes the comments more easily searchable and traceable. There are clearly indicated places where I also paraphrase the online forum user’s words, or alter the wording to make the comments less easily searchable. I did this in cases where I felt the user had been extremely vulnerable and the comment seemed very sensitive. Both of these steps were ethical choices with limitations; in the first place, because of my desire as a researcher to provide attribution to the participant, and in the second, because filtering the participant’s voice through my own has the potential to change their meaning and impose a level of hierarchy, where my interpretation is privileged over their words. There is also some potential for loss of clarity and tone through changes to the wording of any examples. I felt that these steps were necessary given the topic.

This research thus proceeds from the viewpoint that ethics comprises both the weighing of risks and harms with potential benefits, and a sense of respect and integrity surrounding the use of others’ personal comments found online (Nind et al., 2013). I have weighed the comments I have chosen to use as examples, considering the impact for the user in each case, and have not included any comment if the risks might outweigh the potential benefits.

Phase 2 Method: Interviews

Feminist Interviewing

Phase two consisted of interviews with participants who were/are currently pregnant, or with recent experiences of pregnancy. There were eighteen interviews conducted in total, with a further two potential participants who contacted me but ultimately chose not to participate. I

cover more detail on participant demographics in Chapter 4. Recruitment was done using posters in doctor and midwives' offices around Ottawa, as well as bulletin boards in community centers, libraries, and coffee shops. There were also notices posted on Facebook, specifically in neighbourhood parents' groups. More information is included in Chapter 4. Interviews were coded using NVivo qualitative research software, with themes identified prior to coding, based on transcript reviews, and emerging throughout coding. Participants' names were replaced with pseudonyms for the sake of confidentiality.

I approached this qualitative research from a feminist standpoint which values experiential and embodied knowledge as a valuable method of inquiry about the world, and which seeks to highlight stories that have been dismissed by a positivist research tradition as merely 'women's perspectives.' To "attribute authenticity" to women's experience is to "establish women's identity as people with agency," and to "ground claims for the legitimacy of women's history" (Scott, 1992, p. 31). This research occurs against a backdrop of erasure of women's experiences, particularly in pregnancy and birthing, by a patriarchal, neoliberal social context (D.-A. Davis & Craven, 2012). Davis and Craven further argue, citing Hale, that the supposed "neutrality" and "objectivity" of the positivist research tradition have served as a "smoke screen for an alignment with powerful interests" (Hale cited in D.-A. Davis & Craven, 2012, p. 196). Smith argues that while women's experiences are varied and individual, "what we could have in common was explored through experiences grounded in our sexed bodies, our women's bodies" (I would add, and trans men and non-binary people's bodies, and disabled bodies); it is therefore to these experiences that I turn for understanding the governmentality of the pregnant self. Smith further notes that the everyday world provides the perfect locus of

knowledge “to redesign the social organization of our systematically developed knowledge of society” (1992, p. 90).

Smith’s contention that everyday experience is a valuable source of knowledge connects to the principles of feminist interviewing,¹⁸ in which I view research participants as active and integral to the analysis of the research, not simply ‘subjects’ to be studied. Feminist interviewing attempts to minimize hierarchy, out of respect for each woman as the expert on her own experience, and as a best practice to help access participants’ valuable insights about the way that discourses are constructed and normalized (Keating & Fleming, 2009). Angel (2013) argues that the researcher facilitates the retrieval of knowledge through asking the participant to reflect, often for the first time,¹⁹ on events in her own life. Achieving a non-hierarchical relationship is done, in part, through revealing one’s own subject position to the participant, and as much as possible, conducting interviews as a conversation (reciprocity). This was definitely true in this research, and certainly my own experience as a mother (and as the mother of a child with a health condition) contributed to help me form relationships of trust with participants quickly. I also think the guarantee of anonymity, and my positioning as a stranger played an enormous role in helping participants feel comfortable to be forthcoming about their experiences; sometimes we can tell strangers things we would not tell our close friends and family, and I think this was the case with many of these interviews.

Using a Foucauldian discourse analysis, I identified several key discourses which were consistent with the literature I identified in the previous chapter, which are further detailed in

¹⁸ I refer to many of the commonalities among feminist research; however there is definitely not a consensus among feminist scholars as to what constitutes feminist research (Sampson, Bloor, & Fincham, 2008, p. 921).

¹⁹ My experience was that it was never the first time participants had thought about their experience with pregnancy and birth; participants had always reflected a great deal by the time they spoke to me.

Chapters 4 and 5. Overarching themes present through both interviews and online research included ableism/disablism, the responsabilization of the pregnant person towards the health of the fetus and population health, the lifestyle and happiness of the potential child, other family members, and others, and conflation of health with ability (and indeed, with happiness). I also found examples in the online research of resistance to medical authority and insistence on intuition or decision-making based on embodiment, despite advice from experts, which was also consistent with my interview findings.

Researcher Subject Position

One of the challenges of studying discourse from a Foucauldian perspective is that discourse is diffuse, widespread, and normalized in such a way as to seem like simply common knowledge or neutral information. No one, including the researcher, exists outside power, and therefore it can be difficult to identify normalization. While a positivist research tradition advises that the researcher attempt to inhabit a position of objectivity, from a Foucauldian perspective, I reject the notion that this is possible—we all have a personal relationship to the discourse we seek to interrogate. I have been deeply affected by discourses surrounding pregnancy, mothering, and the importance of “healthy” babies. This puts me in an especially effective position, according to Foucault, to conduct this research: “If one is interested in doing historical work that has political meaning, utility and effectiveness, then this is possible only if one has some kind of involvement with the struggles taking place in the area in question” (Foucault, 1980, p. 64). My personal experiences of pregnancy and prenatal testing provided me with in-depth knowledge of the subject area, which certainly allowed me to ask better questions, and to approach interviews from a place of empathy. Here it is worth noting the contributions of feminist scholars who have recognized how empathy has been historically devalued as an overly “feminine” quality; it has been considered non-essential, or even detrimental to the production of rational knowledge

(Bordo, 2004, p. 41). Sara Ahmed uses affect theory to challenge the idea of the objective argument, maintaining that a show of “rationality,” or emotionlessness, is often a show of power. Those who experience and react situationally with emotion are often branded—the “feminist killjoy”, the “angry black woman”—but these stereotypes, replete with emotion, are in fact demonstrative of “political struggle” (2010, p. 39). There are further germane aspects I borrow from affect theory, including the idea that “persistent, repetitious practices of power can simultaneously provide a body (or, better, collectivized bodies) with predicaments and potentials for realizing a world that subsists within and exceeds the boundaries of the norm” (Seigworth & Gregg, 2010). Thus, disabled people, people who have experienced pregnancy, and others whose bodily experiences have fallen outside of what is discursively framed as the ‘norm’ can more readily imagine the potentialities for a different, more inclusive and accessible world. Dion Million’s *felt theory* is also salient: She argues (speaking of Indigenous women) that to write and speak from lived experience, from knowledge that is felt as well as known, provides richly layered stories that are dangerous to power, and this is why these voices are often suppressed (2009, p. 54). Indeed, many argue that for vulnerable or taboo topics in particular, there is a critical need for the researcher to be “emotionally attuned” and “sensitive to the needs of the participants” (Carroll, 2013, p. 548). Ultimately, I cannot even express how useful my lived experience of pregnancy and prenatal testing has truly been to my work on this project.

I acknowledge, therefore, that my own subject position affects my approach. I do not subscribe to the positivist idea that one can ever be free from bias; I would argue, in the tradition of feminist research in healthcare for people with female-sexed bodies, that researchers must find rigorous approaches to social science research by seeking diverse voices and being explicit in declaring their own subjectivities (Sobnosky, 2013). In my own case, this means I have been

explicit both here and with my participants about my position as a biological mother with experience of prenatal testing. Before starting, I anticipated potential challenges including my own outsider status in certain communities and potential language barriers in meeting with diverse participants. Indeed, I think these challenges proved to be limitations of the study, because my self-selected participants did not include people with language barriers. I think that in order to reach these participants, the study would have needed to employ translated posters and interpreters, something not feasible within the scope of this work. I also anticipated that some people would be reticent to speak to me due to cultural taboos around speaking about pregnancy and termination. This may well have occurred, but unfortunately it is impossible for me to know what barriers may have prevented people from self-selecting. I did find, however, that those participants who reached out were mostly very eager to tell their stories, and I had a strong sense that the taboos around pregnancy and women's health, and indeed, motherhood, have left very few avenues for pregnant people to tell these stories.²⁰ It is clear that one of the taboos that prevents us from speaking is the culturally pervasive notion that to criticize any aspect of the experience of motherhood is to criticize our children. But motherhood (which is the way participants identified) is also difficult and often very poorly supported. The act of communicating these stories often seemed cathartic, and participants, protected by anonymity and probably by our relationship as strangers, were very open about their experiences and feelings.

²⁰ It is also possible that people who self-selected to participate had worse experiences than average. Certainly, I had several people reach out to me with long e-mails that detailed their desire to participate because of their experiences. Anecdotally, I doubt it is the case that the participants in this project had a stronger than average desire to tell their pregnancy stories, because the desire to share on this topic is something that I have frequently observed in my private life, both as a mother and a pregnancy researcher. People need to talk about this!

Before proceeding to outline this method, I would like to offer a few specific notes on my own experience which have affected my views and approach:

Pregnant Embodiment.

As previously noted, there has been a strong emphasis in feminist pregnancy literature and activism on highlighting pregnancy as a ‘normal’ state, in opposition to pervasive cultural views of pregnancy as risky, or as illness requiring medical expertise and surveillance (Barker, 1998; Keating & Fleming, 2009; Murray-Davis et al., 2012; Saetnan, 2000; Warren & Brewis, 2004). I wholeheartedly understand where this comes from and why it has been necessary, in the face of patriarchal and profit-driven medical authority. The entrenched view of pregnancy equating illness or constituting risk has contributed to any number of practices which have caused trauma, including separation of mothers and babies in hospital, and unnecessary and cascading interventions such as overuse of medications, forceps, and surgeries (Keating & Fleming, 2009; Parry, 2008; Rushing, 1993; Vedam et al., 2012; Worman-Ross & Mix, 2013). As I also argue throughout, the framing of pregnancy as risky and its medicalization is used to justify sacrificing the mother’s experience, or shaping it in profound ways. However, my own experience has led me to conclude that this idea of pregnancy as ‘normal’ and ‘natural’ is operating as a form of strategic essentialism, meant to combat the view of pregnancy as an abnormal condition requiring medical intervention (Phillips, 2010). This insistence on “normalcy” can unintentionally mask and erase the pain and the labour of pregnancy. For me, pregnancy often felt quite unnatural, and certainly did not always feel ‘normal.’ I experienced very low blood pressure which made me extremely lightheaded, nausea and vomiting, severe heartburn, pelvic pain, numbness/burning in one leg, frequent urges to urinate, exhaustion, anxiety, and migraines. Much like other bodily functions including ovulation and menstruation, pregnancy is not an illness, but it can feel like one. Many participants reported suffering and pain

with pregnancy and childbirth, and some reported that pregnancy complications required later interventions such as physiotherapy and surgeries. My experience leads me to believe that this pain and the labour involved in feeling ill must be recognized, especially in the context of this project in which I examine pregnant people's resistance to and/or compliance with medical authority. In the literature, the idea of pregnancy as normal or abnormal always seems to be a binary between biomedicalization on the one hand and empowering mothers on the other, but compliance with medicine seems quite natural in a context in which we are feeling ill and/or in pain (Keating & Fleming, 2009; Parry, 2008; Warren & Brewis, 2004). I am not sure I was always able to separate my midwife or doctor's concerns for my health from concerns for the health/ well-being of the fetus. Moreover, worries about the health of the fetus, in a context in which the pregnant person is already potentially feeling unwell themselves, seem reasonable.

Decision-Making and Trauma.

In the late 1990s/ early 2000s, feminist scholars such as Bonnie Burstow pioneered new trauma theories which challenged the psychiatric definition of Post-Traumatic Stress Disorder (PTSD) previously outlined in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, published by the American Psychiatric Association. They assert that much in the way soldiers returning from armed conflicts have experienced PTSD, so women and trans people and members of minority groups experience trauma from experiences ranging from sexual violence, to collective and/or intergenerational trauma as a result of violence enacted against their communities (Burstow, 2003). Furthermore, the term "obstetric violence" is increasingly being used to describe the ways in which pregnant people are traumatized by their medicalized experiences of labour (Cohen Shabot, 2016). These are the types of experiences to which I refer in use of this term.

One of the effects of my personal experience of pregnancy is that I am now seeing a strong link between decision-making and trauma. Simply put, many of the decisions we make during pregnancy have the potential to lead to trauma. Quite besides the obvious major decisions regarding termination, many of the smaller decisions made during pregnancy can lead to trauma, even when the parent feels subsequently that it was the best decision. For instance, in North America, we have extremely high C-section and surgery rates. These rates are reflective of over-use of surgery, but even when a C-section is necessary and life-saving, it is an intervention that can be very challenging for the parents and baby. My own experience with my first child was a medically recommended C-section for breech position combined with high birth weight. I regard the decision to have this surgery as necessary and I do not regret it; nonetheless, it led to trauma. As a result of C-section complications, I experienced a long separation from my first son immediately after his birth, and I was overly medicated and dealing with side effects of anaesthesia. Despite the passage of time after his birth, I would see filmic representations of alert mothers holding their newborns immediately after birth, and I would ache for those moments that I lost. I am sure these feelings are augmented by a sense of what is 'normal,' and this underscores how medicine freely undermines certain norms while trafficking in others at the expense of those norms. The norm of risk mitigation outweighs all else, including and especially the norm of having a certain type of birth experience.

There is an important link, therefore, between the concept of informed choice (or consent) and trauma. I would argue that we cannot really make an informed choice when it involves choosing potential trauma we have never experienced before, a point which is likely

true for every medical intervention.²¹ The very idea of a patient having informed choice or being able to give informed consent to a medical intervention they have never experienced is, in a sense, impossible, and therefore we are continually operating in a mode of doing the best we can. Decisions such as giving children for adoption, surrogacy, and surgery that will require separation from our children are especially tricky; there is such clear potential for trauma, even in the absence of regret. The decision to undertake prenatal testing is also like this, in my opinion. We cannot know how we will feel about uncertain results or ‘positive’ tests without having experienced them. I conclude from this that it *is* paramount for pregnant people to make their own choices, but also that we must do much more to provide adequate ‘information’ about these choices, including expanding our approach to affective explanations of potential anxiety and trauma. Furthermore, we must do more to prepare for the unexpected—including providing therapeutic resources for pregnant people if and when they do experience anxiety or trauma. None of this was done for me and very little of this support was offered to most of the pregnant people I interviewed.

These insights from my personal experience mean that I have taken the ethics of interviews with pregnant people, as a vulnerable population, very seriously. Not only for Research Ethics clearance but for my personal standards, I feel it is critical for a researcher in this area, asking about these sensitive and personal topics, to provide the participants with a clear outline of risks and benefits, and to provide resources in case the interview causes a renewal of experiences of trauma.

²¹ Indeed, my second Cesarean felt like a much more informed choice, simply because this time I knew what I was getting into. I think knowing the potential outcomes of our choices can have an empowering effect, even if we cannot really avoid those choices.

Ableism.

One final area in which I would like to briefly comment on my own experience is in terms of ableism. As previously mentioned, I underwent prenatal testing with my first son. This testing was more extensive than what is usually done because of a ‘positive’ nuchal translucency ultrasound. Although I complied with many doctor-recommended tests, there were some prenatal tests I refused, because of the higher miscarriage risk, but also because the number of tests began to constitute a significant burden to my well-being. Two salient observations from my own experience: First, the doctors couched all results in language of liability, making sure we knew that just because the testing had not turned up something ‘wrong,’ did not mean the fetus was ‘healthy.’ This language of liability demonstrates Foucault’s argument from *Abnormal* that medicine and law work in conjunction to codify medical decisions as potential legal ones, aiming to prevent or forestall the need for correctional procedures through early identification of potential monstrosity (Foucault, 2007a, p. 55). My second observation is that with every test, I was told what to think about the results. ‘High-risk’ results were accompanied by hushed tones and words like ‘concerning.’ Low-risk results were accompanied by smiles, words like “Congratulations Mommy and Daddy!” and “reassured.”

At three weeks of age, our son became extremely ill and had to be rushed to the hospital. He was diagnosed with a heart condition, on which I will not elaborate for the sake of his privacy. I spent two weeks in the hospital at his side. To this day, I do not know if there is a connection between his heart condition and the ‘positive’ on his nuchal translucency ultrasound. I do know that his heart condition made me confront my own ableism in a profound way. I have now spent a significant amount of time in the Children’s Hospital of Eastern Ontario (CHEO), not only when he was being diagnosed but also for follow-ups. My son has had other minor health problems as well, including infant hip dysplasia which required him to wear a little

harness around his legs. I have been surrounded by children with the very health conditions that prenatal tests look for, such as Down syndrome and cardiac conditions. This has had a profoundly normalizing effect for me. I see these children and their parents, and their love for one another. My son, who has required significantly more care than I might have expected based on our cultural imaginary of “normal,” is the light of my life. These experiences have profoundly impacted my conclusions regarding health. As many critical disability scholars have argued (Erevelles, 2011a; Garland-Thomson, 2012; Lupton, 1999), everyone in the world will have health problems at some point, and yet we have an obsessive cultural discourse which requires babies to be ‘healthy.’ It is true that caring for a child with health problems is extraordinarily difficult. I think it is also worth noting that caring for all children is difficult—especially in Canadian society which segregates children into different social realms of society than ‘working age’ adults, and has incredibly poor supports for mothers. The obsession with infant health, and the conflation of health and ability, is responsible for significant numbers of prenatal tests, and for anxiety that I do not think is necessary. This is not to discount or erase the material aspects of disability, including pain (Magnet & Watson, 2017), financial difficulties, or lack of resources and support, which make fear of parenting a disabled child in some ways reasonable, and on which I elaborate further in Chapter 6. I offer my own experience as background to my conclusions in this regard because it could not help but influence my approach as a researcher. Through my work on this project, and my own experiences as a parent, I have become deeply convinced that prenatal testing is a biopolitical technology that enables eugenics.²² I also have significant empathy for parents making difficult decisions, whatever they choose.

²² It is also worth noting that because of the changes in my own beliefs about this over the course of this research, I refused Integrated Prenatal Screening with my second son. This caused a lot of problems during my pregnancy, as the medical team had no ultrasound-based dating to rely on and were very reticent to trust my knowledge of when the pregnancy had begun.

Recruitment and Ethics

For this project, I interviewed 18 participants in order to seek a breadth of voices while keeping in mind feasibility within the scope of a doctoral project. Through these interviews, I learned how the participants experienced prenatal testing during their pregnancies, and how discourses of risk, self-care, and disability affected their decisions. Because the goal of the project was to understand engagement with prenatal testing, people who opted out of it were included in recruitment (participants were asked to self-identify as people who were currently pregnant or had experienced pregnancy in the last five years). What was essential in recruitment, consistent with Smith's (1992) approach that considers the variety and individuality of pregnant people's experience, and with the principles of intersectionality (Crenshaw, 1995), was to consider how to potentially include diverse voices within the study, especially considering my own subject position. My discussion of my subject position has included an overview of my own experiences with pregnancy and prenatal testing, since they influence my approach. It is also important in terms of interviewing to note some of the ways I have experienced privilege, for instance because I am white, generally able, heterosexual, cisgender, well-educated, and had my children as a married adult. I situate my subject position because privilege has the potential to act as a blind spot, obscuring questions or experiences that could emerge for someone with a different subject position. It also has the potential to create unintentional hierarchies. This is a potential limitation, which cannot be altered, but I was conscious during recruitment and interviewing of including participants with diverse perspectives, treating participants with sensitivity, respect and reciprocity to minimize hierarchy; and asking open-ended questions. Still, it is difficult to know what was missed because of my own privilege. On the other hand, I have also experienced financial struggle, which has certainly made me more attuned to class struggle and the material realities which surfaced in participants' fears about disability.

In order to recruit diverse participants, I used a poster in locations such as family doctors' offices, midwifery clinics, community centers, coffee shops, libraries with programming for babies and toddlers, and Planned Parenthood. I also used an online recruitment message in social media parent groups based in Ottawa, an especially important step since many people with disabilities and new parents are more active online. In hanging the posters, I paid attention to neighbourhood diversity, as well as placing it in medical centres frequented by racially diverse and low-income people in Ottawa, such as Appletree Medical Centres, Somerset Community Health Centre, and the Wabano Centre for Aboriginal Health, which is a health clinic serving Indigenous people in Ottawa.

Initially, my intent was to conduct interviews by whatever method was preferred by the participant; either in person, or by telephone or videoconferencing. However, only two were conducted in person before the COVID-19 pandemic became a concern, and therefore the rest were conducted through telephone or videoconferencing, according to participant preferences and technological limitations. With consent, interviews were audio recorded and transcribed. The question list and guide for participants are included as appendices. Participants were offered the opportunity to view their transcripts and to redact them if needed, and to follow up if they wished.

This project was approved by the Carleton University Research Ethics Board. My application recognized my potential participants as members of a vulnerable population due to the rapid physical changes they experienced, the emotional nature of the topic, and the exhaustion of pregnancy and new parenthood. Pregnant people, and those in the post-partum phase after birth (which depends on the individual and can last a long time), are often dealing with issues such as lack of sleep, depression, adjusting to their new role, and/or isolation, which

meant an increased sensitivity was necessary. In my application, I outlined my strategy for mitigating these risks:

- 1) By offering a question guide (attached as an appendix) which the participants could use to get a sense of the interview beforehand
- 2) By offering an opportunity to respond in writing if they anticipate any topics being difficult to speak about by phone or in person.
- 3) By inviting the participant to choose the type of interview (phone or in person).
- 4) By ensuring confidentiality.
- 5) By reminding the participant of their right to end the interview at any time or skip any question.
- 6) By providing participants with a list of local resources, should they need to speak with a mental health professional about their experience.

As a researcher, I recognized the risks to the participants' emotional well-being. There is certainly potential for pregnancy, prenatal testing and birth memories to be traumatic. However, from an ethical perspective, this type of interview is important for several reasons. One, as outlined in my ethics application, is that there can be a therapeutic effect to speaking about one's experience, having someone empathetically listen, potentially identify with it, and validate its importance. This is a potential benefit to the participant. From a broader perspective, these types of stories about the anxieties faced during prenatal testing, and potentially difficult decisions based on prenatal diagnosis, and the sense of responsibility felt by parents for outcomes, are not frequently told. These stories have the potential to form an important and valuable cultural narrative. Furthermore, when these stories are not told, our understanding of prenatal testing is

largely formed from authoritative perspectives. This research provided an opportunity to hear the patient side of prenatal testing, rather than the perspective of the medical community.

I did have two participants who requested to respond in writing, as well as two who expressed interest but ultimately decided not to participate. I have also mentioned before that I saw my own subject position as a potential asset in terms of being able to offer participants a great deal of empathy, having recently experienced pregnancy and prenatal testing myself. I think my own experience did prove to be an asset in many ways, but I also personally experienced it as a limitation. I began the online section of my research in tandem with beginning recruitment for interviews, but found that the intensity of my feelings in response to the online findings had the effect of halting my recruitment efforts. Though I am not disabled, this deep dive into ableist thinking produced a strong affective response in me. The research produced anger, and grief, and rage, and I think a sense of lost innocence. I felt angry about the medical institutions who dismissed these commenters, and at the pervasiveness of the discourses that disabled people don't matter. As my pace slowed, and I focused on other work, I found some solace in the idea of "crip time," which has been theorized by several disabled scholars. For instance, Ellen Samuels notes that crip time is slower (in part, because it can take longer to do things when you are disabled), but also that crip time slows because it is about coping with loss—of physical function, of people, of belief in the systems around us (2017). Thinking about crip time also challenges the productivity norms of capitalism (Kuppers, 2014). I had to accept that it was going to take me time to process my affective response to what I was seeing online, and that the length of time it took could not be dictated by the institutional norm of how long it is supposed to take to write a dissertation. It took work and time to get to an emotional state where I was ready to undertake recruitment for interviews more seriously. I also would surmise, based

on this experience, that the academy needs more disabled researchers—both for projects about disability and for projects not about disability—because they will bring a perspective that non-disabled researchers cannot bring. They may also see and challenge norms around productivity and time that need to be challenged, but which are normalized to the point of acceptability in the minds of non-disabled people.

I also had ongoing personal experiences that affected my work, and which I include here (despite the sense of personal vulnerability) because many researchers do work with which they have personal connections, and therefore may be able to glean insights into how personal and affective experiences can impact method. When I began this project, I did not yet have personal experiences of prenatal testing and pregnancy. My personal experience of my first pregnancy occurred concurrently with writing my comprehensive exams and a grant proposal, which was very difficult timing, as the research pushed me to reckon with the ableist nature of these tests as I was personally undergoing them. By the time I was seriously recruiting and beginning the bulk of my interviews, I was pregnant again, and I experienced a miscarriage during the height of my interviewing process. I took very little time off, and I actually found the experience of continuing my interviews, transcribing, and writing my interview chapters to be cathartic and worthwhile, as I was grieving and healing from my lost pregnancy. I also noticed something striking as a researcher: I conducted the interview with Lisa, who had experienced five miscarriages, in September 2019. I did not transcribe it until March 2020, a month after my own miscarriage. When I played that interview recording back, it felt to me as though it had been conducted by someone else. I found myself annoyed with the interviewer for not showing greater empathy and compassion. I think this speaks volumes about the way our lived experiences change us and affect our work. I do not think a single question I asked would have changed because of my

experience; but my tone would have been a little different, as well as my responses to what she told me, and when someone is offering us their vulnerable experiences, tone and empathy can make a world of difference. I also cannot speak to whether Lisa was negatively affected by my lack of personal experience of what she had gone through—but I know that I would have been a better interviewer after it.

Limitations

Qualitative interviewing, while incredibly useful for understanding the affective nature of the topic and the depth of the issues, may also miss some of the breadth of the topic due to the limited scope of interviews. The use of multimodal methodologies was devised as one way to partially account for the diffuse nature of discourse and address diversity concerns by examining multiple sites of analysis. Interviews of people in my local area elicited an in-depth picture of the way people are experiencing prenatal testing, how they are making decisions, and how discourses regarding disability have affected them. Meanwhile, turning to online sources allowed me to broaden the research findings beyond my local area, and extrapolate from the particular into a more general idea of discourses of prenatal testing. This allowed me to get a sense of how Ottawa-based pregnant people fit into the broader discourse. Among these findings was that universal healthcare vs. private insurance (or lack of insurance) plays a major role in experience. I think it also confirms previous findings (see Rapp, 1999) that concern for able and healthy babies is higher among white and otherwise privileged populations; this is evident from both the composition of participants in my own study, and the online commenters. Most of my participants were white and well-educated, and there were markers of privilege in many of the online comments, on which I elaborate in Chapter 3.

Interviewing Methods and COVID-19

As mentioned, because of the COVID-19 pandemic in 2020, a higher number of interviews than I initially anticipated were conducted by phone or videoconferencing software. In some of these, video was enabled so there was more of a feel of an in-person meeting. Those, like the phone and in-person interviews, were audio recorded. There were also a couple of participants who requested to complete their interview in writing, rather than through an interview. In these cases, subsequent to permission from the Research Ethics Board, the interview question list was modified to be more user-friendly and then emailed to the participant to complete at their leisure. These did not result in the same depth of responses, but I felt it was important to accommodate requests for data capturing that the recipient felt comfortable with, and that it was better to capture their experience in some way than not at all. In total, there were two interviews conducted in person, four through Google Hangouts or Facebook Messenger video calls, one written, and the rest by phone.

COVID-19 complicated the process of scheduling interviews because I did a large number of them when Ottawa was in a pandemic lockdown. Schools and daycares were closed, and many of the people I spoke to were parenting from home while their partners were either going to work, or holed up in home offices, working. Some of the participants were, like me, working from home while parenting children at home (often several children, and often newborns). Because none of us could use childcare services at the time, many interviews took place either during our children's naps, or after we had put our children to bed. Sometimes they were rescheduled because 8:00 pm is an exhausting time for parents of small children, or interrupted and restarted to allow time to settle babies halfway through. I think these challenges are worth noting as particular to this type of research, because of the demographic of people being interviewed. Even without COVID-19, seeking voices from outside institutions can come

with complications that are not necessarily present in interviewing people in the context of their work; it is not necessarily going to happen on a 9-to-5 schedule, and it is often going to require greater researcher flexibility.

Chapter 3:

The Search for Support and Countering Eugenics: Online Engagements with Prenatal Testing

Coping with Prenatal Testing: Forum posts

Websites such as WhatToExpect.com and BabyCenter.com have become rich sites of engagement with issues of prenatal testing. Throughout many stages of parenthood, users come to these sites, which are international and often have country-specific versions, clearly seeking community, reassurance and information. There are threads in these sites focused on a myriad of issues, from discussions of conception to understanding early childhood milestones. There are large sections focused on complications of pregnancy, including diagnoses and screening results indicating potential disabilities.

These forums are open to the public and the users are anonymous. Users must be registered in order to begin or comment on forum posts, but these posts can be openly viewed and are searchable through common search engines such as Google. This means that people unfamiliar with these sites can easily stumble upon them when conducting searches related to their own diagnoses and/or screening results. For instance, when I searched “high nuchal fold measurement” in Google, the first hit I got was BabyCenter.co.uk²³. Internet searches for information are an obvious first step following an uncertain and/or unwelcome screening result, and therefore sites like BabyCenter or What To Expect may be a first source of information, perhaps after or concurrent with primary medical sources such as doctors and midwives.

²³ This is significant because of how Google’s algorithm ranks webpages, with pages appearing high if they are linked to more frequently, but also because, from a user perspective, if the webpage appears high in the Google search results it will likely be an entry point into the topic for many users.

In order to address the research questions outlined in Chapter 2, I conducted Foucauldian discourse analysis of pages captured from these forums, mostly from 2019, using the US (.com) websites.²⁴ These sites contain many years' worth of conversations, and therefore for the sake of feasibility, the quantity of information needed to be delimited. I chose WhatToExpect.com and BabyCenter.com as sources for capture for two reasons. One is that these sites are both extremely prominent. Both appeared in the first page of Google results for many search terms I tried, such as "Advanced Maternal Age" or "Nuchal Translucency Ultrasound." They also both have an international presence. Simply put, the wealth of information contained in these sites and the fact that they are a primary location of inquiry for many pregnant people made them clear choices. The second reason is that neither of the sites' Terms of Service explicitly forbid the reproduction of information contained on the sites for research purposes. While I think it unlikely that many users are reading the Terms of Service in detail, I still preferred, from an ethical perspective, not to use any site which explicitly banned reproduction of community posts in other areas.²⁵

However, as mentioned in Chapter 3, I am also aware that it is unlikely that many forum users would have an expectation of having their words reproduced in a research context. I have therefore made efforts to respect these users' privacy by not creating explicit ties between my

²⁴ These versions were chosen because they are used throughout North America, and Canada is the site of the primary research done for this project—thus the experience of the online users was likely to be more similar to the interview participants, since they are functioning within a similar healthcare context and culture. It is worth noting, of course, that healthcare is funded quite differently between Canada and the US, which can have a significant impact on experiences of pregnancy.

²⁵ It is also worth noting that there is an extensive description in the Terms of Use for these sites (BabyCenter.com, 2019; WhatToExpect.com, 2017) of prohibited activities, including making vulgar or 'offensive' statements. As I will show, there are probably very different expectations of what would constitute such behaviour on different forums, as moderators are probably only entering to evaluate comments after users report statements that they find offensive. The standard for offensive remarks would therefore vary and be established by the community and dynamic of a particular forum.

reproduction of their words, and the original placement in the online sites. Given the extreme sensitivity of the subject matter I am sometimes quoting, I am not directly attributing any quotes to a specific forum page, but simply offering a general attribution (for instance, “WTE” for “What To Expect,” or “BabyCenter,” and a year.) In some places, where the information discussed is highly sensitive, I have also slightly altered the specific phrasing, or paraphrased rather than quoting. This is in recognition that while I do not know the users or their identities, these are still their real stories, which they have presumably offered to internet-based communities with similar experiences. In some places, I do identify that these stories contain ableist attitudes or misinformation. I have attempted to do so without placing blame or judgement on any individual user—these attitudes are a product of broader ableist discourses, and sometimes general misinformation within society. These attitudes are therefore, in a sense, unsurprising. They are also worth examination, because they demonstrate how these discourses are reproduced through everyday interactions, and they provide evidence of the way pregnant people are experiencing prenatal testing and approaching decisions based on its outcomes. I proceed, therefore, to describe some of the principal recurrent themes found in these forums:

Seeking reassurance: Dealing with fear and anxiety

The most common motivation expressed by users for turning to the Q & A forums was to do with coping with fear and anxiety. The frequency with which these emotions were mentioned, the prominence of them (anxiety was often in the forum title), and the type of queries (usually very specific) often suggested turning to these online forums as a type of online community. Users were usually very specific about the types of reassurance they were seeking from others on the forum; often, they were looking for others who had received similar screening results, and had subsequently had positive outcomes (“healthy babies”). There were also some who had received unwelcome diagnoses and were coming to terms with them as well as looking for others

who reported positive experiences about similar diagnoses. These positive experiences might include receiving a screening result with a high chance of an unwelcome outcome, but everything being “fine,” or getting a diagnosis of disability, and actually finding the experience to be fine or positive. Finally, many were simply looking to commiserate with other parents who had also experienced fear, sadness, and anxiety related to waiting for tests, or receiving inconclusive or unwelcome test results. Many of these queries suggested, either overtly or not, that the user felt unlikely to find people who had similar experiences and understanding among their ‘real life’ acquaintances, and therefore they were turning to these wider online communities.

It was clear from reading through these requests for information or reassurance that these users were, for the most part, extremely well informed about their tests, the limitations of the tests, and their fetal screenings and diagnoses. It was also clear that most users expected others in these online communities to also be very well informed. Users often employed medical language and acronyms, often without explanations, suggesting that they felt audiences would generally understand, or at the very least, be digitally literate enough to find the answers through Google searches or similar means. For instance:

They think baby has a hole in the heart but because of the position of the baby they couldn't fully determine if it was a ventricular septal defect (VSD) or an atrial septal defect (ASD). ...In addition our little bugger has only 1 umbilical artery which they said can be problematic when the baby also has a VSD/ASD. And if that wasn't scary enough they said in some scans our baby's Nuchal fold measures normal but in others it was slightly bigger than it should be. We didn't do a Nipt [*sic*] test so we don't know if there are any genetic issues. (WTE, 2019)

In this query, one can clearly see that the author’s doctor has offered a very clear and detailed understanding of the potential issues, and that the author anticipates other forum users will understand what an enlarged nuchal fold indicates (it is a ‘soft marker,’ meaning an increased likelihood of chromosomal disorders), as well as the meaning of NIPT (Non-invasive prenatal testing). Many users employed such medical terminology, with many shorthands and acronyms employed throughout the sites, for example, there were frequent references to “T21” (Trisomy 21) for Down syndrome, or “MFM” for Maternal-Fetal Medicine specialist.

It is noteworthy that this high level of familiarity with medical information did not seem to reduce anxiety (which might be expected, given previous literature showing that people are often motivated to do prenatal tests from a sense that it may reduce their anxiety [Gentile, 2013]); in fact, detailed explanations of diagnoses and screening results were often paired with expressions of fear and anxiety, such as: “They’re saying our baby had a complete AV Canal defect, Double Outlet Right Ventricle, and Pulmonary Stenosis... This weekend we were both a mess just finding it hard to take it all in...” (WTE, 2019). Another user on What to Expect offered a long paragraph explaining their medical situation and commented, “I feel like I’m living in my two week intervals of seeing MFM and just when I get excited tests came back positive there’s more to do” (WTE, 2019). At the same time, the user also indicated ambivalence about the testing, which they described as difficult for the mother, but in the best interest of the child, “Ultimately I’m happy my son is getting the best care and so much diligence on his testing. But boy is this rough on mom” (WTE, 2019). This suggests the deeper anxiety at the root of why pregnant people are subjecting themselves to so much testing, even though it functions as a cause of anxiety—the testing is viewed as having the potential to alleviate fears regarding

disability. There is also a clear sense here of the mother feeling responsible to the fetus, a theme which will be further explored.

Overall, expressions of fear and anxiety were commonplace, as demonstrated in these excerpts from What to Expect forums (2019):

- The waiting is excruciating. I'm consumed with fear about what I'll do if it's a bad result, especially at such a late gestation. I constantly think about the worst possible outcome.
- Doctor said it was concerning which is why he sent us to a genetic counselor.
- I'm so sorry you're having to go through this, I know the pain all too well.
- Needless to say, I'm quiet [*sic*] shaken.
- Today we got some very frightening news and I am devastated [*sic*]... I know it's quite unlikely but has anyone had a positive outcome/delivered a healthy baby from results like mine?
- How do you stay calm and not drive yourself crazy waiting for results?! I'm going out of my mind and google [*sic*] isn't helping. This has been the most anxiety driven week of my life...

As in the above comments, the word “devastated” was routinely used to explain the user’s feelings after receiving a diagnosis; the word “excruciating” or similar words were often employed to describe feelings while waiting for results. There were frequent expressions of empathy from other users, responding to the pain, anxiety and stress expressed by those making the queries. Several of the above comments also denote disablist²⁶ attitudes (J. Dolmage, 2014), for instance the above comment in which disability is the connoted “worst possible outcome.”

²⁶ Dolmage differentiates disablism, as opposed to ableism, as a negative construction of values and material circumstances of people with disabilities. Ableism, according to his definition, positively values and renders ability compulsory (2014, p. 18).

Ableism is present, again, in the association of “positive outcome” and “delivering a healthy baby,” as well as a reinforcing of the binary that “health” is accepted as the opposite of chromosomal abnormality. As people unquestioningly reproduce this binary, there is a failure to recognize the social model of disability, and our cultural failure to accommodate difference—blaming the difficulties of disabled people instead on their bodily impairments (Oliver, 1996).

In terms of seeking reassurance, another feature of these forums was the formation of sub-communities around similar experiences and almost pre-vetted attitudes. These communities have developed their own languages, some of which have actually been algorithmically encoded by the host websites (presumably after a pattern of abbreviations was noticed among commenters). So for instance, users will often use the acronyms “DH,” “DS,” or “DD,” to refer to family members (respectively, standing for Dear Husband, Dear Son, and Dear Daughter)²⁷, and the forums sometimes include coding which will translate these acronyms for users who might be new to the forums (with the long version, e.g. “Dear Son,” thus appearing after the acronym in parentheses that are grayed out to show they are not part of the original comment, but a clarification generated by the website.) This community lingo provides a shorthand to understanding the demographics of community membership; it also certainly denotes a community largely composed of cisgender, married heterosexual women (for instance, there is no “DW” or Dear Wife acronym, or “DP” or Dear Partner, from my observation).

Within these forums, sub-communities had also clearly formed, in which there was an expectation of like-mindedness, and some were heavily moderated. For instance, a forum on BabyCenter.com which was specifically for people who had terminated pregnancies due to Down syndrome had a distinct sense of exclusivity. There were multiple posts that had been

²⁷ These acronyms are common throughout online parenting communities.

removed, and replaced with messages indicating their removal by moderators, often followed by comments by other users expressing relief that the moderators had removed these messages, clearly deemed inappropriate for this space. In other words, it seems likely that messages expressing judgement about termination were unwelcome within these forums. Just as in the larger sub-communities, forums about termination had their own euphemistic lingo:

Terminations were referred to as “Tx,” and diagnoses as “Dx.” This forum had also clearly not been considered by the writers of the overall BabyCenter.com translation code, since DS was still being translated as (Dear Son), although to confusing effect, since in this context, it clearly meant Down syndrome.

The termination support forums contained some of the most overtly ableist messages I came across. It was clear to me that many of the people posting on the forums felt ambivalence about their desire to terminate, and that they were therefore ‘justifying’ their decisions through lengthy descriptions of Down syndrome as an unliveable condition. Often, their comments seemed to directly express sentiments regarding people with Down syndrome leading less productive or valuable lives compared to an able norm: “The worst thing about DS is mental retardation—a person will never be independent! And you can cope as a parent of a baby but then it gets more and more difficult, with no good outcome!” (BabyCenter, 2015).

It was clear from many of the posts that these were deeply felt, deeply difficult decisions for those who had terminated or who were considering termination, as will be further explored in a later section. What was especially noteworthy here, however, was how ableism in itself had become a mode of seeking and offering reassurance within the context of these termination boards. For people struggling and feeling a sense of needing to justify their decision, they were asking for others to confirm their conclusions that a Down syndrome diagnosis was a good

reason to terminate a pregnancy. Once again, there was also a sense of the members of the forum being highly informed about the science, with some members even copy-pasting large sections of scientific articles describing the prognoses for Down syndrome:

This latest study shows that dysfunction at the input synapses of the hippocampus propagates around hippocampal circuits in the mouse model of Down syndrome, resulting in unstable information processing by place cells and impaired learning and memory. Over the course of a lifetime, even subtle impairments of this type will profoundly influence intellectual abilities. (O’Keefe cited in BabyCenter.com, 2019)

This scientific description of Down syndrome diagnosis thus functions as a form of othering, or as Savage puts it, providing a “literal, ‘scientific’ reason as to why outgroups were inferior and other-than-human (legitimizing their destruction) as well as threatening (necessitating it)” (2007, pp. 404–405). We see biopolitical reasoning thus infiltrating individual decision-making, and ableist discourse reproduced as a justification that is clearly important to the commenter. The desire to share publicly and seek reassurance or agreement from a likeminded peer community also suggests that we are somewhat deceiving ourselves about how “individual” these decisions really are; it is clearly really important to many of these forum users to find others who can back up and justify their choices. The choices are not made in isolation but in a discursive context, and there seems to be a strong desire to have the choices backed by community. This also explains why we also see a sense of protected space, since presumably dissenting opinions about termination have been removed. The normative thrust of opinion in these spaces was that terminations due to diagnosis of disability are the correct decision, and those in disagreement (presumably anti-abortion advocates) were quickly shut down.

A New Hope: Non-Invasive Prenatal Testing (NIPT)

A significant finding of this research is that NIPT has changed the way people are experiencing pregnancy. This was occurring in the forums in a couple of ways: There was a perception that the advent of NIPT has made the process much safer for the fetus, and this is a considerable relief to many users, who had experienced anxiety about the miscarriage risk associated with amniocentesis. However, the relatively lower risk of NIPT has also contributed to the sense of inescapability associated with prenatal tests; even prior to its introduction, pregnant people had a sense of prenatal testing as the ‘responsible’ course of action, but the miscarriage risk associated with amniocentesis functioned as a reasonable ‘out’ for those overwhelmed by the process or otherwise disinterested. With the advent of NIPT, that ‘out’ is gone.

Much as in other areas, users had a high level of knowledge about NIPT testing, and this frequently manifested through suggestions that others get NIPT, or assuring others that their results were likely correct if produced through NIPT. For instance, one user responded to someone who mentioned they had not done NIPT: “I’m sorry you’re going through that. Probably a good idea to get a NIPT now since it can take a week or so for the results” (WTE, 2019). It is interesting to note that there is a significant relationship between medical authority and technology, where technology often serves to justify the credibility of medicine, and therefore when medical opinion contradicts the technology, or there were medical recommendations not to use technology, this often undermined the medical opinion in the eyes of the user. For instance, one user commented that their gynaecologist had suggested they not bother with an NIPT test since “it’s not diagnostic so no point.” There was an immediate answer: “I strongly disagree with that opinion. Yes, not diagnostic but at your age and if it’s high probability you’d have a pretty good indicator that baby has Down syndrome or not”

(WTE.com). This response is highly indicative of the degree of trust put in the NIPT test, and the fact that this faith in technology functions as a limit to the healthcare provider's authoritative status.

One user also commented that while they felt reassured by the NIPT test, they were frustrated that their doctor did not seem equally reassured:

We had two markers at our 21 week ultrasound which was end of November including pylectacis of the kidneys (which I wasn't phased by since my 2nd baby had the same) and a thicker nuchal fold, which they made it sound like was very concerning for Down syndrome or heart issues. So far heart has been good and I did NIPT after which was all very low-risk so I'm in this murkey [*sic*] state where my doctor is still acting concerned that baby could have Down syndrome since I didn't do the amnio. Every appt I leave a little more uneasy by how often she brings it up. ...I don't appreciate making every appointment so anxiety filled when NIPT is pretty accurate for Down syndrome and the nuchal fold was only slightly elevated and also passed the ideal measurement timing. They seem to be focusing more on their stats associated with my age (39) than on the facts of my situation. (WTE, 2019)

In this passage, we see how many of the commenter's frustrations with their doctor stemmed from their faith in the NIPT test results; the patient was not overly concerned about the potential for disability largely because these results were reassuring them that the outcome would most likely not be Down syndrome, as well as from their previous knowledge of the limitations of ultrasound. The user, like most, was highly informed about the medical situation and comfortable challenging their doctor's opinion because of this information, which includes the patient's own history and previous pregnancy. The user also expressed frustration about the stress of the

appointments based on what they perceived as statistical likelihood rather than their personal situation. There was a significant backlash here against coercive medical treatment, not rooted in any kind of challenge to the ableist assumptions behind the doctor's treatment (in other words, the assumption that disability is a bad outcome, which the user seems to accept), but in the doctor's assumption that there are grounds for fear of disability and the seemingly lower trust placed by the doctor (compared to the patient) in the NIPT test.

The NIPT test appeared to be a particularly comforting and hopeful development for many users due to the risk of miscarriage through amniocentesis. It was clear that the risk of miscarriage was an area where many users disagreed with the way risk was presented to them. Most users seemed to feel this risk was presented as low, and most did not perceive the risk of miscarriage that way. For instance: "My baby died when I had amnio. I regret it so bad. Doctors and nurses reassured that its low risk. I wouldn't do it if I were you" (WTE, 2019). In this case, whether or not the amniocentesis was the cause of the user's miscarriage (certainly a possibility, with amniocentesis carrying about a 2% risk of miscarriage), that was the user's perception. The user also clearly felt that the risk was underrepresented, whether or not that was in fact the case. Other users responded in a way that shows this was an area where medical authority was often in question: "I don't think I am going to risk it, although my doctors also keep telling me 'it's barely even a risk anymore'... I don't know if I really believe that" (WTE, 2019). These fears were echoed elsewhere: "I am 13.4 weeks pregnant and received a positive result for Turner syndrome with NIPT. I am too scared to do the amniocentesis for fear of having a miscarriage" (WTE, 2019). The miscarriage risk here, with amniocentesis, was clearly high enough to outweigh the biopolitical²⁸ imperative to test, in the eyes of the user.

²⁸ Please see Chapter 1.

The fear of miscarriage through amniocentesis also demonstrated responsabilization of the pregnant person and the operation of governmentality.²⁹ Pregnant people have been so completely conditioned to act responsibly towards their fetuses, whether that is through alcohol avoidance, taking prenatal vitamins, eating healthfully, etc.—with the silent fear of having a disabled child, or losing the pregnancy, through one’s own fault, always in the background. This creates conditions in which prenatal testing has become a ‘must’ (Lupton, 2011), but amniocentesis is potentially a limit to this imperative because it, too, carries a risk that is perceived as significant. There were many comments that made clear that the risk of no baby at all was greater in the minds of the parent than the risk of disability—depending, of course, on the disability. This was especially so for parents who were already older and had either struggled with infertility, or anticipated this potential. These parents were extremely reticent to endanger the fetus, even if the risk was considered minor by their healthcare practitioners, who often seemed more worried about the risk of disability than of miscarriage, which is consistent with a biopolitical view of disability. For example, “It took my husband and I four years to finally get pregnant, and needless to say, I’m quiet [*sic*] shaken. Anyone in a similar situation?” (WTE, 2019). It was very clear within the comments that a part of what the commenters feared was the sense of responsabilization (Rose, 2007); there was some comfort in the idea that should a negative outcome such as miscarriage or disability occur, there was nothing the pregnant person could have done to prevent it. For instance: “My friend was telling me even if the baby has it [chromosomal abnormality] trisomies [*sic*] are due to the way cells divide—it’s nothing any of us have any control over and highly unlikely it would happen again” (WTE, 2019). This comment makes clear both the sense of responsibility felt by the parent, and the subtext that

²⁹ Please see Chapter 1.

termination, followed by trying again to get pregnant, was being considered as a clear option. This subtext became clear later in the comment: “I agree, if the baby has full trisomy we know what we have to do. I feel horrible even suggesting it but the more I read and videos I watch—the quality of life is just so poor!” (WTE, 2019). Again, there was a sense of responsibility for outcomes present in this phrasing; termination was not presented as a choice, but as a requirement: “what we *have* to do.” This is consistent with previous research findings that medical professionals, including doctors and genetic counsellors, often show disapproval when parents choose to continue Down syndrome pregnancies, with many pregnant people being openly chastised for their decisions (Roberts, 2015).

Within this context of responsabilization and fear of miscarriage, NIPT surfaced throughout the comments as a sort of new hope for pregnant people. It was clear that most of these highly informed and well-read commenters understood the limits of NIPT (it is a screening test, not diagnostic), but that the much lower risk of a false positive (0.02% [Taylor-Phillips et al., 2016]), as compared to nuchal translucency ultrasound combined with a blood test (4.2% rate of false positives [Nicolaidis, 2004]), made it feel like a diagnostic test to many users. Many commenters pointed to the high level of trust users had in the test, and many more reported refusing amniocentesis, choosing to believe the results from NIPT. They were also often clearly aware of a further limit of NIPT, which is that it only looks for certain conditions, but many seemed willing to accept these results, even with the possibility that the fetus could have a lesser-known condition, as long as the NIPT produced a low-risk for the common Trisomies. Since chorionic villus sampling (CVS) tests would often be required to find further information, and this test is similar to amniocentesis in that it also requires a draw of amniotic fluid from the uterus (with the same risk as amniocentesis), many seemed reticent to go to this step. I would

venture that the higher acceptance of the unknown in these cases might be because these other potential conditions are generally so rare that most pregnant people do not have a clear sense of what they are. Many of the results that can be found through CVS are also extremely small genetic defects (often a missing or mutated piece of a gene), which often have little or no medical presentation in terms of symptoms—in fact, many of us have these genetic ‘defects’, but would never know it without having been tested.³⁰ These conditions therefore do not seem to present a danger in the mind of the pregnant person in the same way the more well-known Down syndrome or other more common chromosomal abnormalities do.

One noteworthy limitation to the faith placed in NIPT by pregnant people is the perception that all of these technologies, including NIPT, increase the stress and anxiety noted in the first section. One user in particular noted that people who live in societies where prenatal testing is less routine seem to exhibit less pregnancy-related stress: “In many societies NIPT test [*sic*] is not being done, so I am afraid these new technologies in medicine is [*sic*] making me feel nervous rather than making it a smooth journey of my pregnancy” (WTE, 2019). Here the user suggests it is the test itself, and not the risk or chance of having something come up in the test, that tends to produce the anxiety. From this comment I infer that the testing process itself reproduces the ableism that is causing anxiety; as the user indicates, people who are not testing seem to be less worried about the threat of potential disability.

³⁰ Any individual’s DNA will have thousands of minute differences from a reference genome, which after all is just one individual example of human DNA, not “the” representative sample. Most of these minor variations are fairly meaningless, and so medicine is accustomed to tracing a boundary around what “normal” genes look like, and defining differences that fall within that range as normal. For instance, genes for different hair colours are all read as normal. Rare and undiscovered genetic diseases are incredibly difficult to diagnose, due to the possibility of the genetic difference arising from one of any number of thousands of potential anomalies, most not indicative of anything important. As we learn more about the variations in genetic code, the definition of “normal” also expands (National Centre for Biotechnology Information, 2007).

There were also comments suggesting that the prenatal testing technologies themselves are not the only ones responsible for causing anxiety; some users also pointed to Google and the hyper-availability of information as a potential stressor. For example: “How do you stay calm and not drive yourself crazy waiting for results? I’m going out of my mind and google [*sic*] isn’t helping” (WTE, 2019). This sense was also echoed by some users who mentioned that their healthcare providers had attempted to mitigate this anxiety by telling them to stay off the internet. This example is particularly indicative of the complex relationship between the doctor, the patient, and the potential information found through internet searches: “the dr. said don’t google and I ran to my car to google and cry [*sic*]” (WTE, 2019). This comment shows engagement with the doctor’s recommendation: A tacit recognition that internet searches might have negative outcomes, but nonetheless a feeling of this activity as a foregone conclusion. It is not fully clear from this comment what exactly forms the potent allure of Google; is it about access to information? A sense of community? The allure of Google searches as a source of information may also indicate some level of distrust in the medical community or the medical model as a source of information, or it may demonstrate that the pregnant person is not getting enough time with their doctor, or is not comfortable enough to ask them questions. It may also be a question of the accessibility of knowledge and language, despite the ease with which many commenters employed medical terminology.

Prayer and Judgement: How Religious Beliefs Surface in Prenatal Testing Discussions

The idea that the online forums studied constitute communities surfaced in a number of ways. Just as idiomatic short-hands and a sense of “permissible” topics provide many of these forums with a feeling of sub-community membership, so do expressions of religious belief, which are normalized throughout these communities. The significant emergence of this theme

was a surprising element for me; I had not expected such a large number of references to God, prayer, and other religious themes. There were a few types of such topics.

Foremost among these were offers of prayers and requests for prayers. Many of these were non-denominational in the sense that there was no indication whether the people offering these prayers belonged to specific religions or not. Whether this indicates a multi-religious community membership or a Christian majority is unclear, although those comments which did speak specifically to religious affiliation were from Christians.³¹ Further, comments related to prayer were usually connected to non-religious expressions of good wishes; “hopes,” “positive thoughts,” or the like. These sentiments were also nearly always tied to outcomes: Sometimes in a vague way, e.g., “Hoping and praying for a good outcome for each of us” (WTE, 2019), and sometimes more specifically, e.g. “I prayed to blessed with this bub [*sic*] and now I’m praying for a miracle” (WTE, 2019). In almost all cases, the subtext was that disability was unwanted and that the prayers were an effort to ‘do’ something to prevent this outcome. In many cases as well, prayers were freely offered to others, and seemed a mode of offering sympathy and developing community between users.

There were also cases where religious beliefs surfaced as a judgement against expressions of desire to terminate pregnancies, or when users were considering termination. Sometimes these were expressions of judgement from others, for example: “God gives life so let Him take it... dont [*sic*] abort... let Gods [*sic*] plan prevail” (WTE, 2019).³² These instances, when they were left in place by site moderators, were very often shut down by comments from other users, such

³¹ It is not possible to know the cultural nuances of posts. For instance, geographical location or mother tongue. This is a limitation, since there are certainly varying cultural contexts to the posts which may have been missed.

³² It is worth mentioning the possibility that some of these comments have been placed there by anti-abortion advocates, rather than other expecting users.

as “take your opinion somewhere else” (WTE, 2019). What was actually more frequently seen, however, (perhaps due to the anti-abortion comments usually being removed by moderators) were expressions of self-judgement for termination, based on religious beliefs.³³ These comments in particular showed a heartbreaking sense of struggle, where the user’s decisions were clearly going to be taken in contravention to their own professed beliefs, due to their conviction that the suffering of the disabled child would be too severe, or that their own suffering would be too severe if they had to give birth and then watch the child die:

The cvs confirmed t13. I’ve been crying so much I feel like I’m melting into the ground. I am waiting now for an appointment confirmation to terminate. My heart. my baby. god forgive me. The loss seems unbearable. Today i am trying to make my peace with it. [sic] (WTE, 2019)

This comment certainly indicates the complex nature of this decision for the pregnant person, and that only a diagnosis that they perceived as very serious would result in this outcome. It is also important to note here the spectrum of disability diagnoses. Trisomy 13, which the above parent reported as their fetal diagnosis, is a potentially very serious medical condition, also known as Patau syndrome. It is much more rare than Down syndrome and babies born with it are much less likely to live. Ninety per cent of children born with Patau syndrome die in the first year of life. In the context of these poor outcomes, most fetuses diagnosed with Patau syndrome are now terminated. While there are babies born with Patau syndrome who live past the first year (in particular, some who have a variation known as “Mosaic Patau syndrome,” in which only some replicating cells are affected by a duplicate copy of chromosome 13), most diagnoses lead

³³ Each of these websites has a set of community standards which govern acceptable posts. The moderation is done by a team employed by these websites; however, they respond to users flagging particular comments as inappropriate, so essentially it is the community itself that moderates the discussions.

to fetal or infant death. Cases like these complicate the notion that terminations due to unwanted medical diagnoses are only grounded in ableism, as well as the argument that termination due to prenatal testing is always functioning as a modern form of eugenics. Very often in cases like these, prenatal testing technologies allow pregnant people to save themselves the heartache of carrying a fetus completely to term, whilst assuming an outcome of a ‘healthy’ baby, only to give birth to a baby that dies within a matter of days or weeks. In Chapter 2, I discussed Foucault’s identification of discursive categories of abnormality, in which people with disabilities are “individuals to be corrected” (Foucault, 2007a, pp. 55–57), except in the case of babies born with life-threatening conditions: “It is a mixture of life and death: the fetus born with a morphology that means it will not be able to live but that nonetheless survives for some minutes or days is a monster” (Foucault, 2007a, p. 63). I should be clear that I do not think Foucault is saying these fetuses are monsters, nor am I. Rather, they are discursively constructed as monstrous by society. Perhaps this is in part because of the taboos around both disability and abortion; as I speak to further in Chapter 6, I saw some language which was used to distance from these types of pregnancies, even as the so-called “healthy” fetuses were humanized. We are, as a society, very uncomfortable with death, abortion, miscarriage, and the very real materials (or as medicine refers to them, the “products of conception”) that pregnant people must come up close with in these situations. This discomfort makes it that much harder for pregnant people to experience events like miscarriages or abortions. I also want to be clear that I am not arguing that some terminations are more ethically justifiable than others—I am not weighing in on the ethics of any individual termination, because I do see this as a personal issue for each pregnant person to decide. However, without commenting on the individual ethics of any particular person’s situation, there are larger social problems here which strike me as profoundly unethical: For

instance, the failure to financially or socially support disabled people. This is a society-wide problem of course, and one of the ways in which biopolitics effectively casts aside disabled people is by individualizing responsibility. It places the burden of “choice” on individual pregnant people, but that choice is only supported as long as it falls in line with certain norms, and deviations are subject to coercion or outright disallowed—this was clear from both the online research and from the interviews related in the two upcoming chapters. As I have argued, these individual choices exist within the context of larger discursive formations. Individual decisions are not devoid of agency, but nor are they independent of the governmentality and biopolitical techniques in which they operate.

Furthermore, without trying to argue regarding the ethics of any individual choice, a prognosis that a fetus is unlikely to survive does complicate the idea that these terminations are all exclusively grounded in disablist discourse, because these parents are not only facing disability or illness but also profound loss. I cannot speak to what the correct ethical decision is for a parent in this situation, nor can I speak to the correct decision for a parent facing a diagnosis of Down syndrome—each of these parents has their own context to weigh, which includes issues such as their financial situation, other children, and many factors. However, the fact that parents are sometimes facing death and loss demonstrates that this issue cannot be reduced to simply discourse or impairment, as is discussed further in Chapter 6.

Defining “Normal”

It is significant how often the word “normal” is used or implied within these forums. The word is never defined, yet the meaning is everywhere understood, and disability always made clear through both the absence of normalcy, and through either the word “abnormal” or others along the same lines (see, for instance, Titchkosky & Michalko, 2009). Many used the word

normal or a variation thereof to frame their comments, and words that surfaced as the opposite of normal are also highlighted in a few comments below (WTE, 2019):

- Anyone with 3 soft markers and yet went on to have a *chromosomal normal* baby?
- Stats are about 50% for T13 or T18. So far the heart, brain, spine, and hands/feet are *normal*.
- Just need to rule out *chromosomal problems* first.
- Praying that the baby's head continue [*sic*] to grow to *right* size. Pray it's a false alarm.
- Praying your baby girl is *perfect*! I'm hoping at least one marker will resolve at my next ultrasound.

Many comments also described “normal” as a way of life, in a sense, that would not be possible due to the presence of disability. For instance, one user whose fetus had been diagnosed with achondroplasia (dwarfism) commented: “I know it might sound harsh, but I’m not sure how I would handle raising a child with such an evident ‘deformity’. I don’t want her being laughed at or at a disadvantage” (WTE, 2019). It is clear here that it was not the medical condition but the social conditioning around the disability³⁴ which the parent most feared. Or, take for example, this way of reassuring someone: “My NIPT came back negative and baby boy was born in April perfectly healthy and chromosomally typical. It’s so hard to stay positive but do try. Lots of success stories out there with abnormal NT [nuchal translucency] readings” (WTE, 2019). We clearly see here the naturalization of ableist sentiments; the commenter encouraging someone else to stay positive only because there are ‘success’ stories—again, these success stories were

³⁴ Achondroplasia is caused by a prenatally-diagnosable genetic mutation. It causes short stature, short limbs, an enlarged head and forehead. It is also associated with many medical issues including spinal issues, hydrocephalus (a buildup of brain fluid), and others (U.S. National Library of Medicine, 2020). As with many chromosomal ‘abnormalities,’ it can cause disabling impairments or illnesses, but my impression was that it is often the visual difference that made parents fear this diagnosis.

clearly defined—“perfectly healthy and chromosomally typical.” Another user reported a positive screening for Down syndrome, and after many users responded with stories of “good” outcomes after positive screenings, they responded, “Thank you for your comment. We have accepted that there is almost definitely something wrong as hard as it is” (WTE.com, 2019). Again, this user defined Down syndrome in terms of right vs. “wrong” ways to exist—there was no notion here of disability as difference.

Much in the same vein as these uses of words such as normal, typical, right, perfect, etc., in opposition to wrong, deformity, problem, or abnormal, so the phrase “healthy, happy” surfaced frequently. The frequent juxtaposition of these words functioned not only as a sort of de facto definition of health, but also served to create an ableist environment—the sites studied here were continually reinforcing a sense of healthy as equivalent to happy. For instance (WTE, 2019):

- My dear friend keeps saying so positively to me—to trust in life and that I will have a healthy happy baby. I keep saying it to myself and meditating.
- There is a termination for medical reasons board... support and advice from people who had to make the same sort of choices may be helpful for you... I hope you have a happy healthy baby in there though.

There were also many comments where the word happy was not used, but the word healthy was clearly associated with happiness, or the lack of health with sadness or fear:

- Sometimes I miss her a lot but I forget about her dx. I see her as a healthy child. But she wasnt! [*sic*]
- Thanks for the positive story thrilled for you and your healthy babe. [*sic*]

These comments create an overall sense of health as the definition of the “good life.”

Engagement with Medical Authority

One major takeaway from looking at the way online users discussed doctors, or their medical teams, was that the entrenchment of medical authority is deeply interconnected with technology and the “scientificity” (Foucault, 1980, p. 82) of the test results. The specificity of identifying genetic material is hard to argue with, which makes it all the more important that margins of error and test limits are rarely discussed with patients, unless in the context of pushing for further testing. For instance, some users report the margin of error of NIPT being highlighted only after the test was finished, and the doctor was pushing them to consider amniocentesis (WTE, 2019). Through forums like What To Expect, we saw how well versed the users have become in medical jargon related to test results, with those who have had positive results routinely asked by other users about their specific test results and then comparing as though this could give them further information:

What were your numbers? Mine were 3.51 I believe. Elevated afp gave me 1 in 40 odds. very nerve wrecking [*sic*] (baby #2 for me) ...Normal was 2.5 or 2. I had my healthy baby boy in February at 40 weeks exactly. (WTE, 2019)

What I want to highlight in the passage above is the way the specificity of the numbers was understood and deployed—the idea that the range of ‘normal’ had been internalized from either the doctor’s authority to determine what constitutes normal, or from other medical sources which have defined this.³⁵ The baby then being born healthy was told as a success story—with the implication being ‘despite the poor test results, I experienced success and so too might you.’ It was said supportively as a “keep your chin up” sort of comment, whilst never considering questioning or undermining the entrenched medical definition of ‘normal.’ This is a worldview

³⁵ I did not observe any comments interrogating these normal ranges, even in terms of asking for sources or how they are determined.

informed by medicine in which there is a defined normal, and there are defined outliers, and medical authority defines which is which.

This is essential because it demonstrates the level of faith put in the medical system to define the meaning of the testing and determine the outcomes. Occasionally a user would point out the fallibility of the testing, “I’d be asking for a repeat scan, maybe at a different place to confirm. Scans can be wrong!” (WTE, 2019), while ultimately tending to profess a high level of faith in the system to determine what is normal and liveable and what is not. This pervasive discourse of hope is a profoundly ableist vision of what we should hope for. This is particularly clear in cases where users talked about receiving prenatal diagnoses for rare genetic conditions which they had almost certainly not heard of prior. In this case the educating authorities are the same medical practitioners and authorities who are responsible for performing and reading the tests. This is concerning because there is undoubtedly medical bias in the way the results are presented and explained: “The MFM [Maternal Fetal Medicine] doctor at the 13-week NT [Nuchal Translucency] scan was very serious and grim about the situation. ... We didn’t get our results until I was 17 weeks along, that the baby had Noonan Syndrome” (WTE, 2019). In this case, the user reported being informed by their doctor that the baby’s “survival was out of the question,” and they terminated the pregnancy at 18 weeks. Without being able to speak to the specifics of this situation, this shows a high degree of faith in the testing process getting things right, and it is hard to say whether the doctor’s “serious and grim” expression was based in the specifics of this case, and the poor prognosis, or simply based in ableist attitudes towards Noonan syndrome in general (a condition which is compatible with life, but which causes significant facial and bodily differences and sometimes intellectual disability [U.S. National Library of Medicine, 2018].) Consider even the following from this online description of Noonan

syndrome from a principal American health website: “Some people with Noonan syndrome develop cancer” (U.S. National Library of Medicine, 2018). This may be an oversimplification, but that is true of everyone. Some people develop cancer. The website goes on to put the risk of leukemia for a child with Noonan syndrome eight times higher than peers; this is not insignificant. My point is not to dispute these risk analyses, but to put them into a context in which they are the only factor being presented as worth considering in an analysis of whether these people’s lives are worthwhile enough for them to be born. They are medical facts taken out of the context of lived experience, which is absolutely a biased presentation (as are all presentations), replete with medical norms.

While there seemed to be very little pushback to medical authority to define normalcy according to a certain narrow window, one way in which I did observe some resistance is in terms of the perceived knowledge of the medical provider. As previously stated, the pregnant people posting on these forums were clearly knowledgeable and had high informational literacy. Therefore, it is perhaps not surprising that they were most likely to question their doctors if they perceived that the doctor lacked knowledge³⁶. For instance:

In my experience, my regular ObGYN was not real knowledgeable about some of the markers, etc. I asked her what the nuchal fold thickness is caused by and it was clear she didn’t really know and i had read more info and studies than she had. [*sic*] (WTE, 2019)

In this case, the commenter was more inclined to disregard the doctor’s advice, demonstrating the profound power/knowledge relationship as argued by Foucault (1980); the doctor’s authority

³⁶ Whilst I did not see comments pointing to specific hierarchies of doctors, I feel confident based on my previous research (Cardin, 2020a) that there is also often a sense of hierarchies of authority among not only different types of medical practitioners, but also different types of medical knowledge. (For instance, from my own experience, knowledge produced by ultrasound is often not only considered more correct, but often backed by official hospital policies that it should be used in place of the pregnant person’s self-report, which both undermines the patient and opens the door for unnecessary interventions.)

in the eyes of the commenter was undermined by the perception that the patient knew more than the doctor.

There were also some very clear instances of reports of medical authority which overstepped into the decision-making realm of the pregnant person, especially with regards to advice on whether or not to terminate. In these cases, forum users were often very clear that their doctors had overstepped, and this led them to question their authority, but this was often accompanied by a sense of powerlessness in the actual situation. In other words, the person was not necessarily offering any resistance to their doctor, but sounding off about the perceived overstepping of authority to their friends, family, or online community. Consider this comment, in which a user describes a situation that happened to her daughter.

The day she found out they told her to abort the baby. She was about 21 weeks. Then they said we will do an amnio and it came back the same as the blood test. So now 2 weeks go by and she is over 25 weeks. Now the hospital won't do the procedure not that we believe in that. But the child won't have any kind of life. Her GYN Doctor never called her. Only when he said to abort. [*sic*] (WTE, 2019)

In this comment, the mother is clearly upset that her daughter has been told to abort, in contravention to her beliefs, and there is an implication that since her daughter failed to comply, or asked for more testing before compliance, that the doctors therefore failed to adequately care for the patient. Again, the comment “but the child won't have any kind of life” demonstrates that the pushback is only against an overstepping of authority, but not against the medical definition of normalcy or abnormality; it demonstrates agency regarding the medical view of the situation, but it is still ableist.

A further finding in terms of medical authority relates to insurance systems in the United States. One user commented that she had undergone an amniocentesis and there was a diagnosis of Trisomy 13 (Patau syndrome), which as mentioned above, has a poor life expectancy. Based on this diagnosis, the forum user reported that her insurance company refused to pay for any further ultrasounds. The user stated:

I feel like i [*sic*] need to see my baby to get another confirmation and for my own emotional health to make a decision on what to do. Kaiser [the insurance company] said they would allow me to do check ups [*sic*] but they will not do any extraordinary measures for the baby due to his diagnosis. (WTE, 2019)

It is significant that the American private insurance system results in situations like this one, where the patient's ability to pay out-of-pocket is thus a significant factor influencing their care. The mother's emotional needs are collateral damage in the service of a biopolitical discourse in which this fetus classified as "disabled" has already been written off, and will no longer be invested in.

Considering and Justifying Termination

I have chosen the terms "considering" and "justifying" to describe the attitudes towards termination as seen in the forums studied, because my observation has been that most of the comments related to termination fell very much into one camp or the other. They were also decidedly split into different forums—as mentioned previously, those still considering whether or not to terminate tended to be in forums about dealing with the anxiety of prenatal screening and diagnosis, whereas those who were justifying were usually people who had already terminated, and often these were in forums specific to support for termination related to Down syndrome. These comments were therefore very different from each other. For those still considering, many had only screening results, not diagnoses, and many were seeking information

about the lived experience of having children with disabilities. For the most part, however, commenters were fairly sure of their desire to terminate, and mostly seemed to be seeking reassurance about this being the right call. For instance, “I do know for myself that I will be ready to let go if the result will be positive for the disease. The pain and suffering I believe would be to [*sic*] great for my baby and for myself” (WTE, 2019). Within the boards where people were considering termination, there were people reporting from both sides; deciding to terminate, and explaining that they had not done so. These were some of the few cases where I saw the word “healthy” used to describe disability: “I opted out of invasive testing, and he was born with ds. He is perfectly healthy and happy, and a very easygoing baby. he is a true blessing! congratulations! [*sic*]” (WTE, 2019).

In the case of Down syndrome termination boards, I observed that the commenters are struggling with some of the most deeply felt decisions of their lives, probably with very little support, and likely with a sense of not being able to talk openly with their friends and family about their decisions. Where comments on most boards were usually short, at most a paragraph or two, many of these comments were lengthy and went into great detail, telling the stories of their losses. They wrote about their journeys, from pregnancy to diagnosis to termination. They wrote openly about their emotional responses, and what can only be described as the traumatic aftermath of their decisions:

I would like another child but this was so difficult. I did this and I'm sorry. I saw my little girl in the morgue and I needed to decide how to deal with the body. I do feel grateful to have seen her, spent time with her. I named her but I didn't get to be close to her. Maybe that is my heart's way of trying to help me get through this, protecting me from getting

too close? This was my choice, it was me that ended her life, do I even deserve to shed tears? What right do I have as a mother who did this when I was meant to love her?

(BabyCenter.com, 2015³⁷).

It is important to note that the above quotation represents one person's experience, and I certainly would never want to generalize that all those who terminate due to disability diagnosis experience this kind of regret³⁸. In fact, an obvious limitation of the site of analysis is that it is more than likely to be people who are experiencing regret or trauma who are using these sites. However, the above quote certainly points to insufficient information for those seeking to terminate and insufficient supports for individuals making these decisions. It also demonstrates that the socialization which presents Trisomy 21 as an unliveable condition, and parenting a child with a Trisomy as a burden, is probably leading to terminations where the pregnant person does not feel fully comfortable with their decision, or has felt some level of social pressure. As I have stated, I do not wish to weigh in on the ethics of any individual's reason for terminating, but I notice these terminations seem to operate differently than those where the diagnosis is incompatible with life—both in the sense of the pregnant person's own sense of ethics and the affective experiences they have. Termination for disability seems to be a different experience than for parents who perceive the fetal diagnosis as incompatible with life.

Visual Knowledge/ Intuition

As noted in Chapter 2, the cultural valorization of visually acquired knowledge is an important aspect of considering ultrasound as a prenatal technology, both in terms of its

³⁷ Due to the incredibly sensitive nature of this quote, I have changed the wording very slightly to make it less searchable, while doing my best to preserve the poster's original meaning.

³⁸ In fact, there is very good research demonstrating that abortion regret is discursively produced, and deployed by anti-abortion activists in a way that falsely assumes that postabortion regret is a moral argument against abortion, when often it is more a product of cultural norms to which we are all subject (Greasley, 2012; Kimport, 2012).

prevalence and its entrenchment as the most ‘correct’ way to learn about pregnancy. As scholars such as Draper (2002) have noted, ultrasound has become a routine part of pregnancy care largely because of the cultural phenomenon of the sonogram photo—these photos helped pregnant people to feel connected to their fetuses, and largely assuaged their fears about the potential risks of ultrasound, or the margin of error associated with knowledge acquired through this means. This has had direct impacts in terms of the care pregnant people receive, including, for example, healthcare providers prioritizing the knowledge produced through ultrasound for dating the pregnancy over the pregnant person’s own knowledge. This can have impacts ranging from overly cautious early pregnancy inductions, coercing the client to undergo unnecessary ultrasounds simply to date the pregnancy, to undermining the client’s sense of their knowledge being valuable, and of being the decision-maker for their own pregnancy.

Additionally, as Hartouni (1997) notes, because research has shown that ultrasound tends to be culturally framed as “taking a look at the baby,”³⁹ it can have a strong influence on the pregnant person’s feelings about the fetus and/or pregnancy, and therefore has been used coercively. There are many places where terminations are not permitted without first requiring the pregnant person to undergo a medically unnecessary ultrasound.

It is clear from several forum comments that ultrasound plays a strong role in creating a visual relationship between the pregnant person and the fetus. Many people who did have uncertain or negative test results reported that having additional ultrasounds ordered was one

³⁹ It is important to note that this is very much a cultural, and not ‘scientific,’ way to understand ultrasound. Ultrasound uses sound waves to create a 2 or 3D rendering on a computer screen of what a fetus might look like, based on our previous knowledge of what fetuses look like and based on statistical probabilities. Technicians using ultrasound visually measure two points on the screen, and then feed this measurement into an algorithm to determine the statistical likelihood of “normalcy” versus certain chromosomal abnormalities or irregularities with fetal development. It is absolutely not a ‘photograph,’ and there is an enormous level of bias and human error involved in the production of this knowledge.

benefit of having a high-risk or uncertain pregnancy—they were afforded many opportunities to visually observe the fetus, which often provided them with reassurance and pleasure. (This was much less the case for interview participants, as is related in Chapter 5.) As one commenter put it, “I get to see my baby via ultrasound every two weeks. Which is a nice perk to the extra monitoring [*sic*]” (WTE, 2019). Indeed, most often, it seems ultrasounds are very welcome and play an important role in reassuring pregnant people—although they are also very quick to look to the margin of error if the result is not welcome. This dichotomous reaction of either experiencing reassurance or searching for the error in the test demonstrates the pervasiveness of ableist discourse in both cases.

When results of ultrasound or NIPT were questioned, I did notice a sense of the pregnant person’s intuition as a key reason to disbelieve the knowledge produced that way. For instance:

I really have this gut feeling my little guy is just fine. if it wasn't for the NIPT they would have no cause to think he might have it [Trisomy 18]. they offered me a CVS and today they offered me an amnio. I know it will tell me 100% of he has it or not but I love him exactly how he is and I just don't want to bother with extra testing (and expenses because yay *** American insurance) when the test will do nothing to help the condition. I just want to enjoy the pregnancy and bond with my baby in my mind until he's here. [*sic*]
(WTE, 2019).

This passage demonstrates some level of confirmation bias in the minds of pregnant people who want very much to trust prenatal testing when it tells them the fetus is healthy but look for the margin of error if not. It also shows the harms caused by for-profit medical care and lack of health coverage. Finally, and perhaps most importantly, I think it speaks volumes about the way prenatal testing can not only create a sense of “tentative pregnancy,” as mentioned in Chapter 2,

but also interfere with the pregnant person's positive experience of pregnancy and relationship to their fetus. It does this because of the deep entrenchment of ableist norms—regardless of the pregnant person's own feelings about the diagnosis, they are catapulted into a medical system that treats the fetus as a problem to be solved or terminated, impacting their attempts to bond with their fetus. Prenatal testing is having a significant impact on the affective experience of pregnancy, through ableist discourse, whether or not disability is diagnosed or even initially at the forefront of the pregnant person's mind.

Direct Engagements with Ableism

Interconnected with the above section on visual knowledge, perhaps one of the most encouraging elements I have observed in these online forums are engagements with ableism, often from parents of disabled children. These commenters often used photographs as representations of their own positive experiences. These act in a way as a form of resistant knowledge production within an overall very homogenously ableist online experience. While the overall impression I get from these forums, as shown in the sections above, ranges from fear of disabled experience and fear of parenting children with disabilities, to statements that directly support the notion of disabled lives being qualitatively lacking, or without value, these posters are interjecting with often very compassionate and reassuring comments, providing an alternate perspective. They are perhaps some of the best placed people to change hearts and minds, and help reduce ableist thinking and/or fear of disability, because in many cases, they have undergone their own journeys to accepting their children's conditions. For example, one parent of a child with achondroplasia (dwarfism) writes,

I have a son with a rare form of dwarfism, and I promise—it is not a deformity. Your imagination is a scary place right now—and it can seem like it's this terrible thing. but it isnt—babies with dwarfism are equally as incredible and perfect as any other child. it is a

beautiful example of diversity in the world caring for him is exactly like caring for any other baby—minus a few medical things we monitor for. it may seem like a bigger difference now than it is in reality. [*sic*] (WTE, 2019)

This post ends with a photograph of mother and son. The mother's arms are open wide in a gesture of celebration, with the son who looks to be about 1-2 years old copying her. His dwarfism is apparent, but also is not the focus of the photograph. The purpose of the photograph is very clearly to showcase their big smiles, and their experience which is being framed as mostly normative.

Another example was a response to someone who had just gotten a screening result of Monosomy X (Turner syndrome) and was seeking reassurance that sometimes these screenings produce false positives. The response came from a person who was further along in their pregnancy, with a fetal diagnosis of Monosomy X based on an amniocentesis, and was explaining their decision to keep the baby: "I hope all is fine with your babies but turners syndrome isn't the end of the world and most girls go on and live completely normal lives, some don't even realise they have any issues until adulthood (WTE, 2019)." This comment is one of very few that attempts to reassure the original poster, not by confirming the existence of false positives, but by speaking to the possibility of positive experiences of disability.

There were also comments pointing to the impossibility of ensuring "health" regardless of fetal diagnosis, in tandem with reassuring others through positive experiences of disability. For instance, in one thread, the original poster stated the likelihood of Down syndrome based on their screening results. Another parent commented that they too had a positive for Down syndrome, which turned out to be false, but that their son was born with autism, for which there is no screening possible. The parent spoke in their comment not only to the impossibility of

ensuring a certain outcome, but also to the lived reality that parenting disabled children can be a good experience:

if [*sic*] it does turn out that he or she has special needs, remember that there is real help and a whole community ready to help you and give your child every opportunity to live up to his or her potential. I hope this gives you some peace of mind. (WTE, 2019)

Earlier in the same thread, the original poster commented that their view of the diagnosis was being influenced by the way it had been presented: “seen [*sic*] my regular Dr today and he really didn’t explain anything other than seeming like I’m in a hopeless situation...” (WTE, 2019).

This poster went on to say that their partner was leaning towards termination, but that they were “struggling with uncertainty” (WTE, 2019). Later in the thread, another parent of a disabled child told them to advocate for their child, with a comment demonstrating the need for resistance to medical authority, and medical framing of disability:

go back to the high risk doctor and tell them point blank that your child is perfect, and while you want to get their advice for how to be prepared for medical complications that may exist at birth—you would appreciate if they stop approaching it so negatively, since that is your child. and although there is a 90% chance that your child will have down syndrome, your child is nothing to mourn or have anyone feel sorry for. ... I also suggest going somewhere like Instagram and finding families with babies and toddlers with down syndrome instead of reading any medical stuff google tells you. that will give you a better picture for sure. [*sic*] (WTE, 2019)

This comment reflects the argument made by so many disability advocates (Erevelles, 2011a; Lupton, 1999; Rapp, 2011) that because prenatal screening and diagnosis takes the knowledge of the condition out of the context of the person, it allows the medical system to completely frame

the meaning of the diagnosis. It makes the parent “dependent on medical expertise” (Grob cited in Rapp, 2011).

Another example which also used a visual representation is a poster who offered a photograph, with the caption, “This is my little man who we are pretty certain will rock an extra chromosome” (WTE, 2019). This caption is lighthearted, and uses humour to cut through the fear and fearmongering present in these threads worrying about Down syndrome. The visual representation in cases of Trisomy 21 is particularly significant in light of previous research mentioned in Chapter 2, that found that the intellectual disability and distinctive facial features of Trisomy 21 are deeply interconnected in people’s minds, and the latter significantly impacts pregnant people’s feelings about the former. In other words, pregnant people were often afraid that the distinctive facial features common to Down syndrome would be noticed by others, and that they would treat the child with disdain and judgement because they would assume a severe intellectual disability, based on those facial features (Rapp, 1999). This fear of social response to physical difference informed many decisions to terminate. Thus, using visual resistance to ableist views of Down syndrome is a commonly seen tactic, both in social media such as these forums, and in advocacy campaigns such as the “Anything but Sorry” campaign by the Canadian Down Syndrome Society, which uses the visual effect of featuring smiling children with Down syndrome on its billboards (Canadian Down Syndrome Society, n.d.). This helps to break through the common “healthy = happy” stereotype noted above, (and perhaps even the pervasive idea that disability equates to lack of health) with simple representations of happy, healthy, flourishing children with Trisomy 21.⁴⁰

⁴⁰ Rosemarie Garland-Thompson argues that visual depictions of disability fall into four broad categories—I see this as an example of the fourth, which she describes as “the realistic,” in which disability is brought close, naturalized, and in which the differences between the viewer and the visualized are minimized (Garland-Thomson, 2001). What is really interesting in this case, however, is

One final note in this section is that there were many examples of parents coming to terms with fetal diagnoses which had initially been unwelcome and preparing to parent disabled children. In this sense, the attitudes towards Trisomy 21 were extremely variable depending on the type of forum. The ableism and serious fear of Trisomy 21 which was so prevalent in termination boards was often not present in other spaces, and in fact there were forums where people who had a diagnosis of Trisomy 21 were incredibly relieved, because this diagnosis has such a relatively good prognosis. Notwithstanding these positive attitudes, there were still comments that might be very hard for a parent of child with Trisomy 21, or for a person with Trisomy 21, to read; for example, “My hubb [*sic*] says to assume we have a DS baby and if he isn’t, it’s a bonus” (WTE, 2019, *words changed for clarity*). Or “if he comes out chromosomally normal it’s a bonus but I’d be very very surprised” (WTE, 2019). These commenters demonstrate resignation with their diagnoses; they are continuing their pregnancies; but these comments are not celebratory. Despite their decisions to go forward with their pregnancies, these comments perpetuate ableist norms.

Prenatal Testing Advocacy: Twitter

I chose to use Twitter as a site of analysis, in addition to the pregnancy forums I looked at, because it has different technological affordances than the pregnancy forums, and therefore the types of discussions that arose around prenatal testing offered further insight into the operation of the discourses around the use of prenatal testing technologies. Whilst both the online pregnancy forums and Twitter provided the opportunity to create a username and post

that the distinctive facial markers of Down syndrome are singled out; the makers of the campaign are deliberately placing them in a context that looks like a “normal” birth announcement to highlight the differences embodied by children with Down syndrome, in order to normalize them. What this does, therefore, goes a bit further than Garland-Thompson’s argument, coming closer to one made by Robert McRuer in his book *Crip Theory* where he argues for a visual mode of celebrating abnormality that might potentially free us from “compulsory able-bodiedness” (McRuer, 2006, p. 198).

under that alias, in the culture of the online forums it is much more normative for usernames to be disconnected from the user's in-person identity, rendering them anonymous. On Twitter, people are more likely to have usernames that include their real names or identifying information. This results in discussions on this topic that tend to be less personal and anecdotal in nature and more political. Whereas in the online forums, what I primarily saw was people looking for assistance in grappling with prenatal testing results, Twitter contained significant commentary on the broader picture surrounding prenatal testing, new developments, research, and prenatal testing in the news, and therefore analysis of discussions there broadened the scope of the issues I was able to consider. In terms of keeping the project manageable, I chose to focus on keyword searches (both directly on the site and using NVivo's NCapture feature), largely through searches for the phrases "prenatal testing," as well as searching in conjunction with "Down syndrome," "autism," and "disability." These searches were done over several months in 2019 and 2020. Content of Tweets was analyzed but not likes or retweets, since the intent for this portion of the research was to analyze contributions to the discourse on this topic, rather than to produce a quantitative summary. The results were split into the following themes, focusing on a few areas of online commentary/activism within Twitter which complement the other sites of analysis in this research and help to broaden the scope of this research. There was significant engagement with all three themes, particularly the second. As outlined in Chapter 2, these are:

- 1) **Medical authority and prenatal testing results:** Parents speaking to the role of medical authority in encouraging abortion of fetuses diagnosed with Down syndrome.
- 2) **Criticism of eugenics:** Comments from activists criticizing the role prenatal testing is playing in the elimination of disabled people

- 3) **Anti-abortion Advocacy:** Use of prenatal testing for Down syndrome to advance an anti-abortion agenda.

These themes were reflected very little through the pregnancy forums but featured very prominently on Twitter. These themes are also interconnected, and they speak very clearly to the importance of recognition and analysis of discourses of disability in this area. In other words, whilst it is incredibly important to demonstrate the connection between disability-selective terminations and eugenics, and the ableism inherent in these terminations, it is still important to keep individual family planning and the right to choose at the forefront of this conversation. The first theme speaks directly to impact of common discourses around disability on decision-making, especially because one can extrapolate that for every parent turning to Twitter to criticize medical providers for their role in influencing their decisions, there are others who are simply swayed towards termination. The second theme of anti-eugenics advocacy is deeply interconnected with the first, because biopolitical “choice” based eugenics operates through discourse and governmentality, at the level of the individual, with medical disciplinary discourse playing an important role. Finally, looking at the third theme, anti-abortion advocates are perhaps quick to use disability-selective terminations to advance their agenda because it is seen as a way to engage progressives, who are generally pro-choice in terms of abortion, but against eugenics (for instance, see Berube, 2018). The way these themes appear in the Twitter discourse can actually look quite similar, at first glance, since both are criticizing abortions, and therefore there is a critical and urgent need for nuance in these conversations.

Medical Authority and Prenatal Testing Results

This theme had the most crossover with the pregnancy forums, in that it featured parents speaking to their own experiences with prenatal testing, but through the medium of Twitter there was much more criticism of the way test results are presented. Whereas most commenters in

pregnancy forums were seeking reassurance that despite preliminary testing, their fetus might not have a disability, these posts were often from parents whose children were already born, and who were recounting the bias of the medical system. Currently parenting a child with Down syndrome, these parents seemed able to put their diagnoses into the context of a whole person, which often produced emotional Tweets containing anger at the way their children's potential lives had been portrayed. For example:

I didn't do any prenatal testing, either, because it didn't matter to me. We had a surprise Down syndrome diagnosis after this guy was born. The way the diagnosis was delivered was terrible but I absolutely wouldn't change a thing about my sweet boy! [*sic*]
(@thethomps, January 28, 2019)

This example, which is one of the milder examples of criticism against doctors, reflects a disparity between the lived experience of the parent and what they were prepared for by the doctor who communicated the results. The parent is also essentially saying that they love their child, and Down syndrome is an inseparable part of who he is.

Others had much more negative comments about the medical care they had received, sometimes well after prenatal testing. For instance, one poster said:

“Didn't you have prenatal testing?” Asked by a triage nurse when I brought in my son who was sick with a virus but happens to have Down syndrome. It made me feel as though they felt he had no right to exist. (@LisaWadden, November 18, 2019)

This comment shows the level of advocacy parents of disabled children will often take on, and the continued struggle for them to exist in a medical system rampant with ableist discourse. This nurse's question reinforces both prenatal testing and termination of fetuses diagnosed with disabilities as a routine part of medical care and part of responsible motherhood. There were

other similar reactions on Twitter. For example, “‘Did you have prenatal testing?’ is never an ok thing to ask, including from medical students + residents. #DownSyndrome #SpinaBifida” (@suerobinsyvr, March 25, 2019). One can surmise that this parent has received this question on more than one occasion. Another parent spoke in a Twitter thread about their experiences with prenatal testing, and their decision not to confirm their diagnosis via amniocentesis due to the potential for miscarriage. In this case the commenter spoke positively of their experiences with their pediatrician, but then pointed out that the doctor turned out to have an autistic child, himself. “Was SO much more open to listening to what we as parents had to say” (@BubblesAndChaos, September 14, 2018). This reflects an important finding, which is that greater context and nuance in delivery of prenatal testing results, and in medical care for disabled people more generally, could likely be achieved by having more disabled people or people who are disability-adjacent and assuming an affirmation model working in health care.

Another commenter (who is also quoted above) felt that the issue of ableism among medical care providers is compounded by outdated information (and perhaps attitudes). They state: “Medical providers don’t give up-to-date information on Down syndrome when they deliver the results of prenatal testing. And almost all assume the parents will terminate. If they provide facts from the 1970s, how is that providing a true choice?” (@thethomps, April 19, 2018). This certainly calls to mind the social context that in the past, children with Down syndrome were routinely institutionalized (Global Down Syndrome Foundation, 2018; McKercher, 2019), and therefore the cultural experience of having a child with Down syndrome has shifted dramatically. Medical discourses may not always reflect this.⁴¹

⁴¹ Certainly, there is evidence of improvements to training of medical providers; my impression is that these efforts have been somewhat piecemeal (Aulagnier et al., 2005; Sheppard, Vitalone-Raccaro, Kaari, & Ajumobi, 2017).

Another poster notes the importance of medical support for those who are anti-termination for themselves, which I think is a significantly different issue than holding anti-choice views for other people. They say, “Discussed prenatal testing for Down Syndrome [*sic*] with OB & parinatologist [*sic*]. Both respond as though my unwillingness to terminate if test comes back positive is some sort of religious quirk. ‘Oh, you’re Catholic.’ So offensive.” (@AprilPonnuru, April 9, 2018). This comment speaks to the importance of medical care providers being responsive to the diversity among their patients, and accommodating those who oppose abortion respectfully. Respecting the right for pregnant people to choose for their own bodies should include respect for the right to refuse to terminate, without marginalizing that person’s religious identity.

Finally, I include one Tweet that does not feature the parent’s own experience but does speak to the exercise of medical authority: “Down syndrome isn’t eliminated by early prenatal testing. PEOPLE whose tests suggest they might have down [*sic*] syndrome are being aborted by mothers who are told to think of them as burdens” (@hdighn, June 1, 2018). This Tweet is similar to many of the Tweets in the upcoming section on anti-abortion advocacy, but I include it here because it specifically speaks to the overarching role of medicine as an institution in entrenching ableist discourse. As this section shows, medical ableism both contributes to the high rates of termination of fetuses diagnosed with Trisomy 21, and worsens the experience of parents who decide against either prenatal testing or termination. This is part and parcel of prenatal testing operating as a biopolitical technique, and in the following section, I look at direct criticisms on Twitter of prenatal testing as a facilitator of eugenics.

Criticisms of Eugenics

“Down syndrome has almost been eliminated in parts of Europe, thanks to prenatal testing.’

THANKS to prenatal testing... Reading this gave me chills down my spine.”

Twitter user (@obianuju), June 1, 2018

The quotation above is a clear example of the abovementioned argument. This user's comment speaks to a systemic problem, without reference to individual decisions. Other comments also speak to the biopolitical nature of disability-specific terminations, but without making reference to termination. They identify a problem which I also speak to in Chapter 4; that an increase in terminations for Trisomy 21 will inevitably lead to fewer supports for parents who are raising children with Trisomy 21: "As prenatal testing for Down syndrome advances, '[Down syndrome] will code increasingly for poverty, making it harder to generate the political will to provide services for people like my son' @Lollarfis." (@PacificStand, November 18, 2018).

There are also examples of Tweets that show a clear understanding of the complexity and nuance of the relationship between abortion rights and disability advocacy: "Something needs to fundamentally change in society about the value of disabled lives. A stigma-free environment to discuss abortion without stigmatizing disability" (@BarefootJakki, October 12, 2019). This tweet points to the connection between systemic terminations for disability and eugenics, and overall attitudes about the value of disabled people, without making reference to or judgement of any specific termination. Or, in another example: "there are countries around the world pushing to eradicate or cure Down syndrome and other disorders, the only way to do such is push prenatal testing and terminate pregnancies. eugenics [*sic*] is real, happening today and many remain completely unaware" (@GoddessofGrain, October 4, 2019).

Eugenics through prenatal testing also frequently arises on Twitter in a context of autism advocacy, with specific pushback against organizations such as *Autism Speaks* which have come under fire for investing in research aimed at isolating autism genetically, in order to develop a prenatal test. Many autistic advocates fear the development of an autism test, similar to the ones

currently used to identify chromosomal conditions, which could lead to the eventual eugenic elimination of autistic people. For instance: “@autismspeaks is an organization that funds prenatal testing for autism so parents can kill autistic children” (@GothLame, July 9, 2020). This research is a very large reason *Autism Speaks* has come under fire, and also explains why some autistic people and advocates discourage the public from supporting it (Maguire, 2016). Some commenters also argue that many of these researchers are using DNA from autistic children without their consent (@A4AOntario, May 24, 2020). There are many similar examples of Tweets arguing about the eugenic nature of this research: “Let’s face it, the majority of autism research is aimed at making sure we’re not born in the future. All sorts of priorities for autistic people and our quality of life, but why would we expect researchers to worry about that?” (@AlistairRae, June 23, 2020). Advocates, both autistic people and their allies, rightly point out that the quest to identify autism and develop a prenatal test speaks to larger discourses of disability and social attitudes that frame autistic people as unwanted: “That this is even a thing, highlights and reinforces that we are unacceptable to society” (@aheeleyRIBA, June 24, 2020). Advocates also oppose the enormous quantities of funding that are aimed at “curing” autism or discovery of a prenatal test, whilst autistic adults struggle to get support (Silberman, 2015).

This point is also very much applicable to the currently existing tests for Trisomy 21 and their usage, and this topic is also clearly very emotional for many of the people posting on Twitter. I also observe with many of these comments, that there is less separation of the collective from individual action, with many Tweets either discouraging prenatal testing, or speaking directly to potential parents. For instance: “Women, before getting pregnant, ask yourselves this question: What will I do if prenatal testing reveals my baby has Down Syndrome [*sic*]? If your answer is, ‘Kill it,’ DON’T get pregnant” (@LaurieBHiggins, March 19, 2020). It

is worth highlighting the responsabilization of women (as those who are presumed to get pregnant) without any mention of the responsibility of men in pregnancies. There is also a sense in this comment of a normative experience of pregnancy which is wanted, planned, and the product of consent, very much ignoring any circumstances which might fall outside these norms.

There were also Tweets criticizing the role the medical system plays in convincing parents that they should abort. For instance:

Some countries have 90% rates of abortion for down syndrome [*sic*]. When prenatal testing enters, it allows for things no one should want. There are people in this world who think it is selfish for people to give birth to disabled kids. There are doctors that push worst case narratives. (@AutismLiterally, February 27, 2020)

Other Tweets criticize the risk of the test being incorrect—a valid analysis, which was also made by some of the interview participants, as seen in Chapter 4, but which nonetheless upholds the ableist attitude that termination would be the correct step if the test were positive and reliable. For example, one advocate commented that her positive Down syndrome test was incorrect, and she stated that she felt coerced to abort: “I was told my son had down syndrome [*sic*] and was pressured to abort by doctors. He was not down syndrome [*sic*] and they almost talked me into it” (@cyndirozen, April 1, 2020). This Tweet mirrors other comments criticizing the medical system for encouraging abortion, but the point is somewhat lessened by the failure to recognize that this is not only problematic because the baby was not born with Trisomy 21.

It is also important to note, however, that there were a few parents who advocated prenatal testing for chromosomal disorders simply with the intent of better preparing for the possibility of parenting a disabled child. @JoshMcGruff wrote: “We had prenatal testing for our daughter who has Trisomy 21 (Down Syndrome) [*sic*]. This helped us better prepare and know

what resources were available instead of being blindsided at birth. I highly recommend prenatal testing” (February 27, 2020). This comment demonstrates the overwhelming assumption that parents often have, going in, of ‘health’ and ‘normalcy,’ which would result in a diagnosis of Down syndrome at birth being experienced as a shock. This individual experience is also certainly worth noting, especially in this case of a parent feeling that prenatal testing improved their access to resources, and thus recommending it to others, although it is also important to place this Tweet into a context which recognizes that prenatal testing that diagnoses Trisomy 21 most frequently results in terminations.

Anti-Abortion Advocacy

Congruently with the theme of anti-eugenics advocacy by disabled people and other advocates, we see a significant number of Tweets using eugenics-based arguments to advance an anti-abortion agenda. Some of these Tweets straddle a line—they are calling out eugenics, but also there seems to be some implicit anti-abortion sentiment. For instance, this one, where the initial question implies that the commenter believes the ‘choice’ to terminate goes too far in some cases: “where are [we] going to draw the line on #NIPT/prenatal testing/choice???? 1 in 25 children are at risk of not making it to birth if we continue in this way. Look at the story of Down syndrome” (@ColetteLloyd, September 20, 2019). There is certainly an undercurrent in this Tweet that abortion rights should be clawed back, although it is not making any specific suggestions about legal changes. Another Tweet reads, “Germany is debating whether prenatal testing for Down syndrome should be free. Natalie is worried that will mean fewer people like her will be around. Via @cnn” (@IvanaKottasova, September 19, 2019). While this Tweet is not explicitly anti-abortion, the idea of financially gatekeeping access to prenatal testing, specifically in order to prevent some terminations, raises serious ethical issues and is highly classist. In a further example, a Tweet calls out *Autism Speaks*, much like many of the Tweets in the section

above, but the language implies an anti-abortion point of view: “#AutismSpeaks is researching prenatal testing for #autism. If prenatal testing for autism exists, just like down [*sic*] syndrome, a lot of moms are going to abort their preborn babies that are tested positive for autism” (@Victoria_Marie4, April 2, 2018). The wording in this Tweet calls out the eugenics of prenatal testing in much the same way as many of the Tweets in the above section, but the wording of “preborn babies” raises a red flag that this Tweet has an anti-choice agenda, perhaps beyond that of advocating for autistic people.

In another example, we see that the anti-eugenics sentiment is really an implicit anti-abortion argument, and in fact the language used is extremely ableist: “Not only has the widespread use of prenatal testing practically wiped out the Down Syndrome [*sic*] population in Iceland and Denmark, but it is also prompting mothers and fathers across the world to unwittingly abort normal babies...” (@CathWomensForum, June 20, 2019). This use of the word “normal” not only upholds a discursive binary between Down syndrome and “health” that has been routinely debunked by disability scholarship (e.g., J. Dolmage, 2014; Titchkosky & Michalko, 2009), it also, perhaps unintentionally, devalues fetuses with Trisomy 21 in comparison to those without. While the intent was likely to argue against all abortions, the implication is that these abortions are especially terrible if the parents thought the fetus had Trisomy 21 but were mistaken. This ableist view, far from advocating on behalf of disabled people, further entrenches the normal/abnormal dichotomy and devalues the lives of disabled people.

There are others who are quite direct about the marriage between disability rights and anti-abortion movements, and encourage others to take advantage of these commonalities: “#ProLife movement foundational principle: human life is intrinsically valuable, not due to

abilities or traits. #DisabilityRights movement foundational principle: human life is intrinsically valuable, not due to abilities or traits. Why don't these 2 work together more?" (@AutisticPriest, May 15, 2019). Others have made similar points about prenatal testing and the ethics of isolating particular genes for termination: "If a gay gene is ever found and can be detected through prenatal testing, the 'her body, her choice pro-abortion crowd' would add 'another reason' to kill" (@mike2libertyCA, April 26, 2019). What both these Tweets have in common is that they are connecting to the very real issues of biopolitical fetal selection to argue against abortion, and in both cases, there is a kernel of truth to this argument.⁴² Many of the anti-abortion Tweets are also from people whose children have Down syndrome, and who are advocating against termination of children like their own. For instance, "In 1994, after some prenatal testing, we were told our oldest son 'likely' had Down Syndrome [*sic*]. Doctors and extended family members wanted him DEAD. If you wanted THIS little one, this GIFT, dEaD [*sic*], DO NOT BUY OUR COFFEE" (@lifeboatcoffee, March 21, 2019). This Tweet is, of course, personal to the commenter's experience, with a photo that is presumably of their own child attached under the Tweet, but also carries an implication about others' decisions: That choosing to terminate a fetus diagnosed with Trisomy 21, or supporting those who would, is tantamount to wishing that couple's child dead. Another such example states,

Donate to @JLFoundation instead of the #MarchOfDimes. Jerome Lejeune discovered a 3rd copy of chromosome 21 was the cause of Down Syndrome [*sic*] & he spent his life fighting against eugenic prenatal testing after he learned doctors were using his discovery to target innocent babies. (@She_Brings_Joy, January 18, 2019)

⁴² As noted, Rapp's research indicated that parents who received fetal diagnoses of intersex chromosomes sometimes terminated from the mistaken impression that they had received a diagnosis of fetal homosexuality. This does suggest that in the event a "gay gene" could be isolated, it would result in homophobic terminations.

The username for the person behind this Tweet is “Sarah St. Onge began life as an unwanted embryo” and her bio states that she had a ‘life-limiting diagnosis’ for her ‘unborn baby,’ using the hashtags “#Christian” and “#PostAbortive,” among others. She also has a pinned Tweet which says,

This is the first time I held my daughter. I knew in this moment she was dying & there was nothing I could do. I’d known since I was 9 wks pregnant she may not survive—well before my state’s cut-off of 24 weeks. No one seemed to care: they’d already decided she was pointless.

This last sentence in particular is noteworthy, because it expresses a sentiment that is found throughout the literature on prenatal testing (e.g., Fritsch, 2015; Mills, 2001; Tremain, 2006), that came up earlier in this chapter in the section on pregnancy forums, and also to an extent through my interviews in the upcoming chapters: That once a fetus is diagnosed with a disability, many parents experience a sense that their fetus is no longer worth anything to others, to the medical community, or to society at large. This poster argues from their own experience of their fetus being treated as collateral damage in a society that only values people who are able-bodied and neurotypical. In this situation, we see how the biopolitical use of prenatal testing immediately writes off fetuses that have been classified as disabled (destined for termination), regardless of the parents’ choice.

The Tweets in this section often demonstrate the way such fetuses fall at the wayside of the biopolitical project of fostering life. As we saw throughout the research from Twitter, this happens both at the level of discourse and in concrete ways such as failure to provide supports to autistic adults, and failure to pay for a pregnant person’s ultrasounds and doctor’s appointments once there is a diagnosis of fetal disability.

The anti-abortion tweets are also worth including because they demonstrate the danger of taking the eugenic argument too far; it is deployed by people with an anti-choice agenda to encroach on abortion rights. Being skeptical of termination based solely on ableist assumptions about normalcy and health is not tantamount to being pro-life, and as Berube notes, we should be wary of valid concerns regarding eugenic uses of prenatal testing being used by conservative politicians as an entry to undermining abortion access (2018). Fundamentally, the argument I am and will be making throughout this dissertation is that this issue is less about abortion and more about confronting ableist discourse.

Findings in Brief

As we have seen in this chapter, the forums on websites such as What To Expect and BabyCenter function as communities which people turn to as a coping mechanism to deal with their circumstances—often, unwelcome or uncertain test results. These forums are often a first line of research for pregnant people, and even people who do not choose to post on them may use them as a resource, which was clear through my interviews. They also surface very high in Google results. There is an overall sense from the comments that the pregnant people using them are highly informed and have very high levels of medical information literacy. They are often using their medical providers as a primary source of information, but they are also questioning medical authority through these forums. However, this questioning is perhaps taking the place of actually pushing back against medical misinformation or overstepping. Throughout these forums, it was clear that prenatal testing processes cause serious fear, anxiety and stress and the forums act as a coping mechanism for this. People reassure each other and there were frequent requests for, and offers of, prayer. However, these forums also usually work to re-entrench dichotomous ideas of “health” vs illness or disability, with words such as “normal” often employed

uncritically. Seriously ableist attitudes, about Trisomy 21 in particular, are often reproduced in a context where the posters are grappling with their decisions to terminate. Sometimes, in other settings, the attitudes about disability are much more open and accepting, and in some case, parents of children with disabilities are using these forums as opportunities to communicate about the positives of their situation, directly with people who may be in the midst of making decisions about termination. These communications often turn to visuals as a way to demonstrate their, and their children's, happiness. Furthermore, much as will be shown in the interview chapters to follow, Non-invasive Prenatal Testing (NIPT) has surfaced as a major comfort for many pregnant people, with its reduction in amniocentesis-based risk of miscarriage. Nonetheless, it is also further entrenching the commonplaceness of prenatal testing as well as the cultural imperative to test. Finally, it is clear in the forums that the ableist attitudes of medical care providers often have a souring effect on the experience of pregnancy.

Twitter had quite a different function than these forums, with engagements manifesting more as advocacy and less as a way to deal with personal experience, or as information gathering. In this chapter, I looked at three themes that emerged on Twitter: engagements with medical authority in the context of prenatal testing results, criticisms of prenatal testing as a form of eugenics, and anti-abortion advocacy.

The first theme demonstrated the serious negotiations that parents of disabled children have with their care providers not only during prenatal testing, but after their children are born, and the impact that medical ableism can have on both experience of pregnancy and increasing terminations. The second theme showed the concern many advocates have for the impacts of prenatal testing in terms of increasing ableism and decreasing the population of people with certain disabilities. It showed engagements particularly by people in autistic/autism communities

and parents of children with Trisomy 21 (Down syndrome), and demonstrated, among other arguments, the important point that reduction in the numbers of people with these conditions or differences reduces the impetus to provide resources and supports. Finally, the third theme showed the use of anti-eugenics language by anti-abortion advocates. While these commenters do sometimes employ compelling arguments in their Tweets, this section showed that they often perpetuate ableism through usage of words like “normal,” or through the implication that the terminations are only wrong because the testing might produce false results (in other words, that it would only be wrong to abort “healthy” babies). Whilst these anti-choice advocates often overreach, their Tweets are worth examination because they often do speak to the biopolitical experience of people with disabilities being treated as unimportant by institutions such as health care.

Chapter 4:

Interviews, Part 1: The Imperative to Fetal Health

Ten Fingers, Ten Toes: “As long As It’s Healthy” and the Conflation of Health and Disability

“There was one little baby who was born far away, and one who was born on the very next day.

And each of these babies, as everyone knows, has ten little fingers and ten little toes.”

—Mem Fox

When my eldest son was a baby, someone gave us a copy of Mem Fox’s (2008) “Ten Little Fingers and Ten Little Toes,” a little board book for babies and toddlers, that is all about teaching diversity. It goes through all kinds of differences between babies—some are born on the ice, some are born in a tent, some are born in a town. The illustrations show diversity through different races, hair and eye colours, and socioeconomic conditions. Each description of the babies’ diversity is followed by the cutesy phrase “and each of these babies, as everyone knows, has ten little fingers and ten little toes.” From the first time I read this book out loud to my baby, it did not sit right with me. This book, ostensibly all about celebrating difference, demonstrates ableism in its assumption of how we define a complete body as a normal one. This baby book provides a very clear example of the continued assumed normality of ableism through discourse, particularly when it comes to our cultural expectations around babies, even as we have begun to embrace other forms of difference. When it comes to dis/ability, the pervasive discourse prescribes a correct and normal way to be born. What I found in this research is that this widely circulating assumption seems innocuous to many people, until they have reason to begin a process of critical reflection about it, either through the ethical questions that sometimes get raised by prenatal testing, or by their life circumstances presenting them with something other

than their expectations of a “healthy” baby. This chapter looks at the views of interview participants about disability and health and how these have affected their experiences of pregnancy. It also looks at broader effects of cultural discourses on fetal health, including how these impact the views of their medical providers. In total, eighteen participants were interviewed about their experiences with pregnancy, and as I have noted in Chapter 2, I refer to them by pseudonyms to keep their identities confidential.

In general, some of the findings I will explore in this chapter include: That pregnant people I interviewed who themselves have disabilities were often less ableist in their attitudes than other participants, and more prone to question the abovementioned discourses, but still worried about producing fetuses with disabilities. Moreover, wanting to produce ‘healthy’ babies was partly about the avoidance of trauma for the mother, a very reasonable worry especially considering the encounters many of these women had already had with medical systems. I also found that having children with disabilities or illnesses did, in fact, cause extra stress, but there was also clear evidence of systemic social barriers as a primary reason for this. I found that discourses of disability intersected with gender and sex in unanticipated ways. I found that even very different participant experiences reflected the overall biopolitical nature of prenatal testing technologies. There are also significant findings about medical authority: As expected, authority was exercised and deployed by medical providers in very coercive ways; I also found that medical errors were a significant issue, and that turning down chromosomal tests was complicated and not always possible. I found that testing decisions were often linked to fear of miscarriage, as well as ageing for women, among other reasons, and that cultural normalization of testing was a major factor. Finally, I found that while many participants had positive attitudes about disability and a history of positive engagements with disabled people, these did not

necessarily translate to lessened anxiety, nor to feeling that it would be alright for their child to be born disabled or ill. Ultimately, the sense that the lives of people with disabilities are difficult and burdensome was still strong.

When I interviewed women for this project, one of the questions I asked was “Have you ever heard pregnant people, either your acquaintances or in the media, use the phrase ‘As long as it’s healthy,’ to describe their fetus?” Almost without exception, people responded “Oh, yeah!” and “All the time!” In a couple of cases, before I could even finish the question, participants cut in with “As long as it’s healthy—I knew what you were going to say!” or sometimes, they brought up the phrase themselves much earlier in the interview. And often, they also mentioned the phrase “ten fingers, ten toes,” as a variation on this theme. Sometimes, participants agreed wholeheartedly with the phrase: “Yeah, that’s what we’re saying. We didn’t care the sex of the baby as long as it’s got ten fingers, ten toes. And it’s healthy, that’s all we want” (Lisa). Or Leah, the mother of an autistic child: “Well, I kind of agree with it. We all want healthy kids. We all want to be healthy ourselves.” Leah did point out that the definition of health is ambiguous, however—it was unclear whether or not she equated her child’s autism with ill health.

Martina, a mother of three who had had a false positive Down syndrome test, thought the phrase was a reminder of values, and that health/ability was what mattered, more so than a parent’s other preferences for their child:

All it takes is a little glimpse of the possibility of something being wrong and ...the pain and sadness and worry that could bring you, and even just the inconvenience or difficulty in your life, and then you realize none of that other stuff matters, and I really do just want a healthy child, and everything else is gravy.

Others pointed out that this phrase is very specifically used to deflect questions about sex. For instance, Catherine said:

There are things worth getting worked up about and things that aren't. For me, whether it's a girl or boy is fun, but doesn't really matter. It's fun to find out, and buy clothes or whatever, but that's not the thing that I really cared about going to the ultrasounds ...What is the life of this child going to look like? What is my life going to look like taking care of this child? And that's why the health was important to me.

Some even suggested that this phrase gets used to undermine the ubiquitous obsession with gendering babies, refocusing on something that is supposedly a neutral fact: Everyone wants a healthy baby. For example, Sadie said:

We deliberately didn't tell anybody because we didn't want to deal with everybody's bullshit about gender, and we also didn't want literally everything they bought us to be blue. Because, since I have a trans brother, I have a lot of feelings about gendering babies. ...We just pretended we didn't know ...and then they would laugh and say, "as long as it's healthy, right?"

For Sadie, herself disabled, this response was not preferable to the gender question, and she said she would respond to this supposedly rhetorical question with "No, I think I'll love it either way," to which she said, people would be "totally taken aback." She was not the only one to see the phrase from this perspective. Sam, who was one of two participants in my study who chose not to do prenatal tests for disability, said she was influenced by a friend who was raising a child with a disability:

She had written a lot about how terrible it is when people say "Well, the only thing I'm interested in, I don't care if it's a boy or a girl, I just want a healthy baby." Which seems

like a really benign thing to say, unless you have a child who is disabled, in which case it becomes a more insidious thing. (Sam)

Sam said her friend's opinion on this gave her pause, and she was influenced to think very seriously about how we view disability as a uniquely negative outcome, and it made her realize that testing would force her to seriously consider whether to terminate the pregnancy, if the result were unwanted. She also reflected that when people use this phrase,

What we're trying to say is actually, that we're not hung up on the details on this pregnancy, we're just hoping for happiness. ...But hearing my friend talking about what you're actually saying when you say that, is that life is terrible for disabled people.

One of the other participants in the study, Tanya, had a chronic illness which she described as not disabling in her particular case, but it had given her a high level of exposure to disability and she often felt she was classified by others as "not healthy"—a designation to which she objected, as a person who led what she felt was a healthier than usual lifestyle. She also had one child with learning difficulties, which gave her some insight into parenting children with disabilities.⁴³

When I asked her about the phrase, she told a story about when she was pregnant. A friend had asked her husband how the ultrasound went, and he had reflexively answered, "Oh, well as long as there's five fingers and five toes." The friend, who had been born missing one toe, had exclaimed, "What's wrong with four toes?" Tanya explained that the friend was not really offended, and had said it in a very good-natured way, but that his question had left both herself and her husband thinking about their preconceived notions of both what is considered 'normal' and what is considered 'different.' She said, "As long as it's healthy'; I don't think it's a fair

⁴³I think it important to note that she spoke only about her child's specific challenges, and she never used the word "disabled" in speaking of her child.

phrase. Like the ten fingers, ten toes, that's one people say all the time at baby showers. There's so much more to it, healthy life" (Tanya).

When asked about the phrase "As long as it's healthy," some participants seemed to reflect on its meaning more deeply for the first time. For example, Elena's answer initially was almost a routine response, describing people as well-meaning for using it—but as she continued to speak, she became increasingly critical of the phrase:

When I was pregnant, I used to think, well, these people mean well; what they're saying is I wish your baby is born healthy and as perfect as possible, just like you imagined it. But when you really think about it, it's like, what if it's not healthy? Then what? What does that mean? Is the baby less in some way, to you, to me, to whom? Are you saying, "Oh God, I wish your baby is not sick, and you don't have to go through that"; what if I have to? What are you actually saying? ...The phrase is just awful.

Just as Elena's response showed a questioning of normalized ableism in culture, Annie used her answer to reflect on the meaning of the word healthy: "I don't think it's correct to equate the term healthy with free from any disability, and I know I've certainly done it. Maybe it's a convenient shorthand." While some contested the idea that health was about disability at all, most mentioned disability in conjunction with the idea of health and spoke to the idea of 'healthy = desirable' as an entrenched norm—and as noted, some of the participants agreed with this norm, while others had difficulty with it.

Several also spoke about the potential complications of childbirth—not merely those that caused more permanent illnesses and disabilities in babies, but those that cause separations of mothers and babies and increased parental anxiety during infancy. Examples included stays in

Neonatal or Pediatric Intensive Care Units, especially extended ones; failure to thrive⁴⁴; surgeries after birth; and other complications. However, the examples mentioned by participants were not limited to the infants' health but included the mothers' health as well. There was a sense that when people say, "as long as it's healthy," they are wishing for a pregnant person to avoid complications that could cause trauma to the infant or parent. For instance, Grace said, "I guess I've always thought of it more in terms of baby will come out and be healthy, be a good weight, be able to breathe, all those things."

There were several participants who also said, almost in contravention to the above point, that the phrase is so focused on outcomes that it is dismissive of the pregnant person's birth experience, which is an aspect of this phrase that I had not previously considered. In this view, one can have an experience that is very traumatizing or violent, but that is ultimately classified as positive because of the outcome that "the baby is healthy." Lauren, a recent first-time mother, commented that this is dismissive of the mother: "Whether it was a terrible birth or it was traumatic... regardless of everything that happened, as long as your baby comes out healthy then that's what matters." This reiterates the widespread cultural notion that mothers should be self-sacrificing and perhaps even find solace in suffering. Along a similar line, Martina commented that "we treat women as incubators" and that this manifests in a cultural responsabilization (Rose, 2007) wherein everything pregnant people do is subject to scrutiny, sacrificing their experiences of pregnancy on the altar of healthy babies and of mitigating all risks, perceived or otherwise. Several participants spoke to this, in a way, often telling me at great length about obstetric trauma they had experienced, and then finishing up with sentences like, "But of course it was

⁴⁴A medical term for infants not gaining enough weight according to expected curves of growth.

worth it to have my baby.” This focus on outcomes will be further explored in this chapter, in the section “Pressures on behaviour.”

Finally, there was a comment about the ubiquitous “as long it’s healthy,” from Jennifer, whose baby was diagnosed with a heart condition which was not caught during her prenatal testing, and which will probably require a lifetime of surgeries and treatments. Her comment resonated with the points Lauren and Martina had made about the way that “as long as it’s healthy” minimized the mother’s experience, but the comment was also striking for its compassion to the place people are coming from when they use this phrase. Jennifer said,

After having a baby that was unhealthy, and having to go through the trauma of that, I try to remind people that even if your baby is not healthy, it’s still a blessing. And it’ll still give you a lot of joy. People don’t really like hearing that, because no one wants to imagine themselves going through anything like what I’ve gone through, but... I see it as people not wanting to imagine going through trauma.

This fear of traumatic experience gets to the heart of why the discourse of health at all costs is so effective; in the ubiquity of disability-selective termination, we see a human desire to avoid challenges, and disability literature shows that many people justify testing and termination as wanting to avoid a painful life for their child (Swain & French, 2000). The difficulty enters when the lives led by people with disabilities are painted as exclusively difficult, challenging, traumatic or painful, without positives, in conjunction with routine use of technologies that are employed to classify fetuses according to a strict binary of dis/ability. It was very clear from my interviews that the desire people have for their children to not experience pain or suffering is often more acute than for themselves. However, the above passages also demonstrate the high level of reflexivity among participants about discourses of disability as uniquely constituted by

suffering. Certainly, there were people in the study who seemed to accept without question that the definition of health excludes disability, and that health is the ultimate goal to be sought for babies, regardless of cost. Indeed, this stigmatization of disability, as I will show in this chapter, has led to some truly traumatic experiences for some participants, particularly those whose children were born with disabilities. In some cases, participants felt the suffering of their children very deeply, to the point of regret in having the disabled child.

While there was also clearly agency and what Stuart Hall would term negotiated and oppositional responses (1997), or what Foucault would term resistance (Foucault, 1982) to these discourses, I read a very high level of compliance with medical authority in most participants' answers. Despite feeling that the definition of health might be too narrow, or despite many comments showing that participants felt people with disabilities could lead good lives, most people still chose to do whatever prenatal testing was routine and recommended by their healthcare providers, and many indicated that they would be prepared to take the lead from their healthcare providers in terms of subsequent decision-making. Furthermore, as I will show in the section on medical authority, those who felt strongly about opposing any particular medical recommendation usually anticipated that there would be a fight, and they were not usually prepared to deal with the battle unless the topic was something they deemed of major importance.

To me, this goes a long way towards explaining the rate of termination of Trisomy 21 (Down syndrome) pregnancies⁴⁵ (Government of Canada, 2017), and why it is that studies show

⁴⁵ There is no statistic kept on this in Canada, but we can infer an approximate rate from the number of babies with Down syndrome being born, and from the US rate. Canada's rate of births with Down syndrome (0.15 per cent of births) is similar to the United States, (0.14 per cent of births), which does keep statistics on testing and termination and has a termination rate between 67% - 85% among those who had a confirmed diagnosis (Natoli, Ackerman, Mcdermott, & Edwards, 2012)—it is likely that Canada's termination rate is therefore similar.

that even parents who do not anticipate terminating pregnancies diagnosed with Trisomy 21 usually do (Lawson, 2006). It also demonstrates the continuation of a cyclical relationship between discourses of disability and termination. Consider only one aspect of this cyclical dynamic: The more often fetuses diagnosed with Trisomy 21 are terminated, the fewer resources will be made available to help those who do continue their pregnancies. The fewer resources and supports, the deeper will be the challenges for the parents. The deeper the challenges, the more people will feel ill equipped to sign on to a parenting role they perceive as a burden to themselves and to society at large.

Chapter Roadmap

In this chapter, I present the first section of findings from my interviews with pregnant or recently pregnant women.⁴⁶ I begin with a brief overview of the participant demographics. Following this, I look at participants' views about disability as well as their feelings about terminating pregnancies, showing the ways these are often connected. Then, I delve into another topic which influences termination decisions, as well as the participants' experiences of pregnancy: The views of their medical providers (as reported by participants). From there, I look more broadly at participants' experiences of medical authority. This section explores experiences of dealing with medical authority during pregnancy as a whole, because the exercise of this authority in other areas of pregnancy can seep into the way pregnant people experience prenatal testing. Continuing on the theme of engagements with healthcare providers, I will also offer a few examples of medical errors reported by participants, which are a noteworthy finding of this

⁴⁶ In the past few chapters, I usually use the term pregnant people in recognition of trans men and non-binary pregnant people. I also recruited participants using the inclusive language "all genders welcome." However, all participants in this study identified as cisgender women, and therefore in this chapter I use the word women to refer to these participants. Whenever I am speaking to pregnant people more broadly than those in this study, I continue to use gender inclusive terminology.

study. Following this, I look at testing decisions and what influenced them. Fear of disability in the child was certainly among the reasons to test, but I will also look at four other principle reasons (all interconnected with disability) that surfaced: Economic incentives to test, fear of miscarriage and stillbirth, advanced maternal age, and routine expectations (in other words, the idea that testing is simply what is ‘done.’) Finally in this chapter, I include some of the participants’ positive views of disability. These were certainly present for most participants, and ultimately, I think these views suggest a potential road forward for prenatal testing where it can be less routine, and less fraught with anxiety for mothers. These participant opinions suggest a hopeful lens through which this work, which is at times very emotionally fraught, can be viewed.

Participant Demographics

For this chapter, I interviewed eighteen women, all living in Ottawa, Ontario. As mentioned in my description of method, my recruitment was fairly wide. Posters were hung, with permission, in family doctors’ offices, midwives’ offices, libraries, community centres and coffee shops throughout the core of the city of Ottawa.⁴⁷ I also sent posters to the Down Syndrome Association of the National Capital Region, and to Planned Parenthood Ottawa. I posted social media notices in several groups for Ottawa parents on Facebook, and this proved to be a very fruitful recruitment tactic. I began recruitment in the summer of 2019 and finished in late winter 2020. By happenstance, my busiest interview period was during the time when Ottawa, like much of the world, began physical distancing measures to prevent the spread of COVID-19. Although I cannot speak to whether this affected willingness to participate, it did

⁴⁷ I included the following neighbourhoods in my recruitment: Old Ottawa South, Glebe, Hintonburg, Lowertown, and Vanier. For those unfamiliar with Ottawa, this includes most of the downtown, residential neighbourhoods, excluding the larger suburban areas. Within these neighbourhoods, there is a wide range of diversity in terms of socioeconomic class, racial and ethnic diversity, and languages spoken.

affect interview scheduling, due specifically to the particulars of participant eligibility,⁴⁸ which I have covered in more depth in my methodology chapter.

Of the 18 people I interviewed, none identified as trans or non-binary, and everyone was comfortable being referred to as a woman. Sixteen were in relationships with a male partner; of these, fourteen identified as heterosexual, two as bisexual, and two as having a bisexual partner. The other two were single parents. When asked about their race and ethnicity, sixteen participants self-identified as either “white,” “Caucasian,” or “Canadian,” three as Jewish, and one as Latin American/ Hispanic. Several participants mentioned that they were immigrants or were married to immigrants, and several mentioned being members of ethnic communities: Polish, Ukrainian, and Italian-Canadian. Everyone reported English as a language spoken in the home, and several other languages were also reported.

The question of identifying themselves or their loved ones as able or disabled was somewhat complicated, which is unsurprising. Only one participant said yes to the question “Do you have a disability?” and she reported having a chronic immune condition⁴⁹, which she said was not in itself disabling, but she said the medications she was taking for it were disabling. She also reported having Post-Traumatic Stress Disorder (PTSD), caused by experiencing pregnancy with her condition. Another participant responded “no, but...” and then also described having a chronic immune condition for which she was taking medication, which could be disabling at

⁴⁸ The study was open to participants who were currently pregnant or had been pregnant in the previous five years. The result of this was that all the participants had small children at home (as did I), and therefore we did a lot of scheduling around childrens’ naps and bedtimes.

⁴⁹ In all cases of reported medical conditions, the participants were extremely specific about their, or their family members’ conditions, or in some cases told stories involving friends with medical conditions or disabilities, always using very specific terminology and language. By contrast, I am being deliberately vague in reporting some of these conditions, because of the need to maintain participant confidentiality. Some of these conditions are very rare and could potentially aid to identify them. I do, however, want to make a note of the way they were reported because it demonstrates the very high level of education and information literacy of the participants, and also their agency over their own health.

some point in her life. This demonstrates that what is disabling for one person may not be considered so by another, and dis/ability is temporal and a complex element of identity. The same was true of describing family members and children; some said yes, they had a family member who was disabled, and some said “no, but...” and then went on to describe situations which they themselves did not classify as disabilities, but which others did. In total, eleven participants reported no disability or illness in their families. Of those who said yes, or for whom it was complicated, there included the following: a chronic genetic disorder causing medical issues, autism, intellectual disability, congenital cardiac problems, and learning disabilities/difficulties. There was also a participant who terminated her pregnancy in response to a prenatal diagnosis of Monosomy X (Turner syndrome.) Of course, among those who did not report disabilities in their families, some of their children were very young babies, so they may simply not have knowledge of their children’s full medical profiles yet.

There were also two participants who self-identified as being healthcare providers⁵⁰ sometimes working with pregnancy, in addition to being parents, and both spoke also about their experiences related to their jobs. One further participant also had a job in the field of prenatal testing. It is worth noting that many participants who had experiences that they perceived as uncommon expressed concern that their experience would “skew” my study results. These included: Being in the health field, having a disability or illness, and experiencing a medical error in their care. Not one of these supposedly ‘unique’ experiences was in fact, unique—everything that someone feared would skew my results was experienced by at least one other person. This speaks to the pervasiveness of prevailing discourses, and how when we do not fit a

⁵⁰ Again, I am being deliberately vague about participants’ professions to ensure participant confidentiality.

norm, we are often made to feel like outliers, rendering aspects of our identities invisible. One of the benefits of challenging these discourses of marginality is that we often discover the commonality of our experiences, and this is, in my opinion, especially true for women's health care research, where there is extraordinary power to the telling of our stories and the discovery of shared experiences.

Further to this, while I cannot speculate as to every participant's reasons for speaking to me, I did receive several initial contact emails from participants who wrote at length about their experiences with the medical system, and some also brought these up in interviews as a reason for contacting me. As I will get into in Chapter 5, most participants were highly informed, and actively seeking to take ownership of their own health. I also got the sense, sadly, that many felt abandoned, neglected or traumatized by their experiences with pregnancy care and this was a major reason for participating.

I also mentioned in the section above that two participants chose to opt out of chromosomal testing. This number is based on self-reporting and it is a bit complex. I am not entirely sure it is accurate, because all participants reported getting standard ultrasounds, and the standard ultrasound done around 11-13 weeks in Ontario, which is called the Integrated Prenatal Screening (IPS) includes a chromosomal screening. In order to avoid that screening, the pregnant person would need to specifically request that it not be done or would need to refuse that ultrasound completely. Therefore, for those who reported opting out, they may have done so, or they may not have fully realized what the tests were looking for. There was also at least one participant who wished to opt out of the chromosomal testing but found it difficult to selectively opt out of one aspect of the Integrated Prenatal Screening. Sometimes, needing information related to their own health from the screening required a whole package approach, which also

meant fetal chromosomal screening. I think it worth highlighting as a finding of this chapter, that counting how many participants did the screening or did not is actually complicated, first because opting out is difficult due to normalizing discourses and pressures from the medical system, but also because of the technical complications or impossibility of separating some parts of testing from other needed information, as is explored in Sadie's case, later in the chapter.

Disability, Health, and Feelings about Termination

Attitudes about Disability

Participants' attitudes about disability were often very clear from the statements they made about potential termination; attitudes about disability and termination are inextricable. Many participants mentioned intellectual disabilities in particular, with descriptions such as "unable to function in society" (Lauren), "so hard on the parents" (Lisa), or "catastrophic" (Mila). As in the findings from the online chapter, the word "devastating" was also used frequently.

Those who had children with disabilities or medical concerns all reported that disability and illness added a layer of stress to parenting.⁵¹ One example is Jennifer, who had a prenatal test which could theoretically have detected her child's heart defect, but it was missed. Her child was diagnosed soon after birth due to a routine heart test. She said:

Having a child with an illness, everything is a little bit more stressful. There's no way the other parents with healthy children can understand what you're going through if you have an unhealthy child, so that's been a struggle for me as well, because I have friends who

⁵¹ I would add my own voice and experience to this as a parent of a child with a medical condition.

don't understand why I don't want to leave my baby, and why I don't want to take her out in public. It's hard to explain that because there's no way they can possibly understand.⁵²

For Jennifer, not having other parents relate to her was a major source of anxiety in raising her daughter. By contrast, for Leah, whose son is autistic, her anxiety was because she felt unprepared as a parent; she felt that parenting strategies for children on the autism spectrum were not readily available, and she said it was much more difficult to do research on this than it would be for parents of neurotypical children:

It's not intuitive. So many conversations I've had with therapists, I'll be like, I want to potty train my kid. So you read a potty training book. ... So then I start talking to the developmental psychologist, and she's like, yeah, that works for neurotypical kids. Let me tell you how you're going to deal with it. There's [*sic*] no resources for parenting an autistic kid.

All participants whose children had disabilities reported that they had added challenges, often due to their love and compassion for their children and their perception that their children were suffering, mostly socially. Isabelle, whose child had what she described as “global delay,” felt very excluded from other families, which she perceived as being because of her son's frequent “meltdowns.” Leah worried that her son was highly social, but that because he had difficulty learning normalized social behaviour among neurotypical children, he would be left out, especially as he got older and she was less able to intervene in his play with other children.

Participants who were not parenting children with disabilities often also perceived these as

⁵² This interview with Jennifer was an important example of the type of interviewing I covered in Chapter 2, where each interview is conducted as much as possible, as a conversation. I had a similar experience of a congenital heart condition that was missed in prenatal testing and caught after the birth of my child, and spoke to Jennifer briefly about that experience. I mention it in this context since my own experience may influence my re-telling of Jennifer's.

potential challenges, and mentioned a number of other difficulties that might face them if their children had illnesses or disabilities, including facing bullying, needing a lot of medical appointments or interventions, not being able to achieve independence, and added emotional labour for themselves. They had often given significant thought to what life might be like if they had a disabled child, and these considerations often factored into their feelings about potentially continuing or terminating a pregnancy.

One recurring theme which arose for many participants was the worry about the potential effect a child with a disability would have on siblings. Many mothers who already had children had also reached Advanced Maternal Age (AMA) by the time they were pregnant with a subsequent child, and in doing prenatal testing, they were increasingly worried that having a child with a disability would pose an unfair burden on siblings. Martina, who had a positive screen for Down syndrome with her third child, gave this considerable thought, saying, “We already had two kids, so that figured into it for us, we had to think about what it would mean for them if they had a sibling born with that condition, and what we felt comfortable with there.” For her, this did not mean that they needed to terminate the pregnancy, but rather that different financial decisions might need to be made in order to ensure that her older children would not be financially responsible for a disabled sibling in adulthood.⁵³ Many pointed to the financial effects disability might have on the family, and looked to this as a major issue in the future. This was an area where the economic situation of participants clearly came into play, understandably, with participants’ anxiety about this seeming somewhat proportional to their resources.

⁵³ The potential validity of this type of concern is highly contextual; some countries have excellent supports, programs and care options for disabled adults and others have next to nothing. In Ontario, recent political changes removing funding for disability could certainly have impacted people’s perceptions about the potential for help. Certainly, the stories we hear of disability have historically featured expensive institutionalization, expensive therapies, and overall lack of financial supports, so these concerns are contextually reasonable (Maguire, 2016; McKercher, 2019).

Others were more focused on present effects on siblings, and worried that a disabled child would take too much attention away from siblings. Isabelle, mentioned above, described the emotional toll on her older child as “huge,” and made clear that the work of balancing the attention given to her two children was a major effort for herself and her husband. She was also very worried that if she and her husband, as ageing parents, were not able to sufficiently provide financially for her son in future, he would be relegated to subpar institutional housing where the risk of abuse would be higher. She also pointed out that the emotional strain of all this could have impacts on the parents’ mental health, and she gave the example of a friend with an autistic son. The friend had been hospitalized for several weeks for psychiatric reasons.

Some participants also noted that prenatal tests did little to quell their anxiety: Firstly, because of the many disabilities that do not currently have prenatal tests, secondly, because complications can arise in childbirth causing disability, and thirdly, because disability is not necessarily congenital—there was an awareness that things can always happen, and some mentioned this as a source of anxiety. “A child could get in an accident tomorrow and be disabled” (Catherine). Several also mentioned that their level of anxiety about a prenatal diagnosis would depend on the disability, and that they had a sense of some disabilities being much easier to adapt to than others. Participants drew this line in very different places. Trisomy 21 is a clear example of this, since most participants brought it up. Some were very clear that such a pregnancy should be terminated due to the poor anticipated quality of life, and for others, Trisomy 21 seemed like a manageable prognosis. A lot seemed to hinge not only on their tolerance for uncertainty, but also on the level of independence that the parent expected the child to be able to achieve. Elena, for instance, said,

A blind person can have still a relatively normal life, with all the challenges that it implies. But someone with a deep or a very strong intellectual disability for example, it's very hard. Some types of disabilities allow you to become an independent adult; others don't, and you will be forever taken care of. And that's very hard for the person and for those caring for them.

Although she expressed this concern, Elena was among the participants who said she would have continued a pregnancy diagnosed with Trisomy 21; whereas, others felt this was a clear reason to terminate. A few participants also said that their objection to having a child with an intellectual disability was more about their own potential experience than the child's. They observed that children and adults with intellectual disabilities that they saw in their everyday lives seemed happy; however, they felt this was not enough. Lisa, whose cousin was intellectually disabled due to being born with the umbilical cord wrapped around his neck, said:

Every time I've seen a disabled person, even my cousin, it's really sad to see. These people are—I mean, they're perfectly happy with their lives, my cousin's happy, he's got everything he needs—but it's so hard on the parents. I don't think I could handle having a seriously ill child, it would break my heart every day, I couldn't handle it. And also I find life is hard enough being normal.

This sentiment brings us back to the concept of avoiding pain or challenges on behalf of one's children (or one's self), a highly normalized response to a tragedy model of disability and also one that is deeply interconnected with “better dead than disabled” discourses (Swain & French, 2000). It is sometimes couched in the language of pain avoidance on behalf of the child, but there is also a desire for a “normal” life for oneself reflected strongly in this comment.

There were also a few strong feelings about termination that I did not anticipate, one of which was a strong association between congenital disabilities and boys. Several participants expressed hoping for girls or being more nervous about having boys because they had an impression that boys were more likely to be born with congenital disabilities or illnesses, especially (but not limited to) neurodivergence or intellectual disabilities. This is, in fact, true for some conditions, where girls cannot be carriers, but there are other chromosomal differences such as Monosomy X (Turner syndrome) which only affect girls (Mayo Clinic, n.d.). This idea may also stem from the much higher rates of diagnosis of autism among boys, for instance⁵⁴ which has led to a cultural mythology that girls are less likely to be autistic (Maguire, 2016; Simone, 2010). In any case, Lauren commented,

I'd read that for men it [congenital developmental disabilities] can be more genetic. A male baby can be more disposed to those type of things. ...And that actually did go into my thinking in terms of being concerned for our child having some kind of challenge ...and then I was having a son.

While for Lauren, this association between male sex babies and congenital abnormalities caused anxiety, Isabelle seriously considered terminating her pregnancy when she found out her fetus was male.

We're plagued with mental issues in our family, on my mother's side, specifically. And especially the boys. So when I found out I was having a boy, I seriously considered

⁵⁴Boys are perceived not only to have higher rates of autism, but also more “behavioural” issues (external presentation)—a misconception that girls don't also have these. Simone (2010) argues that the higher diagnosis rate for boys is not because boys are in fact more likely to have autism, but that girls are underdiagnosed because their characteristics manifest differently and are understudied. Autistic boys tend to engage in behaviours like “meltdowns,” hyperactivity, or aggression, or cope with excessive stimuli through “stimming,” which can be frightening to people who don't understand what it is. By contrast, Simone argues that girls often process overstimulation through internalized symptoms such as getting migraines.

aborting, just because he's a boy, and I was kind of proved right. Don't get me wrong, I love him, but you know... we don't know what his future holds or ours.

This finding of the association between male fetuses and neurodivergence is a significant one to this study, upon which I expand in Chapter 6. Isabelle's case was one of having done not only the prenatal tests recommended by her doctor, but extra ones for which she paid out of pocket. She expressed strong concerns about having a child with a disability of any kind: "it's not fair to them, it's not fair to us, it's not fair to society." For her, the gamut of testing she underwent made her son's diagnosis especially difficult, because it demonstrated the limits in the science of prenatal testing. She felt very upset that the breadth of prenatal tests had been unable to guarantee her a "healthy" baby. There continue to be many conditions for which it is impossible to test, and the possibility of disabilities or illnesses acquired during childbirth or after it. She thought it likely that her son's intellectual disability had been caused by the use of forceps during his birth, a risk (although rare) of which she was not informed.⁵⁵ When she explained to me that her many prenatal tests, for which her son had tested negative, were a source of frustration, given his diagnosis, it was clear that her experience of parenting a child with a disability had been very traumatic and that his suffering was a primary reason for that.

[Speaking of the prenatal tests] that's why now that he does have special needs, it was extra hard to deal with because if there would have been a test for that, we would have aborted for that also. I love my son, but it's really unfair that he has to live with this.

Given her parenting experience, she had significant insight into the challenges facing parents of children with a high level of needs. She included the emotional stress for the parents, significant financial hardship in paying for therapies and specialized classes, and the level of research

⁵⁵ See Mayo Clinic (2021).

required to access resources. She said there was no comprehensive or centralized place to find out about what resources were available, indicating a major shortcoming in social supports. She was also very anxious about the future, anticipating that her son would need lifelong care, and nervous about what this would mean in terms of financial strain on her husband and herself, especially as ageing parents, since their son had been born when they were in their forties.

Anxiety during Prenatal Testing and Feelings about Termination

Much as seen in the chapter of findings from online forums, anxiety was a prominent feature of pregnancy and prenatal testing for participants, and this anxiety often stemmed from fears surrounding disability or illness. Although some did report that they were not nervous about disability or that they had never given it much thought, for most it was at least in the back of their minds as they entered prenatal testing, and for many it was the primary reason they underwent testing in the first place. In some cases, the thought of potential disability caused significant anxiety—particularly for those participants who had family histories of illness or disability, or histories of miscarriage. For those in the latter group, many were concerned that their previous miscarriages had been caused by undetected chromosomal abnormalities (which is very likely), and therefore the idea of the fetus being diagnosed with a chromosomal disorder was deeply associated with pregnancy loss and grief. For others, they worried about potential pregnancy loss without having any personal experience of this issue. There were also participants who identified as having disabilities, and their experiences of anxiety about potentially parenting a child with a disability varied a little bit from those who did not identify as having a disability. For example, Tanya said:

So, I have an illness, it could lead for me to be physically or cognitively disabled at some point, depending on disease activity. I kind of always worried, what would it be like to be

a parent of someone who might have something—a brain illness or disability from birth. We knew we could normalize it as much as possible for them—obviously, there’s a lot more resources now than when I was younger. But I don’t know, I guess as a parent, you just kind of always want the best for your kids. You want to make their lives as easy as possible. I also worried with myself, because my illness could be affected with stress. So I worried of having a child with increased needs that might affect my health, and then if my health was affected, then I’m there even less for them, which kind of ends up in a circle.

This worry that her own illness would impede parenting a child with a disability caused an added level of anxiety beyond what was experienced by those who identified as able. This worry was grounded in her concrete and lived experience of chronic illness. (Which is not to say that discourses of disability play no role here; all of us are affected by discourses around us and disabled people may also internalize these ideas.)

For those without such concrete lived experiences, many had some experiences of disability in their own lives such as previous experience working with people with disabilities or having extended family members, or friends with disabilities, but especially for those whose experience was less immediate, their primary associations with disability were largely equated with struggle and suffering. For instance, Catherine said:

Part of the thinking around whether or not we would terminate a pregnancy was, are there some conditions where a child’s life is a lot of suffering, and a lot of surgeries, and a lot of medical interventions that don’t necessarily yield improvements to quality of life? For me, I have no interest forcing my child to go through that, just to keep them living, keep

them breathing, when they might be more at peace to not have those medical interventions.

She was not alone in this view that some disabilities or illnesses would impede a person's quality of life too severely, and therefore termination would be the better option. Several people felt strongly that this choice was more responsible. Isabelle was very clear on this: "Our philosophy is, if there is anything that would be difficult for that child to live with specifically, that we know ahead of time, we do not believe in letting that child live with that kind of condition." For her, this included many prenatally diagnosable conditions, including Trisomy 21, whereas, as mentioned above, others drew the line in different places. Some saw Trisomy 21 as a diagnosis where they would wish to continue the pregnancy, but many other conditions would entail suffering they deemed too severe. Many who had undergone prenatal tests brought up conditions that often cause pregnancy loss or stillbirth as a reason to terminate, even if there was a small chance a fetus would survive with that condition. For most, their own suffering should the fetus die after a longer pregnancy was too difficult a possibility with which to contend. Sadie, for example, who expressed strong anti-termination sentiments when it came to Trisomy 21, noted that she felt completely different about conditions which were not survivable, even if the fetus had a small chance of surviving months or years after birth. "Because your baby is going to die and you are choosing when," she said, but then also noted that she would likely feel compelled to continue such a pregnancy herself, in any case.

Others were vehemently anti-termination for themselves but chose to do prenatal tests as a way to get information that would help them to plan for the potential of raising a disabled child. There were also participants who expressed that their partners were very clear about their opinions, but they themselves felt undecided. For instance, Julia said that her husband was

“pretty firm that we would not have proceeded” with a Trisomy 21 pregnancy, but that “I’m not sure what we would have done.” She did note that “it’s my body, my pregnancy,” but one can still imagine a partner’s feelings in this respect acting as a strong potential factor in decision-making, especially if the pregnant person was undecided.

Many participants had given substantial thought to the range of potential fetal diagnoses and had engaged in discussions with their spouses about what they would do in several possible circumstances. Others had considered that prenatal testing might later necessitate these discussions, depending on the results, but took an approach of making a decision only if it was needed. Many in this category expressed their gratitude that their outcomes had not necessitated these conversations, and said they still weren’t sure what they would have done. Although it is impossible for anyone to know what decisions these participants might have made, one can see how this prior indecision might have made them particularly susceptible to medical suggestion, whether direct or indirect. Some also said that they had made definite decisions about what they would do, knowing they always had the right to change their minds, or that they had made decisions but wavered somewhat in the face of comments from their medical providers.

I will wrap up this section with three participant stories that are illustrative of a range of views on termination and disability, but all of which reflect the larger argument that participants’ pregnancy experiences are significantly influenced and altered by the existence of prenatal testing, the pressures on women to test, and the responsibility that is placed on women, or which they place on themselves, to have babies according to a standard of normalcy which is directed by an ableist culture. These stories also all reflect that prenatal testing technologies are a key element in enabling and producing an ableist biopolitical norm.

Grace.

In Grace's first pregnancy, she did Non-invasive Prenatal Testing (NIPT). She chose to do NIPT despite being under the age of 40 (at which point it is free in Ontario), and without a history of disability, or a positive on the Integrated Prenatal Screening (IPS). She said a friend had told her about it, and she felt it would offer "peace of mind." She and her husband had taken the time to seriously discuss the potential of raising a child with a disability before the testing was done. Her fetus screened positive for Monosomy X (Turner syndrome), which was confirmed via Chorionic Villus Sampling (CVS), a procedure similar to an amniocentesis. She then underwent what she termed a "medical termination":

What led to my decision to do a medical termination was the emotional toll of actually being pregnant, and not knowing if it would end up resulting in getting to term. ... That I could have gone to 6 months, and lost the baby, or 8 months, and lost the baby. Or we could have not made it to term - to deliver a live baby. And that more immediate prospect was a little too much for me to imagine going through.

In the next section, where it is more relevant, I will expand on Grace's experience of receiving test results from her physician. Grace's termination happened at 12 weeks. She reported a high level of support from all medical personnel involved in her care, and also said that the family members and friends she told were very supportive of her decision. Her second pregnancy happened soon thereafter, and she gave birth to a child without chromosomal abnormalities the following year. I neither include this story with judgement of Grace's decision, nor do I think it should be read as a sort of "happily ever after." I want to underscore that these decisions are rarely simple, and for some people the availability of prenatal testing and termination probably has improved their overall experience of pregnancy. In a previous time, Grace might have carried this pregnancy for much longer, and then lost it, and suffered much more acutely with a late

stillbirth, rather than early pregnancy loss in which she had some level of agency. The flip side is the high number of terminations of fetuses with Turner syndrome, as compared to previous generations, when more people with this condition were born.⁵⁶

Julia.

Julia delayed getting pregnant because her husband had a medical disorder for which he was undergoing surgeries. When they decided it was time to try to start their family, they encountered fertility issues. They turned to in vitro fertilization (IVF), a process which was complicated by her husband's disorder. There was a fifty per cent chance of passing on his genetic mutation. She described her husband's case of the disorder as relatively mild but explained that there was a wide range of symptoms and the disease could be more life-threatening or more disabling than it was in his case. After she underwent egg retrieval, the fertilized eggs were sent for preliminary genetic testing in the US. They were tested specifically for her husband's mutated gene, a procedure which was developed specifically for them by mapping his genes. They were also tested for a range of common chromosomal abnormalities. This testing left them with two embryos that tested negative, which were returned to them. These two embryos were implanted in separate pregnancies, resulting in their two children. During each of Julia's pregnancies, she also underwent NIPT to ensure that the first round of prenatal testing had not missed anything. This case to me is striking for its high level of medicalization and technologization, and for how utterly different Julia's experience was than anything she would have experienced even a generation ago. There is also something ethically striking about their use of technologies which, had they been created a generation earlier, might have prevented her husband from being born in the first place. Without weighing on the individual

⁵⁶ For instance, see Botelho's research published in the *Boston Globe*, detailing stories of women with Turner syndrome (2014).

circumstances affecting Julia's family, this access to technology invites us to ask questions about what types of people we value, and whether that should even be a consideration. I explore this idea further in Chapter 6.

Sadie.

Sadie had very strong views on prenatal testing and termination. I think these views are worth noting here because first, they act as a sharp contrast to the majority of participants who favoured termination for disability, and second, they were formed through her experience as a healthcare provider. Sadie did mention that she thought her views were very unusual among people in her field, and she also said this was a very challenging issue for her, in her work. Her own pregnancy was complicated by the fact that she has an autoimmune disorder. This condition made it next to impossible to turn down prenatal testing, because the same tests which are used to screen for chromosomal abnormalities are also used to identify issues with the placenta, for which she was at higher risk due to her health condition. She could not get information about the placenta without also screening for the common Trisomies.⁵⁷ This was very disturbing to her because, in her words,

I feel quite strongly against the eugenic practice of eliminating fetuses with Trisomy 21. ...I struggle a lot interacting with the medical system because I think there's a lot of pieces to how we've designed the system that are maybe not totally congruent with how I see the world. ...That we are looking to optimize the human body and that we have developed a eugenics program that is freely available to every single person, and that we've almost constructed as a right, for pregnant people, is really problematic to me, as

⁵⁷ Sadie requested that her doctor not inform her what the results of the chromosomal testing were. Her doctor refused, saying that legally, once they had test results they were required to inform the patient what they were.

somebody whose ancestors left Poland just in time. I feel really quite strongly about the presence of eugenics in our culture.

Sadie's views in this respect were the most vehemently expressed of anyone with whom I spoke, and she was certainly the only person to use the word "eugenics" in our interview. She also spoke of supporting previous clients in their decision to terminate pregnancies for a variety of reasons—she was clear that she was not anti-abortion but opposed termination due to chromosomal abnormality. She said that it was illogical because the idea of a healthy norm is an illusion: "If you don't think that you can love a child who isn't perfect, I have very bad news for you. Because something's going to be wrong with your kid." She was also clear in her feelings that the individual choices were not hers to make, and she had supported clients to terminate pregnancies, even though that would not have been her own choice. For her, one of the hardest parts of this was listening to her fellow healthcare providers normalizing these terminations. She offered the example of an elective termination by a woman who she said could "not contemplate parenting. ... One of the nurses said to my colleague, you know, I don't agree with this. It's one thing if there's a disability or something." I included Sadie's story here because it is an excellent example of the agency of a person who is both a healthcare provider and a parent, in developing such an oppositional view towards prenatal testing. It also provides profound insight into the ways discourses of disability have permeated prenatal care, and the difficulties that are often faced in trying to opt out.

Disability and Termination: Views of Healthcare Providers

In this section, I cover participants' reports of their experiences speaking about disability and/or termination with their healthcare providers. I did not specifically ask what type of healthcare provider participants used, but all participants told me, and there was a range

including obstetricians, family physicians, midwives, nurses, doulas, and other healthcare specialists involved in non-pregnancy related aspects of their care, such as oncological gynecologists and specialists for their pre-existing medical conditions. Several participants had experiences with more than one type of care, having switched their care providers between pregnancies, or even in some cases during pregnancy. Those who did choose an obstetrician usually also dealt with family doctors, sometimes several of them, since their care was not usually switched to the obstetrician until twelve or in some cases, twenty weeks gestation. For this reason, prenatal testing usually happened with family doctors or midwives. Some participants also shared experiences in other Canadian provinces or other countries, having had babies elsewhere before moving to Ottawa.

Many participants reported that they had received excellent, supportive care from their healthcare providers. Others were livid, often traumatized by the experiences they had had with medical care. In this section, I focus specifically on their reports of their healthcare providers' attitudes towards disability and termination.

Grace, whose termination story is told in the section above, had perhaps one of the most directly coercive experiences when her doctor informed her of her test results: Based on the ultrasound, Grace notes, "Our obstetrician at the time, my OBGYN was able to tell—not able to tell that it was Turner syndrome, but right away, he said, 'Something's wrong, things don't look right, *this is not going to be your baby.*'" I think it is worth noting, in telling this story, that while I found this way of telling Grace her test results to be extremely coercive and ableist, with the doctor essentially making a decision to terminate on her behalf and telling her what to do, Grace actually did not have this reaction to the doctor's words. She reported feeling very well supported by her doctor in this respect, likely because his assessment was in agreement with her

own desires and decision-making. Still, to me this interaction does not give the patient an opportunity to make an informed decision. In a situation like this, I think a person who did not want to terminate might feel very uncomfortable to say so, and someone who was undecided would be much more likely to be pushed towards termination by this exercise of medical authority.

Grace also reported two other instances of a healthcare provider telling her what to think about her situation. She said that after her termination, she spoke to a friend who was a doctor, and “I talked about her as a baby, and my friend (who’s male) was like—why are you doing that to yourself? You don’t have to.” The friend encouraged her to think of it more clinically, as a fetus, and of the abortion as a medical procedure. In this case, Grace did push back a bit against the framing, saying, “No, because all my hopes and dreams were attached to that pregnancy, too, right? I’ll call it what I want.” She also mentioned that in speaking with another friend who was a doctor, that friend had given her language through which to think about her termination. “It wasn’t like an aborted pregnancy, it wasn’t a terminated pregnancy, it was an interrupted pregnancy.” Grace found this way of framing what had happened to her very useful, but I think it also speaks to how we use euphemistic language to process decisions that might otherwise be unpalatable, which I will further explore in Chapter 6.

The potential to push a pregnant person towards a particular decision is also apparent in Martina’s story of receiving a false positive for Trisomy 21 on her Integrated Prenatal Screening (ISP) test. After being told on the phone that she had screened positive for Trisomy 21, without any context to inform her that this test was not diagnostic, and further testing would be required for a diagnosis, she went to her doctor’s office for further information on the testing and for next steps. Martina reports: “She immediately started talking as though she assumed I would

terminate the pregnancy if the result was the fetus had Down syndrome. Just without me indicating anything.” In this case, having previously decided with her husband that they would wish to continue a pregnancy if the fetus were diagnosed with Trisomy 21, Martina was offended by the doctor’s manner, but also reported that she began second-guessing her own decision because of it:

...It made me feel quite uneasy and more sad, because I thought, well am I crazy for not wanting to terminate—she’s just assuming that’s what we’ll do, so does that mean this is so dire that that’s absolutely what we should be doing?

This demonstrates the extreme vulnerability of pregnant people to medical authority in a situation where they have less access to knowledge, and they are often making an assumption that the medical provider is acting without an agenda. In fact, the above examples show an inherent bias towards termination of fetuses perceived to be disabled.

Another interview, with Lauren, also demonstrated the strong likelihood of pregnant people being influenced by their healthcare providers in making this decision. When asked what she might have done if there had been a diagnosis of illness or disability, her response clearly demonstrated the significant weight some patients put on the doctor’s recommendation:

I think that there would be a spectrum. I think partly it would be what the doctor would recommend, if the child was going to be born with such a physical or mental handicap that they ...wouldn’t have a life worth living, to a certain extent, I think that then, if the doctor was recommending—it does happen sometimes that they recommend that you terminate the pregnancy—then I think that consideration would have been something. ...I mean, who decides these things? But anything that meant that it might be harder for them

because it is a disability, but they could still live a long and happy life to a certain extent, we would just keep the baby and deal with the challenge.

This quote is remarkable to me for the power of decision-making given to an unknown and hypothetical medical authority, particularly given the last sentence, which showed that Lauren had in fact given some thought to what constitutes a valuable life, and had her own opinion about this. This kind of scenario demonstrates that medical knowledge is not always required to make an ethical decision for one's own circumstances, and yet shows a heavy deference to authority which could easily be used to coerce.

Medical Authority and Responses to It

Further to this point about deference to authority, even when the pregnant person does not change their mind based on a medical recommendation, these directed expressions of what constitutes correct behaviour, spoken by healthcare providers, can seriously affect their experience of being pregnant. For instance, Sadie mentioned that her experiences in referring her clients to other healthcare providers often demonstrated the coerciveness of those consultations, not only with regard to prenatal testing but the gamut of decisions related to pregnancy:

All the time I've sent people to consult, to deal with an issue, and they've said I didn't want to do that, but the doctor said that my baby would die, or the doctor said that I was putting myself at risk, or whatever, I wasn't safe, it wasn't the right thing to do, and I'm still going to do what I want to do, but I don't feel good about it now.

Indeed, while the above section outlined a few instances of medical providers pushing pregnant people towards termination, and demonstrated feelings about 'abnormal' pregnancies within the medical community, there were many more instances of medical providers exercising authority in ways that were not directly related to prenatal testing decisions. These are important to

consider as well, because they contribute to the overall power dynamic between the healthcare provider and the client, and they establish a pattern. From my perspective, if the doctor has shown themselves to be unwilling to accept a patient making their own decision on something small, I suspect the patient will be less likely to be comfortable pushing back on future occasions. This is especially important given that in Ontario there are doctor shortages which mean that patients often wait years to access a regular family doctor; simply moving to a different healthcare provider is often not an option. Often, the responses reported by participants demonstrated that they found themselves either bracing for a fight with their healthcare provider or giving way on smaller matters to avoid it—picking their battles, in other words. When they did have a provider who respected their decision-making, they often still used hierarchical language to describe it; for instance, Tanya, who reported that she enjoyed having a midwife because “she let me guide things a little more.” This framing demonstrates that it was still up to the midwife whether Tanya felt able to take a stronger leadership role with regard to her own pregnancy.

The stories of medical providers exercising authority with regard to participants’ decision ranged from very overt, and offensive to the participants, to very subtle. On the extreme end of the spectrum was a story told by Isabelle, that she had questioned her doctor about the need to do the gestational diabetes test when her risk factors were low.⁵⁸ She said the doctor responded to

⁵⁸ This test was perhaps the most frequent example participants gave of either refusing a test, or wanting to refuse a test, particularly for those in second or subsequent pregnancies, since it involves drinking an extremely sugary drink and then doing a blood test about an hour later. Many participants expressed that they did not want to do the test, both because it is unappetizing, especially for those who were experiencing pregnancy-related nausea or food aversions, and because of concern that the sugar content would be bad for the fetus. Furthermore, those who test positive may be subjected to a gruelling round of follow-up testing, and need to follow stringent dietary protocols for the remainder of the pregnancy. Women who have experienced this before may be especially unwilling to repeat the test, but their high risk level would likely make doctors very unwilling to accept a refusal.

her query with, “Were you not spanked as a child when you went against what your elders told you?” Isabelle continued, “He tried to make it as a joke and then pressured me to go for the test.” This response demonstrates not only an extreme level of medical hubris but also complete contempt for both the patient’s right to ask questions about her care, and for her dignity. Isabelle also reported that when she switched to a midwife, there were fewer tests in general—for instance, fewer urine tests and weigh-ins were optional. In lieu of these tests, she said, the midwife was more concerned with blood pressure, fetal heartrate, and having longer conversations with the patient.⁵⁹ Tanya corroborated this in her experience, saying, “The midwife will also actually measure your abdomen, and check your fundal measurement, and actually feel baby in your belly. The high-risk clinic was all based on the ultrasounds.” Tanya was among several participants whose pregnancies were classified as high-risk, and all reported that they experienced many ultrasounds above what they would normally expect, although even many participants with ‘normal’ pregnancies experienced a lot of ultrasounds. I will speak more to this in the upcoming section on experiences of pregnancy.

Some participants reported a high level of support from their doctors and healthcare providers, although in conjunction with this, many also said that they felt the support they received was partly contingent on some combination of their own privileged subject position, and their compliance with what they perceived as the correct decisions. As Catherine put it, “I never felt I was being swayed one way or another, but I think at the same time, I accepted a

⁵⁹ I did not specifically ask any participants to rate their healthcare providers or to compare doctors to midwives. Still, these sort of findings surfaced, alongside many reports of doctors that were very helpful and supportive. I do think it worth declaring my own bias here, since I have focused on midwifery in Ontario in previous research (Cardin, 2020a), and also chose midwives for my own pregnancies. I also had my care transferred to obstetricians with both of my full term births, and in each case I thought the obstetricians were wonderful.

standard slate of tests, so I never pushed back.” Sam’s comment spoke both to her own privilege in having her decisions supported, and the fact that she accepted many recommendations.

I think it helped that we were both educated. My husband’s a university professor, and so we automatically had the privilege of making these decisions and having them be accepted because we were seeing midwives, and because we were educated people, but also I think it helps that we were clearly considering each option, and we said yes to most of them.

Others, even those who complied with recommendations, felt unsupported and uninformed.

Elena, for instance, spoke of experiencing anxiety during her pregnancy, and the doctor recommending prenatal tests as a way to reduce her anxiety. She said, “He was a very detached kind of doctor. Typical male doctor who just focuses on the medicine, and whatever you're feeling, go talk to your therapist or your priest, right?” Elena did do the testing, but also said that the tests had the opposite effect of increasing her anxiety, and she felt completely unsupported on that front.

Medical Error

Interviews reflected a surprising degree of medical error given the high-stakes decisions often influenced by testing. These errors happened more frequently than I would have expected, and their impact was often significant. With prenatal testing, one of the most common issues experienced by participants was that their doctors were not sufficiently informed about testing, especially Non-Invasive Prenatal Testing (NIPT), which is a relatively new technology. This resulted sometimes in doctors not being able to answer participant questions (negligence, not error), which were often fairly complex, but also in participants being given incorrect information, some of which could have serious consequences if the participants had not

conducted their own research. Martina, for example, did not use NIPT in her first pregnancy because it was not yet available in Canada. During her second pregnancy, her doctor informed her about the newly available testing, and told her that it was diagnostic, which is incorrect—it is a more accurate screening procedure. The risk associated with this incorrect information is low, since if the test were positive, likely she would have been informed of further testing as the next step. Nonetheless, there is a chance of the screening tests being used to make decisions, when such tests are inconclusive and should not be used as the sole basis for decision-making. It is also not only false positives that are an issue, but human error, as in Lisa’s story below.

Lisa.

Lisa did NIPT with her pregnancy, having previously discussed with her husband and decided that they were not prepared to continue a pregnancy diagnosed with a chromosomal abnormality. The result came back and they were told they were having a healthy boy. Two weeks before the fetus was born, she had a routine ultrasound, and she was chatting with her husband and using male pronouns to refer to the fetus. The ultrasound technician cut in and said, as Lisa relates, “Well, it kinda looks like a girl. But he said, don’t take my word, trust your NIPT, because it’s genetic and so accurate. ...So I thought, okay...” The week before the fetus was born, there was another ultrasound, and again she and her husband were using the pronoun “he.” This was a different ultrasound technician, and again, they cut in to say, “it doesn’t look like a boy.” Lisa, who is a biologist, became very concerned that the fetus would be born with a chromosomal condition called XY gonadal dysgenesis (Swyer syndrome), a condition in which a baby has female external genitalia but a Y chromosome. Babies with this condition are generally healthy, but there is no onset of puberty and surgeries are sometimes required as the condition can cause cancer. Lisa spoke with her midwife, who said it could be a mistake with the test, but mistakes were rare and unlikely. This chance of an “XY female,” as Lisa said, carried a high

level of anxiety for her and her husband: “Nobody wants a sick child, and the whole point of this testing was to make sure that we have a healthy kid.” They spent several weeks after their baby was born doing genetic testing through the Children’s Hospital of Eastern Ontario (CHEO) and lived with a high level of anxiety related to this testing for weeks. After all testing came back “normal,” the original lab that had done the NIPT took a blood sample from Lisa and compared it to the original sample. It was not her blood. They had mixed up her results with someone else’s. Lisa said, “What scared me the most was just that if we were told that we had a Down syndrome baby, we wouldn’t want to keep it. So we could have terminated a perfectly healthy pregnancy and that was really scary.”

There were a few things that really stood out for me in Lisa’s story. Of course, there is a great deal of internalization of ableist discourses (e.g. the assumption they would abort a fetus with Down syndrome). The story also shows that sexual and gender diversity can be read as disability and there is some crossover between these discourses.⁶⁰ A baby born with XY gonadal dysgenesis would not be disabled, but would have some medical issues, however it is difficult to know how much of Lisa’s fear of this was rooted in disability/illness, and how much was rooted in having a baby who would fall under the category of “intersex.”

Finally, the magnitude of the medical error in this story and the potential consequences of that error are a significant finding. Whether or not anyone else agrees with Lisa’s reasons for termination, there is an illusion of accuracy surrounding these tests which means that people are investing a great deal in their outcomes. The error drives home the degree to which society views these technologies as productive of neutral and scientific information on which we can base

⁶⁰ Indeed, previous research has shown that diagnoses of sexual chromosome abnormalities often lead to termination, often because the parents are under the mistaken impression that these constitute a diagnosis of homosexuality (Rapp, 1999).

decisions around termination, when clearly associated ideas of health are cultural and ideological.

While stories of medical error did not surface frequently, there were a few others worth mentioning briefly. Annie was told she was having a boy, rather than a girl, because of the nurse misreading her test results. The error was corrected in the same visit, and so Annie viewed this error as mostly amusing. Because of the topic of the error, it seems fairly innocuous. Had she been given an incorrect medical diagnosis, it would probably not be seen in the same way. It is really worth remembering in this context that the idea of a male or female sexed baby being equally desired is a cultural norm that is not universal, and some families would have found this error very stressful. I point this out not to defend the notion of one sex being more desirable, but to further contextualize the degree to which the binary of dis/ability is also socially constructed and culturally specific.

One final example: There were elements of Jennifer's pregnancy that also fall under the category of medical error, since her baby's heart condition was missed prenatally, while she received unfounded screening results in other areas that caused her anxiety. These results, like the parents who received false positives or inconclusive diagnoses, often feel like medical errors to the parents in question and are reported that way, although they do not truly constitute medical errors in the same way as Lisa's story of results being mixed up. Rather, they reflect the limits of the testing and therefore the perception of error arose from a failure to adequately communicate the meaning of the screening results. Better communication to parents might include explanations of limits of the testing, and the significance of the results. (What we refer to as a "false" positive isn't really so; it is that the definition of positive on a screening test is "greater than 0.5 per cent chance of the fetus having a chromosomal abnormality,"—this does not mean

the fetus has been diagnosed with anything, and this is rarely communicated clearly to the parent.) As I also explored in the previous section on communication about tests, much of this communication should happen as part of a presentation of risks before doing testing, with parents informed that ultrasounds and NIPT are screening tests, not diagnostic (and the difference explained), that the tests are limited, that they can be inconclusive, and all of this can cause anxiety, rather than presenting the tests uniquely as a source of information that will help to diffuse anxiety.

To Test or Not To Test?

In this section, I begin to move away from attitudes around disability, which of course do form the background behind most people's testing decisions, and begin to look in more detail at some of the most frequent reasons participants stated for turning to prenatal testing. These reasons contribute to additional layers of anxiety around testing and also contribute to ableist discourses.

It was also clear to me during interviews that many participants had given significant thought to the ethical implications and questions that arose due to testing. Annie said,

I'm conflicted with these tests. I think they're marketed as a way of providing reassurance to women that they have a "healthy" pregnancy, but I think as I said earlier, I think a lot of people are really personally conflicted about what that means.

There was some awareness from various participants that the tests themselves might be causing anxiety, perhaps more so even than the risk of disability. Martina mentioned a friend who had had a false positive with her first child and refused to do the testing at all with her second. She said:

I get it, because the odds are so low that you actually do have a problem, and the odds are actually comparatively quite high that you're going to get what is effectively a false positive result that is going to cause you enormous stress and anxiety, and so I kind of get just wanting to opt out of that experience. I don't think I could have done it, but I kind of understood it after that.

This acknowledgement of the emotional impact of these tests, in conjunction with a sense that they are a 'must,' for whatever reason, speaks enormously to the pressures on pregnant people and the increased imperative to test. Besides fearing that their fetus would be disabled or ill, the following four reasons were the most frequently cited by participants as factoring into their decisions: Economic incentives (in other words, they were pushed to test by doctors who were profiting from this decision), fear of miscarriage, advanced maternal age, and routine expectations.

Economic Incentives

This issue of economic incentives did not surface frequently, but it is definitely worth noting since several participants mentioned it. Several participants noticed that with prenatal testing, they were being sold a product. Several found this confusing: Because health care is socialized, paid by tax dollars, and therefore usually free for patients in Canada, some did not realize that health care is still a for-profit industry, and therefore were surprised by economic incentives to test that seemed a clear conflict of interest for their doctors. The economic incentives became more obvious to those who paid out-of-pocket to receive Non-invasive prenatal testing (NIPT), a test which is only covered through OHIP for a person with risk factors for chromosomal abnormalities, such as Advanced Maternal Age (AMA), a previous family history of chromosomal abnormalities, or a positive on the Integrated Prenatal Screening (IPS).

One example of this was Elena, who, in both her pregnancies was younger than 35 and had no family history of chromosomal abnormalities, but requested NIPT to help alleviate her anxiety. She said in her first pregnancy, the “doctor also had a lab in his office that did the tests, so he was very eager to charge me for it.” In her second pregnancy, with a different doctor who didn’t have a lab in his office, he took more time to make sure she understood the NIPT was not necessary, but then respected her choice to do it. On the other hand, Annie was provided a Dynacare brochure⁶¹ about NIPT by her doctor’s office without being prompted, and she read this as commercialization in the health care system.

Martina commented that testing “threw me for a loop” because it “looked like American-style branded health care,” and she felt that it was marketed as a sort of miracle:

Oh my God, from nine weeks on, before your jeans are even too tight, you can know if this child is healthy—you can know if it’s a boy or a girl—by the time you tell Grandma and Grandpa, you can know all of this.

For Martina, this experience was very jarring because on her first time using NIPT, she was in a small percentage of people for whom the test does not work, even after two blood draws, and they refunded her fee. She found this to cause serious anxiety because the information prior to testing did not include the possibility that it might not work, which she read as an economic conflict of interest—in other words, the company that is profiting from selling the test is also informing people of its risks, benefits, and limitations.

Fear of Miscarriage

Fear of miscarriage surfaced as a major reason that people did prenatal tests. Many of the participants had had miscarriages; some, many times. For instance, Lisa, who already had one

⁶¹ Dynacare is the for-profit company that administers NIPT and analyzes results in Ontario.

child and was pregnant again when we spoke, had gone through five miscarriages. Some, such as Allison, were able to do prenatal testing specifically designed to look at hormone levels to help put them at ease. She was living in Alberta at the time, and her physician gave her an open-ended requisition to have her hormone levels checked, so that she could continually have her blood tested and be reassured that the fetus was continuing to grow. After four previous miscarriages, this level of care helped to put her mind at ease.

Miscarriages are thought to be frequently caused by chromosomal disorders that are, in medical terms, “incompatible with life.” Because of this, some participants who had previously experienced frequent miscarriages felt that prenatal testing for chromosomal abnormalities might help them understand why they had previously been miscarrying, and/or whether or not this pregnancy was likely to be viable. For instance, Lucy said:

We didn't know why I miscarried 5 times. My husband had an older brother who died when he was a few days old. My mother-in-law said it's because she fell when she was pregnant. My father-in-law said it was ...congenital so we didn't have much information and felt a prenatal test would help give us reassurance about the pregnancy or that we were informed if there was anything to know.

Whether or not a NIPT could offer this information, it certainly speaks to how prior miscarriages can heighten the pregnant person's sense that something could go wrong. Some participants also had their miscarriages revealed through prenatal testing, an event called a “missed miscarriage,” in which the ultrasound detects that the fetus has most likely died, due to the absence of heartbeat and/or growth too small for gestational age, and then the pregnant person is left to wait for the miscarriage to begin or seek a medical treatment option to speed things along. This potentially heartbreaking situation was also a reason many people sought prenatal testing, to hear the

heartbeat at the Integrated Prenatal Screening and be reassured that their fetus was growing. This suggests that there is a potential need for more non-integrated screening opportunities, since it should be possible to use an ultrasound or doppler to hear the fetal heartbeat and be reassured about life and growth, while still opting out of a chromosomal test, if the pregnant person were to choose that. Unfortunately, Integrated Prenatal Screening with chromosomal testing is sometimes the only option for the pregnant person to detect a missed miscarriage early or hear the fetal heartbeat and put their worries to rest.

Advanced Maternal Age

Unsurprisingly, Advanced Maternal Age (AMA) surfaced as a major reason that people did prenatal tests, both because of their own concerns about age and because doctors routinely recommend extended prenatal testing for people at certain age markers (this depends on jurisdiction). Several participants noted that they factored advanced maternal age and its associations with increased disability risk into their family planning, such as Alexandra, who reported, “I had my first child as soon as I was able, and my second child as soon as I was ready.” There was also certainly evidence that 35 had been understood by participants as a cut-off age at which the risks were suddenly increased, as with Annie, who commented, “I’m 35, and certainly conscious of greater risks associated with pregnancy at this age.” For others, even just approaching the age of 35 increased their worry and pushed them in the direction of prenatal tests. For those mothers who were 40 or older at the time of their pregnancies, this was usually a significant concern. Lisa, who was 45 in her pregnancy, said, “The eggs have half expired, there’s going to be issues, so yeah, it was a big possibility, for sure.”

The desire to test in these circumstances was not always strictly motivated by fear of disability, but especially by the illnesses and chromosomal abnormalities that could potentially

be fatal. Many participants were very nervous about the potential for a rare genetic condition that would lead to stillbirth or any situation where the fetus might not be viable later on, and felt that knowing this information would offer them the potential to terminate earlier and avoid the pain of that situation, or put their minds at ease. For others, disability was often conflated with “issues” or other vague terminology used to describe their increased fears based on their age. Sam, who opted not to screen for Trisomies, noted that her age may have made her feel more comfortable, with her first pregnancy happening at age 30. She mentioned a friend who was pregnant at the same time and had recently turned 40, and was encouraged to do the NIPT due to her “geriatric pregnancy.”⁶² She reported that her friend felt very reassured by being offered the extended tests, and even a little guilty to have free access to it when younger women would need to pay out of pocket. Additionally, Sadie, who, as mentioned above, is a healthcare provider, also noted that AMA came up frequently in clinical discussions with clients who had increased anxiety based on age. She also noted that “my friends who are getting pregnant right now are thinking about it all the time.” Therefore, the communication around age and disability risk seems to be a significant factor in the way pregnant people are thinking about testing.

Routine Expectations

Finally, it is significant that many participants chose to get testing because it has become a routine and normalized expectation in our culture. Rarely did anyone say this directly, which makes sense and demonstrates the invisibility of power relations; we rarely see expectations that are normalized around us. However, the routine expectation was often made clear through my questions about their feelings when deciding to get tests. For instance, when asked if she

⁶² An outdated term for Advanced Maternal Age (AMA) which is sometimes still used by doctors, as evidently in this case.

remembered how she felt when deciding whether or not to get tests, Allison responded, “No, it wasn’t a question.” Leah, when asked why she had asked for NIPT and paid out of pocket to do so, replied “because you do get the results faster, and the data’s way more accurate.” There was no sense in this reply that choosing to do any testing at all might be optional.

In fact, sometimes people pointed out that they were not given enough information to understand why someone might choose not to test. For instance, Jennifer said,

My way of thinking was, I should get as much testing as I can to make sure that I know everything I can, but then it made me question, why would people not choose to do this test? And I didn’t really have that information.

I asked her if she ever asked her midwife that question, and she responded that she did, but did not get a satisfactory response. This may reflect an unintended bias towards ‘normalcy’ on the part of healthcare providers, who, not wanting to exercise undue influence and steer their clients towards a particular option, are not providing sufficient information about the reasons some people opt out. In the absence of greater communication, clients are often unconsciously being steered towards the most routine option, since breaking away from the status quo would require a greater deal of agency, and thus a stronger motivation.

I offer an example from my own experience to illustrate this point: My Integrated Prenatal Screening in my first pregnancy came back with “positive.” I did NIPT as advised. After my NIPT came back low risk, my midwife told me that nonetheless, the doctors were advising me to do a number of extra ultrasounds in case the false positive indicated something worrying and as yet unknown. This seemed reasonable, and in the absence of information as to why I should perhaps not do so, I complied. A later ultrasound was inconclusive: I was told that what they were seeing could be a normal variation, or could be very serious, and they would

follow up in two weeks. They told me it was difficult to determine what they were seeing because there are not enough ultrasounds done in late pregnancy, generally, for doctors to have a good understanding of how wide the normal variation can be. I felt this risk should have been presented to me and I mentioned to my midwife at a later date, after the situation was resolved, that I thought it would be helpful to include the risk of inconclusive late ultrasounds causing anxiety in the informed choice discussion. She told me that she thought heavy surveillance of pregnancy through ultrasound carries a high risk of causing the pregnant person emotional trauma, but that she had not wanted to sway my decision away from the doctor's recommendation if I felt comfortable with it. The problem with this line of reasoning is that the client must have sufficient knowledge to decide whether or not they feel comfortable. Furthermore, pregnant people are socially conditioned to feel comfortable following medical advice, and to feel assuaged by reassurance from a doctor that they are making the right decision. Thus, the non-status quo medical opinion should be offered for their consideration, as well.

The social conditioning to feel safer when following the doctor's orders is certainly reflected through comments from participants, which showed that complying with the doctor's advice provided relief from anxiety. When participants make decisions that are congruent with medical recommendations, there is a sense of performing "good" and responsible motherhood, and they are more readily able to emotionally justify their decisions to themselves and others.

This demonstrates the problem with doctors recommending Integrated Prenatal Screening (IPS) as a routine health check. It is understandable that the medical community is doing this, because it also provides an opportunity to look at early fetal growth, date the pregnancy, and check the pregnant person's body for health conditions which might be affected by pregnancy. IPS did surface in participant stories as an important health check: There were several stories

from participants of IPS or other early ultrasounds turning up underlying conditions. One example is Lauren, whose pregnancy was determined high-risk and monitored closely due to an early ultrasound finding an ovarian cyst. However, it is clear that participants are not always being adequately informed that the Integrated Prenatal Screening is not just a routine health check for themselves and their fetus, but also includes a screening test for their chance of a chromosomal abnormality; a screening from which they have the right to opt out. For instance, Lauren said that the Integrated Prenatal Screening was described to her thus: “Yeah, my doctor just recommended it. Said, you know, this would be the chance to check to see if there’s a heartbeat, just to make sure that the pregnancy was viable, basically.” When asked how she felt about deciding whether or not to do it, she responded: “I don’t know, it didn’t really seem like much of an option. I think they did present it as an option—like, you could do this if you want, whatever, it seems like everybody does [it].” This statement makes clear both that participants are often choosing the routine choice because of their own comfort in complying with whatever is recommended, and that doctors are sometimes not really presenting this screening as a choice with risks and benefits on both sides. And yet, as is clear throughout, and was also apparent from the online research, the anxiety being experienced before, during and after these tests is serious and significant.

Positives of Disability

I chose to end this chapter with a few of the participants’ many positive statements about disability because it provides both a fuller picture of the discourse, and a model for a less ableist future. I would caution, however, against an overly optimistic view based on these statements. The reality is, many participants had a high level of exposure to people with disabilities in their own lives. Many had worked with disabled people, had disabled people in their own families or

extended friend networks, and some had disabled people in their immediate families. Despite this, and perhaps sometimes because of it, there were many signs of both overt ableism and deep-seated fear of disability. Very few chose not to test for chromosomal abnormalities; some expressed the wish of being able to test further than is currently technologically possible; most feared that having a child with a disability would make parenting much more difficult. However, many also felt conflicted about the conclusions they had drawn with regard to disability. Several pointed out the resilience of the people they had known who were disabled, and expressed the sentiment that those people led good lives. Many were not arguing that it was better to be able-bodied/neurotypical, but they felt a sense that life would be such an uphill battle for any child with a disability, and they spoke to the injustice of that. In that, I do not read ableism so much as fear; the fear of a mother for a child, which, combined with the cultural responsabilization of women for children, produces and reproduces a de facto ableist biopolitics in culture.

One participant spoke of a friend who has three children, the youngest of whom has a rare disability. She observed that parenting that child demanded a higher level of management and scheduling than many parents are called upon to handle.

It's incredibly stressful in the sense that she's going to way more therapy sessions—physical therapy, speech, all these different things for her son, for her youngest, but it takes away from—having to explain to her older kids. But she talks about her son being so—he's loving, he's happy, he's her easiest baby. (Grace)

What Grace was pointing out was a view based in the social model of disability; that it is the social context of disability that is disabling, more than the actual condition. There is an added gender dynamic here, since so often mothers take on, or are burdened with a more demanding degree of domestic managerial tasks, as compared to fathers (Jack, 2014). It also speaks to a

cultural desire to provide the other children with a normative experience of childhood, based on an idea that exposure to disability would primarily disrupt that.

Sam also mentioned that wider adoption of new technologies could be a major help for families with disabled children. She told a story of friend whose child was non-verbal, and that an eye-gaze based talking device “similar to what Stephen Hawking uses,” had helped that child to speak to her own child, and the two girls were able to develop a strong friendship. She added that one of the better improvements in this technology in recent years was the addition of children’s voices to the devices, which has had a huge emotional impact for the parents and friends. She also mentioned that her favourite teacher in high school was a wheelchair user, and this experience had a lasting impact on her views. She said that very soon after this, she shattered her ankle and was forced to take a year off from university because of the poor accessibility of her school, and that these two experiences in close succession made her very convinced that disability was caused mostly by lack of social support. She was also one of the only two participants who opted out of testing for Trisomies. The other was Alexandra, who also had extensive experience of people with disabilities in her own life: She had grown up with a close friend whose brother had Down syndrome, and she had two close neighbours whose children were autistic. She described those parents warmly, saying, “They found a way to make that life normal. There was as much love in those homes.” Alexandra’s opinions on disability were so open-minded, but it was also so clear from her interview how much effect common discourses had still had on her—she was worried about Advanced Maternal Age, and she reported experiencing a high degree of anxiety in ultrasounds.

There was, however, clearly a connection between these types of exposures to disability, and positive feelings about people with disabilities, in most cases. Some of the most positive

comments came from Tanya, and Sadie, the two participants who had the most personal experiences of disability. Tanya, as mentioned, said she was not disabled, but that she had an autoimmune disorder which made people treat her as disabled, and which could potentially become disabling at some point. She also had a child with learning difficulties (she was very specific about those challenges, and she did not speak of her child as disabled.) She said:

I just wish we wouldn't even say disability. I wish we had better terms. I just wish we all would recognize, we all have strengths and areas that are not strengths, and we can all help each other in different ways and all learn from each other in different ways.

Sadie, who is disabled, said something similar:

My hope is that with every year that goes by the future for every child with a disability is better than it was the previous year, because we are getting better and better at helping people manage the physical aspects of their disabilities and limit the ways in which their disabilities negatively impact their health. And I hope that we are also getting better at trying to move the needle a little bit and recognize the diversity of human beings and celebrate the ways in which every person has strengths and weaknesses and makes an important contribution to society, just by being a citizen. I think it's better than it was twenty years ago and I hope that in another twenty years it's going to be even better.

I end this chapter, therefore, on this incredibly positive and hopeful note from Sadie, which I think does speak to the possibilities that exist for a counter-discourse to flourish even within the increasingly routinized medicalization of pregnancy and the imperative to prenatal testing. In the following chapter, I review some of the findings that were common to both the online research and the participant interviews, and discuss that imperative further.

Findings in Brief

The phrase “As long as it’s healthy” carries significant cultural connotations—for some participants, it was a self-evident statement, reminding them of the importance of health as a measure of the good life, over less important factors such as the sex of the fetus, while for others, it was dismissive of disabled people. Some participants also commented on the role this statement plays in minimizing the pregnancy experience for the mother, dismissing trauma or obstetrical violence as long as there was a final outcome of a healthy baby. Some spoke to the clear role played here by cultural norms of responsible motherhood.

Some of the participants had personal experiences of disability, and others had children with disabilities or chronic illnesses. The line between these was blurry, with some people reporting that chronic illnesses were disabling, and others not. Sometimes personal experiences of disability coincided with less prenatal testing, or with greater comfort at the idea of having a disabled child, but not always; in at least one case, the participant worried that her own chronic illness would interfere with her ability to care for a disabled child. Most participants spoke to their deeply felt fears around having disabled children, which included the trauma they might experience themselves, having too much to manage, the fear that their children would never be independent, the expenses associated with disability, and more. Some had given significant thought to this, especially those who had experienced false positives on their Integrated Prenatal Screen (IPS), or the participant who aborted due to fetal diagnosis.

Just as for the online commenters, participants experienced high levels of anxiety and stress associated with most aspects of their prenatal tests. These were often worse for participants who had traumatic experiences in previous pregnancies, and there were few, if any, supports offered.

One very substantial finding was an association between gender and disability, in two ways; one, that more than one participant reported being nervous because of a cultural stereotype that boys are more likely to be disabled (and a family history of neurodivergence in boys), and therefore the knowledge that they were having a boy caused anxiety. The second way was that a potential diagnosis of being intersex was perceived as a type of disability, and there was anxiety around this.

The participants had highly variable experiences and views on termination, all of which reinforced how prenatal testing technologies constitute biopolitical techniques. Whether it was Julia, using extensive embryo testing during IVF to choose a fetus without the gene for her husband's chronic health condition, or Sadie, reacting as a health care provider to colleague's statements that terminations were more ethical in the case of fetal disability, the takeaway was the pervasive ableism that pregnant people contend with, and often reproduce. This ableism is predicated on the idea that the good life is characterized by health and the mythical norm. This discourse was clearly reflected in medical biases, according to many participant stories.

Both medical error and exercise of medical authority surfaced in interviews, both having significantly impacted pregnancy experiences. Decisions to do prenatal tests were often based on routine expectations—prenatal testing has become firmly entrenched as a norm of responsible motherhood. Where the participants had more deeply considered whether or not to test, advanced maternal age was often a significant concern, either due to their own internalization of 35+ as more dangerous for pregnancy, or because of recommendations by their healthcare providers. Many also tested specifically because of a past history of miscarriage, because of pressures placed by doctors who were profiting from the testing, or due to social normalization of the

testing through advertising. This final reason is further explored in the following chapter, as part of the communications about testing.

Chapter 5:

Interviews, Part 2: Communicating Pregnancy and Shaping Experience

Introduction and Chapter Roadmap

Through participant interviews, I found that the way prenatal testing and pregnancy more generally are communicated can have a profound impact on shaping experience. Pregnant people are navigating a significant quantity of new information, and making important decisions, often very quickly, all of which is impacted by many aspects of communication from many sources, including medical providers, family, friends, and online information. Whereas the previous chapter based on interviews focused on prenatal testing and attitudes around disability and its conflation with health, this chapter provides a broader perspective related to how these issues are communicated. During interviews, the access participants had to information and the communication around testing struck me as significant, both because of the high levels of informational literacy they demonstrated, and because of the interconnection between these communications and their experiences of pregnancy. The examples in this chapter, therefore, serve to demonstrate the central thesis of this dissertation: that prenatal testing technologies (as designed and used in North America), as they are constituted by biopolitical, eugenic discourses surrounding disability, have infiltrated and affected nearly every aspect of the experience of pregnancy. This was evident in the ways in which participants described how pregnancy was mediated. My findings indicate that pregnant people are worried about disability, and even when they are not, their healthcare providers often are, and this worry and anxiety has pervaded institutionalized prenatal care in a way that negatively affects many people's experiences of pregnancy, and in a way that further entrenches discourses of disabled people as unwanted.

In this chapter, I look at the ways participants experienced communication about tests and results from their healthcare providers, which were deeply interconnected with discourses of disability as problematic. Relatedly, I also explore the sources of information that participants consulted to find out about tests, which sources they perceived as better, and why. This section provides significant clarity about how testing decisions are made, and I think also provides an excellent starting place to suggest some improvements to these communications. I then offer some of the participants' experiences of pregnancy that are unrelated to prenatal testing, because these tie into the responsabilization of pregnant people and mothers in general, which has a ripple effect to prenatal tests. In this section, I also dig a bit further into some of the sources of information addressed as they affect experiences of pregnancy, in particular, discussing pregnancy books and some prenatal testing advertising. I think these slight digressions are worthwhile because they form part of the discursive environment that is informing pregnant experience and decision-making, and because the examples I offer were specifically mentioned by participants.

Communication about Tests

Communication about tests—what they test for, their risks and benefits, and in particular, what the results mean, were described as inadequate by almost all the participants in this study. They were often left wondering what tests looked for or what results meant, and turned to friends or online sources to compensate for the lack of information from their medical providers. Communication about tests remained unclear to many pregnant people, and it often caused more anxiety than the results themselves. Communications around tests directly contributed to the negative impressions participants had of what the results might mean for their lives. Whether or not it is intentional, these communications build and reinforce a discourse that disabled lives are

a burden, likely because healthcare providers have internalized (and sometimes propagated) those discourses themselves. These interviews also revealed the level to which communications are non-standardized, with far too much leeway in terms of what information is provided or not provided to patients, and the issues reported by participants show a need for healthcare providers themselves to know more about the process and meaning of prenatal tests. I can only speculate as to why—it may be that these inconsistencies occur because prenatal testing is done by private companies who are not mandating standardized information packages, or because there is no oversight or governing body dictating what needs to be included in the information communicated about these tests.

The way results were offered caused unnecessary anxiety at times, and the current system does not allow for anyone to opt out of results that are bundled (sometimes the tests themselves can be opted out of, although not always). As mentioned in the previous chapter, Sadie, for example, with her own knowledge as a healthcare provider (and on the advice of her doctor), decided to do an Integrated Prenatal Screen for the sake of getting results about her placental growth, but asked to opt out of information about Trisomies, and was denied that option. It is a significant finding that tests are bundled in a way that the doctor is compelled to provide information the pregnant person has specifically requested not to be provided with. This certainly also speaks to a cultural or legal bias within medicine that information about disability, once known, must be shared with the “patient”—compare this to information about the sex of the baby, which is often discovered during ultrasounds, but which the parents are free to opt out of knowing, because it is not considered medically important. I think there is also an implicit assumption here as well that parents need the information about disability because it might

contribute to termination decisions, unlike sex, and that assumption may be subtly conveyed to the parent by this policy.

The phrasing of prenatal testing results was also very problematic at times—where medical lingo is routinely used without necessarily considering how scary it sounds, out of context and without proper explanation. For instance, Catherine said she received communication from an early ultrasound that showed the fetus’s organs growing outside its body. This information on its own sounds very alarming, but this is perfectly normal in early pregnancy. The issue was this was happening later than one would expect. She was told there would be a follow up ultrasound in a few weeks, at which point the problem would either have resolved itself or the pregnancy might be “incompatible with life.” This was her perspective on this result:

That caused a lot of anxiety for me, but at the same time, I don’t think she [the midwife] did anything wrong in telling me that, because it’s true and I don’t want to be misled, but that was based on the information she had available. She didn’t say it was [incompatible with life], or that it was likely, she said, just sit back, we don’t really know at this point, we’ll see in two weeks and then we can talk in two weeks depending on what happens.

This communication is complex—the information offered to Catherine was correct, and there is a legal requirement to communicate it (College of Physicians and Surgeons of Ontario, 2019), but it is an example of inconclusive information that does little other than produce anxiety, the adverse impacts of which have been noted in previous studies (Alder, Fink, Bitzer, Hösli, & Holzgreve, 2007; Richmond et al., 2017). There were, equally, quite a few cases of pregnant people being told their fetuses had some type of difference (which of course, depends on a cultural mythical norm) that might be worrying, but not being told why. Jennifer, for instance,

said that her baby was diagnosed in utero with having a too-small head, but no one ever really explained to her why or how this might be a problem. She spent weeks thinking about the Zika virus babies she had seen in the news, and doing Google searches for microcephaly, and not finding information to be easily available or accessible. Months after her baby was born, with other medical issues that have been her priority, she still is not clear on what the too-small head might mean for her child's future. For now, it appears, it could be an issue at some point, or it could be a variation on 'normalcy'—human heads do come in a wide variety of shapes and sizes. This is an example of failure to emphasize that a range of normalcy exists, as well as the limitations of both medical technologies such as ultrasound for fetal diagnosis, and existing medical knowledge pertaining to ultrasound results.

One area of communication about tests that was highlighted by multiple participants was ultrasound technicians. Ultrasound technicians are the first line of contact for many people in getting their test results, and although they are not responsible for giving those results, participants reported being greatly affected by their experiences during ultrasounds. Several described how they knew the ultrasound technicians were supposed to have a "poker face," but that because many do not, the neutral faces often caused a great deal of anxiety, with participants worried that because the technician was saying nothing, something was wrong. Several participants noted that this testing has to be conducted with the utmost sensitivity to how much anxiety the pregnant person may be experiencing. Tanya, for example, said:

It's nerve-wracking, sitting there, and having them twist you this way and that way, and stand here and sit there, and lie this way, okay, no, stand up a sec, okay, no, go pee, come back, lie back down. And when they keep trying to look at the same area over and over

again, you have to wonder if there's something wrong, and they're trying to make sure they have a good image of it to show the doctor or the midwife.

She suggested that without giving anything away, even just a bit more communication such as “I just can't get a good image from this angle, can you roll over on your side?” would go a long way to putting the pregnant person more at ease. Sam echoed this concern, saying that during ultrasounds she had experienced, both prenatal and otherwise, ultrasound technicians said, “the craziest, off-book stuff.” Better training for ultrasound technicians was an important recommendation, in her view: “I feel like, if your PhD had the power to change how people share information about prenatal testing, one of my major concerns would be better training for techs.”

Tanya also expressed that for high-risk pregnancies where many ultrasounds are ordered, the variability in length can cause anxiety, with a person wondering why their last ultrasound was twenty minutes but the current one is forty-five. She said she spent a lot of time watching the clock, trying to glean whether everything was fine. In this case, a bit more communication to the pregnant person about what to expect, and that there is variation in ultrasound time, might help reduce anxiety. She also had a very specific note about the way results are delivered, which seems simple: When everything is fine, doctors should begin by saying that, before giving the specific details. In one pregnancy, she complained to the hospital after a doctor took 45 minutes explaining the results before concluding with “everything looked fine”:

The way they told us the results that time around was, okay, so we looked at all of these different things, and let's just go through step-by-step of what we looked at, and what we found—okay, so we started with the head, and the head looks fine, and we double checked the circulation, and well, that's okay, too, then we moved to this other body part,

and the way he delivered the message where he was going body part by body part and system by system... you're just waiting on the edge of your seat going okay, which body part's the one that has a problem with it?

In a 'normal'-looking pregnancy, the mistake in communications strategy here is just so blatant and clear, and shows a profound lack of awareness or caring for the affect and experience of these tests on expecting parents.

Another example shows how medical jargon, used out of context, can cause anxiety. Martina received a false positive for Down syndrome on the IPS. There were two major communication issues to highlight in this story. One is that because she had a previous NIPT that had not worked, Martina requested to do an IPS in tandem with her NIPT, as an insurance policy of sorts, in case the NIPT failed again. However, she was now over 40 and IPS has a very high rate of producing false positives at this age. No one ever informed her of this, and she only received this information after her false positive scare, when a doctor later told her that given the high rate of false positives for older women, the test should never have been ordered in the first place, or at least the doctor should have informed her of the high chance it would screen positive due to her age. The other major problem is that she was told, over the phone, that she had "screened positive for Down syndrome," with no other contextual information whatsoever. In Martina's words:

I think the very language they use for that is an enormous problem. I understand that that is technically true, that they got faxed a piece of paper from a lab that said your patient screened positive, but what that sounds like is your baby has Down syndrome and you need to figure out what you're going to do about it.

In fact, an IPS is flagged as “positive” whenever the fetus is deemed by the algorithm to have a 0.5% or higher chance of having Trisomy 21. (In other words, still up to a 99.5% chance of no Trisomy.) This is a screening, not a diagnosis, and while the difference may be clear to a healthcare provider, health care professionals cannot assume an understanding of the difference in their communications to parents, even if this has been explained before the IPS, which it often is not. The IPS will also return more specific odds for that pregnancy, again determined by an algorithm, that includes blood markers, the mother’s age, and measurements from the ultrasound. All of this is complex, and as Annie noted, very difficult to understand for a person not informed in medical jargon:

You do your best to muddle through exactly what you’re testing for, and what that means and how to interpret those results, but it was certainly our experience that those communications materials that are prepared could be a little bit easier to understand. We understood we were testing for particular abnormalities, but what that really meant in practice wasn’t super clear to us.

Indeed, one key piece of this is that doctors, nurses and even ultrasound technicians are often a first point of contact for pregnant people, so the importance of correct and clear communication from these healthcare providers is paramount.⁶³ It also needs to be carried out in a way that recognizes that this is a stressful situation for pregnant people, who are likely going to be reading a lot into silence, and who are going to head straight to Google if answers are not forthcoming or satisfactory—as we see in the next section, where the internet was a major source of information

⁶³ I think it is also worth noting here the difference in these categories of healthcare providers and the type and breadth of training, and certainly different salaries. Medical sonography in Ontario is a two-year college program, as compared to the many years of training which doctors receive. This is not to undermine the need for improved communication, only to highlight that this needs to be taken into account.

reported by participants. Finally, we see the assumption made by medical providers that disability constitutes a burden for parents as a background to all of these test results, which is in itself productive of anxiety and contributing to the reproduction and reinforcing of the cultural environment in which disability *is* a burden. Culturally pervasive ableism is a problem grounded in discourse, which has material consequences, and test communications are a large part of that.

Sources of Information

Participants were asked what sources of information they used to find out about prenatal testing—information such as what the tests entailed, what they were looking for, as well as the sources they used to understand the results, when applicable (since only participants who had results that caused them anxiety sought more information). This section also looks at the sources of information they used to find out about pregnancy more generally, since for many participants, they were looking for information on prenatal testing as part of a larger information seeking venture on pregnancy. Three major findings emerged from this question.

Highly Informed Participants

First, as with the online comments, the participants in this study were very well informed. They were actively seeking to be informed and have agency in their own health; they asked their healthcare providers questions that were well-researched, detailed, and specific; and they had excellent informational literacy skills. For the most part, they knew exactly how to find good information and how to evaluate it. They also often felt that this level of information literacy was necessary for them in order to compensate for deficits in information provision from their healthcare providers. Lauren, for instance, said, “The biggest takeaway for me is how much in any health situation you need to take control of it yourself.” She said that her obstetrician and other doctors always took the time to answer her questions and she never felt rushed; but, she

emphasized that if she had not taken the time to ask those questions she would have gotten very little information. Martina's experience also reflected this, and she said that there is a level of privilege involved in this even being possible; this was a point brought up by several participants who were aware of their own privilege in accessing the healthcare system in the way that they did. In Martina's words:

I also realize that I have way more resources and ability and inclination to look for more information to understand this than the average person... I, at least, could read and understand the language to give myself a bit more rational reassurance.

This comment speaks to the privilege of both information literacy and higher education, and of the lack of language barrier experienced by all participants in this study. Several participants also had access to healthcare providers in an unofficial capacity; for example, they had a friend who was a doctor, or they worked in healthcare-adjacent fields, and many felt much more at ease speaking to these friends and getting their questions answered in this informal setting. This, too, constitutes a type of privileged access. It also leaves open the question of liability and transparency: Should doctors informally offer pregnant people information on which they may rely to make decisions, outside of the professional dynamic, where there is theoretically some kind of recourse for a patient who receives incorrect information?

Several of the participants also specifically reported that they had used academic articles to further understand the tests or their results, and several specifically mentioned they had access to PubMed, which definitely constitutes privileged access to information⁶⁴. In fact, some participants informed their doctors about the availability of testing and/or the meaning of the

⁶⁴ PubMed is a database of medical articles from academic, double-anonymous peer reviewed journals. Access is determined by paid subscription and is expensive. Institutions such as medical research facilities, hospitals and universities usually pay for access and therefore being employed by such an institution would be one way many people would gain access.

results. In Isabelle’s case, the NIPT was new enough that she said she told her physician about it, and her physician looked it up. “She was like, oh yeah, I think I saw an email about that, or something.” Martina, whose story was also mentioned in Chapter 4, was told by two separate healthcare providers that they could not answer her questions: “I remember the resident looking at me like I was asking him to explain the solar system or something.” The second time, she said,

I had all these very specific questions like what does this mean, when is the NIPT result coming back, does this happen a lot, what do the odds mean? And she literally laughed and threw her hands in the air and said “I don’t know. I don’t do this all the time. I’m a family doctor—I have no answers for you.” Which is like, oh my God, it’s fine if you don’t have specialist information, but don’t literally snicker at me, and tell me you don’t know any more than I do.

Understandably, many participants found the experience of not being able to get answers about NIPT from their healthcare providers frustrating; it may also simply reflect how new these tests are, and that even experienced doctors are still learning about this area of testing. It also reflects the extent to which participants were doing research on their own or sharing information informally prior to their appointments with doctors.

Use of Online Forums, Websites, and Pregnancy Books

The second finding in this section is that many participants were actively using the type of online forums explored in Chapter 3. I did not ask specifically about online forums, but many brought them up, and there were both positive and negative reactions to them as a source of information. Some seemed sheepish in confessing they had used online forums: They saw the forums as poor sources of information that could cause anxiety, but were drawn to them, nonetheless. Others mentioned them only as a poor source, and only in relation to other sources.

For instance, Martina, who, as mentioned, had a false positive Down syndrome screening, thought there was a danger to these sources in that the experiences were out of context:

You don't think to yourself, that's a half a percentage possibility, you think to yourself about the one person on Babycenter that you saw who said they had a similar result to yours and then a week later their follow up post was yes, and it's proof for me.

Catherine said something that echoed this—that for her own mental health, it was important to stick to sources of information that she deemed better, and to avoid chat forums:

Don't read a whole chat forum—because undoubtedly there's somebody who's had heartburn and they've posted on the internet, and then they had a miscarriage, and you don't need that. And so in that way, I tried to be quite disciplined in looking at reputable sources rather than going down this rabbit hole, which I did do a little bit in the beginning of my pregnancy and then just found it's not a healthy place for me.

Some participants, on the other hand, felt these sources could provide important qualitative information that was lacking in other areas—they looked at other places for data, but felt these forums could provide a window into people's actual experiences dealing with similar circumstances to their own. Lauren explained the importance of this thus:

So really the quantitative and the qualitative side, I wanted to see both. I wanted the numbers that really explained to me why something was either bad for me or what a test was for, so that I understood what was going on. And then anything that was more about people's experiences.

Grace, too, felt this way, and used both Babycenter and Reddit forums. She described her use of these as initially passive—she wasn't posting, just reading, but then also told a story about making a friend through a forum. When she had her test results that indicated Monosomy X, she

looked at a Babycenter forum specifically for people with this prenatal diagnosis and began chatting with people there. She hit it off with another mother in Norway, who had the same test results, and they moved their chat to private messaging. She and this other mother became a source of support for one another as they both went through their terminations, and then both got pregnant again in the same month. For her, this forum had therefore been an excellent source of not only information, but support. Others also mentioned them as potential sources of support: Jennifer found a community of other parents of children with congenital heart conditions, and Alexandra mentioned that if she had a child with a disability she assumed this would be a useful way to find support.

Additionally, some participants felt that the quality of these forums was variable and had strong opinions about which were better than others: “We ended up steering away from What to Expect, and steered more towards BabyCenter” (Sam). In fact, when I initially asked about sources of information, I expected vague answers about Google searches, but in keeping with the high level of information literacy I noticed throughout the interviews, many participants listed the websites they had used and had strong opinions about each of these websites as sources of information. For instance, several mentioned the NIPT websites as an important source—there are a few such websites for the private companies such as Dynacare. NIPT is marketed under the brand names Harmony and Panorama, and some people mentioned using the Harmony or Panorama websites directly. Later in this chapter, in the section on NIPT, I will further explore these companies’ advertising, arguing that it is worrying that these websites are so frequently being used as sources of information. Other websites that participants listed included WebMD, The UK’s National Institute for Health and Care Excellence (NICE) guidelines, Prenatal

Screening Ontario, the Society of Obstetricians and Gynecologists of Canada, Motherisk (which is now defunct), WhattoExpect.com, and BabyCenter.

Participants were also very specific about what pregnancy books they had read, and which were better or worse. It seems that *What to Expect When You're Expecting* (Murkoff, 2008), which is sometimes popularly referred to as the pregnancy “Bible,” may be going out of vogue. Lauren described it as “out of date” and said, “It’s just a terrible book; I just didn’t find it very helpful in any way.” In its place, *Expecting Better* by Emily Oster (2018) is perhaps having a moment, since it was highly praised by several participants, and was described by Martina as a “sanity Bible.” Oster is an economist, with no medical background, who researched pregnancy when she had children, and approached pregnancy as a series of statistical questions about risk and benefits. The result is a book which I am not surprised is popular, because it advises pregnant people to do their own risk/benefit analysis rather than always listening to their physicians, and also paints a number of activities they probably want to do as safe. I will explore this further in the upcoming section on experiences of pregnancy. Other books mentioned by participants included *The Baby Book* (Sears, Sears, Sears, & Sears, 2013), *The Mother of All Pregnancy Books* (Douglas, 2011) and *Ina May’s Guide to Childbirth* (Gaskin, 2003).

Several participants also pointed out that simply classifying the sources of information they were using as “better” or “worse” was overly simplistic. Not only was it a question of quantitative vs. qualitative information, but also of the depth and type of information being sought. Elena, for instance, said of Prenatal Screening Ontario, that the information wasn’t bad, it was “just very basic. If you want to know more about the risks and percentages and really go to what exactly the information is and how does the test work, then you need to dig a little deeper.” Martina commented that this was especially important in trying to understand test results:

Yeah, it's not just the level of accuracy, it's also the level of sophistication. With my third when the result came back as screen positive, I didn't want information on the basics of what to expect from the testing, like you would find in *Parents* magazine or whatever, or the BabyCenter app. I wanted—tell me exactly what these numbers mean, each of these blood components, the ratio they come up with, the nuchal fold measurement. ...So I guess, because I was looking for both more accurate information and more specific information, I was looking for more technical sources rather than yay, you're pregnant, here's how the testing goes.

In both Elena and Martina's statements, we see a clear need for sources of information that are complex, responsive to specific questioning, and also accessible, since not every pregnant person is going to have access to a medical research database, or the informational literacy to understand what they would find there.

Inconsistent Healthcare Providers

The third central finding in this section is that several participants felt their access to information from healthcare providers was compromised by the lack of continuity in their care. There were several participants who experienced pregnancies where they were switched from one doctor to another, especially in the early months of pregnancy, during prenatal testing. This meant that they were put in the position of repeating everything they had said to the previous doctor, not yet trusting the doctor they were seeing, and frequently, finding the answers to their questions insufficient. For those who had a consistent care provider, especially one they had been seeing for an extended time prior to pregnancy, this was a significant boon in terms of the quality of the information to which they had access. Participants reported that when their providers had been developing a relationship with them over an extended period, they also were familiar with

the participant's level of information literacy and therefore were more forthcoming with a complete picture, often printing articles to give to their patients.⁶⁵ Tanya, for example, who had a long-time, trusted relationship with her physician due to her autoimmune disorder, reported that her physician and midwife both printed articles for her, and she paraphrased her doctor's words thus: "We don't provide this to all patients, because not all patients, sadly, can appreciate and understand the research article, but we know you will, and we know this will help ease your questions and anxieties."⁶⁶

Martina mentioned several times during our interview how the inconsistency of her care providers during her third pregnancy, when she screened positive for Down syndrome, contributed profoundly to her poor experience. She was very clear that having continuity in her care would have meant she was more comfortable asking specific questions, and she would have felt more confident about getting answers. Constantly switching providers, and therefore having to reintroduce her situation at each visit, felt like a waste of both her own time and the doctor's. "It was a condition of me bumping around to all these different doctors. I did not feel like I had good guidance. I felt like I was basically doing my own case management." Even the ability to take charge and do one's own 'case management' reflects a level of privilege, and this situation

⁶⁵ I want to highlight this finding in particular as something that was really important to several participants. In keeping with a feminist approach to research that views participants as actively involved with the research and not as "subjects" to be studied, it was important to me to highlight findings that participants themselves flagged as significant. There were several times that participants signalled the importance of a topic to me through phrases such as, "I hope your study can help with this," or "This is one of the reasons I really wanted to participate." This finding is important because multiple participants were clearly affected by the lack of continuity in their care.

⁶⁶ I did not ask participants specifically about their incomes or socio-economic class, but it was clear to me that many of the participants were highly educated, which is reflected in their experiences with medical providers. I think it is also important not to make an assumption that these experiences would be universal.

creates added patient vulnerability. More familiarity with one's care provider is crucial to create a power relation in which the patient can advocate for themselves if necessary.

Grace also mentioned that switching between providers was the only downside of what she otherwise described as exceptional care. She had to switch teams, firstly, in order to do her chorionic villus sampling (CVS) to confirm her fetal diagnosis, and then for her termination. Certainly, one can understand the need to have different specialists for different areas, but she did report that the changes contributed to her level of stress. It is worth noting, however, that even if the pregnant person has a consistent family doctor, there might be some switching between medical providers; from a family doctor to an OBGYN, from doctors to pharmacists to ultrasound technicians, etc. I would suggest that successful communication in these circumstances needs to begin from a point of recognizing and respecting the pregnant person's own knowledge about her situation—no matter who the provider is, the pregnant person is always there as a consistent point of contact about the pregnancy.

Finally, Elena also said that switching healthcare providers increased the sense early on that her medical team was treating her pregnancy as tentative until she reached 12 weeks:⁶⁷

They told me first you keep going to your clinic until the 12 weeks, before that we won't see you. ... And it was almost like, so are you saying that my pregnancy is not really one, or is not really valuable, or is not really there or worthy of your time until three months? Until you actually see the ultrasound, the heartbeat, everything is fine, then you can see me? So, it kind of felt almost like everybody was thinking I would miscarry. Ah, most

⁶⁷ It is typical in Ontario that a pregnant person would see their family doctor until 12 weeks, or sometimes later, before being referred to an OB-GYN. Those who seek midwifery care generally start their relationships a bit earlier, with prenatal appointments starting around 8-10 weeks of pregnancy.

likely she'll miscarry, so why bother? I knew it wasn't exactly that and I can rationalize in order to do it that way, but it didn't feel good.

As in the case of Grace, this change of provider at 12 weeks may be reasonable, but clearly the communication around it could be improved, to not leave the pregnant person feeling like their pregnancy is unimportant, and in the case of a miscarriage, to make sure that person is sufficiently supported. In the following section, I further explore the concept of “tentative pregnancy,” which I first brought up in Chapter 1, and the way this concept ties in to both the responsabilization of motherhood and the normalization of disability-selective termination.

Experiences of Pregnancy

Of all participants, only Annie reported that the tests offered “comfort”—others anticipated the tests being a way to alleviate stress, but then often discovered they were not. They simply moved on to being anxious about something else. Several participants, on the other hand, pointed out that it was not results or potential results but the testing itself that had caused stress. This was especially true for some of the high-risk participants who had an unusually large number of ultrasounds. Several reported that simply being subject to more tests than usual increased their stress. As mentioned previously, Isabelle even compared her experience having a midwife with a doctor, and mentioned that one element that made the midwife experience less stressful was fewer tests—not tests for the baby, but tests like urine tests or weigh-ins. She found this additional testing by her doctor to be unjustified, but also felt uncomfortable refusing it, and this in itself caused an added layer of anxiety.

In this section, I look at few elements of the pregnancy experience that were brought up by participants, which are not directly connected to prenatal testing. I think they are important to include, however, because prenatal testing is not taking place in a vacuum—it is part of the

overall experience of being pregnant. It is affected by other forms of responsabilization; when a pregnant person experiences widespread social pressures on their behaviour in other ways, that wears down their energy to face the pressures related to prenatal testing. It contributes to the overall sense that there is a correct way to be pregnant, a way they 'ought' to act, which in turn makes them more vulnerable to those messages as they relate to testing for disability or illness. Finally, an overemphasis on knowledge gleaned from visual testing has impacts for both prenatal testing and the experience of pregnancy as a whole. In this section, therefore, I look at three major areas that emerged about the way participants were experiencing pregnancy: Tentative pregnancy and miscarriages, pressures on pregnant behaviour, including Non-invasive prenatal testing as a specific new form of pressure, and the production of visual knowledge. Each of these topics, while not always directly about prenatal testing, is interconnected with the experience of it, and ultimately, with the outcomes and the decision-making of the pregnant person.

Tentative Pregnancy

The concept of tentative pregnancy can be defined as the idea that a person does not really feel or accept their pregnancy as 'real,' until after a certain point at which an external authority confirms it (a home pregnancy test, a doctor's visit, an ultrasound, a negative prenatal screen). Often it means that the pregnant person does not want to accept the pregnancy as real until after prenatal tests have confirmed the 'health' of the fetus, so that they feel comfortable making the decision to continue the pregnancy. Tentative pregnancy is not just about waiting to tell others about the pregnancy until either prenatal tests return, or the 'magic' 12-week mark is passed, but also can be a sense of not wanting to emotionally invest in a pregnancy that may not last. Certainly, the latter was the case for many participants who had suffered miscarriages, and waited to celebrate subsequent pregnancies once they felt more sure of their success.

The concept of tentative pregnancy surfaced frequently in interviews, although rarely was that phrase actually used. Most of the time it came up in the context of participants explaining why they waited to a certain point to share their pregnancies with friends or family. For some, this was a routine decision—there is a cultural expectation that waiting until 12 weeks to announce a pregnancy is what is usually done. This is due to the decreased chance of miscarriage once the 12-week mark is reached, although much like the somewhat arbitrary designation of 35 as advanced maternal age (Cardin, 2020b), while the statistical risk of miscarriage does decrease with time, there is nothing magic that happens at 12 weeks. Miscarriages are possible up to 20 weeks, at which point fetuses who die are designated as stillborn (another arbitrary distinction; there is nothing that happens to differentiate a 19-week fetus from a 20-week one.) In fact, some people who experienced miscarriage felt the 12-week waiting period imposed by culture is in itself problematic; it serves to reinforce the taboos about talking about miscarriage, other pregnancy losses, and abortion, and leaves the parents to deal with pregnancy loss alone and unsupported. Sam, after experiencing the loss of her second pregnancy at 6 weeks, told her friends and family much more quickly about her third pregnancy, because she did not want to experience losing a pregnancy alone again. Others, like Catherine, were very conscious of abiding by the 12-week rule, fearing that having to tell people “over and over” about a loss would be much more painful. Catherine experienced a high level of anxiety in her first pregnancy due to needing surgery for an underlying condition (in herself, not her fetus) discovered early in pregnancy, and this trauma led her to seek therapy. Her surgery caused her to experience her pregnancy very tentatively, and her therapist pushed her to start viewing the pregnancy as ‘real’ by taking concrete steps, such as telling people and starting to buy baby gear. Others, such as Elena and Isabelle, felt more tentative about their early pregnancies because their

family physicians did not refer them to an obstetrician until the 12-week mark, so both of them had a sense of the pregnancy not ‘counting’ until that point which was imposed by their healthcare providers.

Some participants particularly noted that, were the prenatal testing to return results which meant they did not wish to continue the pregnancy, it was really paramount that they have only told those people who could be trusted with the knowledge of the termination, both in terms of discretion and tact. Many did not tell their families before the results came back because of knowing their families’ views on abortion, or because of not wanting their parents to go through the same anxiety as them. Grace, who did terminate her first pregnancy, also pointed to the importance here of having early test results, since for her, finding out too late would have meant potentially looking pregnant at work, and then feeling the need to explain:

It’s that you can’t get away with anything in the sense that you’re a woman, you’re physically pregnant. My husband could go to work every day, they don’t know what’s going on, they never know if his wife isn’t pregnant anymore, unless he tells them.

Grace’s point shows that tentative pregnancy is not just about fear, but the very real situation in which women find themselves, that pregnancy losses after a certain point can result in unwanted questions. There might also be practical reasons to postpone informing work colleagues, such as anxiety about how the decision to have children might be perceived, which might mean pregnant people would avoid informing their work until absolutely necessary.

The only person who actually said they experienced ‘tentative pregnancy’ was Sadie, who is a healthcare provider and was therefore familiar with the phrase from pregnancy literature. Her familiarity with the phrase and concept might in theory have made her less susceptible to it, but she reported experiencing a very high degree of it due to her disability,

which made the overall likelihood of her being able to carry her pregnancy to term much lower than average. She also felt that tentative pregnancy is deeply interconnected with gender norms and the construction of motherhood in culture. She reported that she was intensely careful during her pregnancy about how she acted; for instance, she measured the temperature of every food she consumed, and never touched a drop of alcohol. She felt that these practices were unnecessary and, as a healthcare provider, she said she would not advise her clients to undertake such strict measures. And yet, she said:

[It's] very powerful how much our culture teaches us that being a mother—not being a parent—being a mother, is about being a good enough person, and fulfilling your social role, and sacrificing what you want to do, for what's best for your kid, or for what an authority figure tells you you should do, and accepting your place in society with grace, even though it completely erases your needs. And as I was doing it, I had this weird feeling of, this is very out of character for me. This is the only time in my life where I have ever felt the need to correctly occupy my social role even the tiniest bit, but I want this baby so bad, that I can't take the chance, of whatever universal power selects people for parenting will pass me over, in favour of somebody who didn't eat any Brie.

I found this statement to be a remarkable testimony to the cultural socialization that mothers often feel to be deserving, or to be seen as deserving, and I think Sadie is correct in her assessment that it is tied to gender norms around motherhood in a way that it is not associated with fatherhood. This cultural socialization is produced by discourses of traditional motherhood, with the more primary responsibility placed on women for caregiving of children. But, it also has to do with the physical connection of the mother's and fetus' bodies through pregnancy, where

they are part of the same body,⁶⁸ and the mother's body is therefore in a sense, culturally treated as an incubator or a conduit into life for the fetus—and erased in the process.⁶⁹

Pressures on Behaviour

This sense of the erasure of the mother, and of her agency, was reported consistently through the way participants were treated during pregnancy. Many of them had a strong sense of cultural expectations that they should act a certain way, particularly with regard to alcohol, food, and exercise, and many had a sense that the cultural norms were not always aligned with the research. Again, it was clear that most participants were very well informed about what was safe for pregnancy. They had read baby books, asked their doctors and midwives, and consulted websites they had assessed as good sources. They had made their own risk/benefit assessments. And yet, not only did they experience a high degree of second-guessing about their decisions from a wide circle including family, friends, colleagues, and members of the general public, but they often felt the need to justify decisions they were making for their own bodies, or call on authority figures to explain their decisions. For instance, Annie said,

My baby was born in December, and I travelled internationally until November, for my job. And certainly, had to do a lot of convincing of my employer that yes, it's safe to do,

⁶⁸ This applies also to breastfeeding, where the baby and mother are no longer sharing a body, but remain intimately physically connected.

⁶⁹There is some cisnormative language in this section, and it is intentional. I do not want to erase the experience of trans men or nonbinary parents, who experience pregnancy without defining themselves as 'mothers.' However, here, I am trying to speak to an overwhelming and widespread cultural phenomenon that is both gendered and sexed, in which the interconnectedness between the physical body of the woman and the child is used to discursively bolster gender norms around motherhood and womanhood. My pointing out this gendered discourse should not be read as erasure of trans birth experiences, I simply cannot speak to those in the context of this study, not having had any trans participants. Some trans men have noted also being erased by the genderedness of the process of pregnancy, where the deep association between "pregnant" and "women" results in them being culturally read as fat men (Surkan, 2015).

it's been approved by my doctor—it's a funny thing to be pushing for less accommodation, wanting to just be treated normally.

The idea of having to justify one's own health-related decisions as safe by reassuring the employer that the doctor has said so, shows the high degree of paternalism with which pregnant women are treated.

Those participants who continued to exercise at a rigorous level all experienced this, receiving comments from strangers, especially towards the end of the pregnancy. Isabelle told a story about bicycling to work and having a security guard tell her, "I wouldn't let my pregnant wife bicycle like that." Elena noticed in people's looks at the gym: "When I was exercising, I noticed people at the gym looking at me, especially when I was bigger, like oh my God, should you be here?"

Other comments shared by participants ranged from Sadie's mother-in-law looking pointedly at her full plate and then asking, "How much weight did your doctor say you could gain?" and Mila's family members asking her things like, "How much do you miss sushi?" and "How's it been without any coffee?" This left Mila (who is a healthcare provider, herself) feeling awkward about telling these people that she was consuming both. Despite understanding that her family members were less aware of current research, Mila said, "I had the ability to feel comfortable in the research, and the knowledge that I had, so I wasn't overly affected by that pressure, but it 100 per cent is there." All participants felt a strong sense of the importance of taking responsibility for their own health and their baby's health, but they often came to very different conclusions about what would be acceptable. In fact, Catherine pointed out that these differences were much more based in culture than in a scientifically observable reason for avoiding certain behaviours. She had been pregnant in the UK, and her doctor there had

informed her that it was acceptable to have an occasional alcoholic drink, but she said that, “I felt culturally for me, that wasn’t acceptable.” Sadie, meanwhile, felt that this expectation that no alcohol should ever be consumed was less about science and more to do with cultural expectations around the “purity of the pregnant body” (nonetheless, she complied with it.) All these examples demonstrate the consistent reproduction of everyday discourses of self-care during pregnancy and care for the fetus, and responsible motherhood. They show how scientific evidence is involved in the creation and maintenance of social expectations, but culture and communication are also deeply involved with the continuance of this governmentality. They are entrenched as mores or doctrines, as much as they are medical guidelines.

By contrast, some others who were interviewed felt perfectly comfortable with moderate amounts of alcohol and were even quite specific in telling me how much they had consumed: “I had this little, tiny juice glass, and once a week, I would half fill it with beer, and sip it for like an hour” (Martina). This level of attention to detail suggests that while they felt comfortable with this risk assessment, there was also a need to reassure me (the listener), and potentially others, that this decision was well-considered and responsible. In the case of restricted foods, participants often reported that they adhered to dietary recommendations strictly at the beginning of their pregnancies but became more relaxed as time went on. Others said that they had been stricter in first pregnancies, and more relaxed in subsequent ones—this clearly demonstrates how these social norms are less about adhering to medical requirements (which after all, would not change from one pregnancy to another), and more about cultural communication: That pregnant people feel able to relax their restrictive behaviour, with time, suggests that as they become comfortable in their own experiences of motherhood, the social pressures to perform a ‘perfect’ version lose some of their power.

Several participants reported that they found restrictions on exercise to be very limiting. Tanya, who had a high-risk pregnancy and was told to avoid getting her heart rate up too high, complied with this recommendation but was very frustrated by it and said she complained often. Others, like Isabelle, found this restriction on exercise to be not based in evidence and ignored it. No one felt that giving up or restricting their alcohol consumption was a major disruption to their lifestyle, but some felt that other pregnancy-related restrictions were very limiting, and in some cases, they did ask their doctors to justify the restrictions, and/or refused to comply. In particular, one participant noted the restriction against antihistamines and other cold medicines, and said she found this to be too burdensome to follow. There were also two participants who were advised to go on bedrest, and neither did. Both pushed back against their doctors and asked for this recommendation to be medically justified, and neither felt satisfied with the responses. While the sense that pregnant women should act responsibly is strong, it is clear that compliance with medical authority is somewhat proportionally related to the level of disruption that a recommendation might cause in someone's life.

Several participants also reported being severely second-guessed by family members about their choice of healthcare providers, ranging from "I can't believe what an irresponsible decision she's making by having a midwife" (Sadie) to "Why do you need to see an obstetrician?" (Mila). Participants also faced comments about their choices around "natural" childbirth and whether they planned to breastfeed, with many friends and family members feeling free to express strong opinions on both these topics. Interestingly, this also ranged, where some participants faced strong pressure to breastfeed, and others felt unsupported in their decision to do so. The social pressures reported were much more do with family and culture than

with scientific evidence for one choice or another.⁷⁰ All of these findings point to the importance of communication about pregnancy in a holistic sense: Discourses of responsible motherhood and ‘correct’ performance of pregnancy are continually reproduced through everything from televised depictions of pregnancy to stories told by family members. Expected behaviours are thus entrenched through culture and become difficult to opt out of; this is important both because, increasingly, it is clear that prenatal testing is becoming part and parcel of these norms, and because the weight of the cultural expectations during pregnancy is constant and wearying, leaving many pregnant people with only energy for the battles they absolutely feel they must fight.

Moreover, Elena described an experience that showcases the connection between responsabilization and outcomes. If the pregnant person was careful and the outcomes were positive, they tended to become more relaxed later, or in subsequent pregnancies. Whereas, at one point in Elena’s second pregnancy, her doctor said the baby was looking too small on the ultrasound and asked if she was working too hard.

It immediately in my head went to, I’m overexerting myself, this is my fault. And then he was wrong, the baby was perfectly fine, but for those few weeks until I got the ultrasound, I was terrified and feeling so guilty about it, because the doctor said rest, and I couldn’t.

This was also often reflected in the experiences of those who had miscarriages—that after poor outcomes, participants were much more careful and restrictive with their behaviour, even if they

⁷⁰ On this note, health-related pressures were certainly not the only ones raised. For instance, some participants talked about not wanting baby showers but feeling culturally pressured by family to have them. Lucy described a situation where her wedding ring grew too small to wear due to swelling while pregnant and said that her mother-in-law pushed her to buy a new one because, “I am pregnant, I need to be wearing a ring.”

intellectually understood that the miscarriage had not likely been caused by moderate caffeine consumption or some such behaviour. Lucy, who had experienced multiple miscarriages, said the pressure over her behaviour did not come from others, it came from herself: “I didn’t want to give myself any reason to blame myself if I was going to lose this baby too.” It was clear that these cultural norms around acceptable behaviour became more entrenched for people once they had experienced a negative outcome.

These cultural norms restricting behaviour for pregnant people surfaced often, they were often a point of contention with pervasive discourse, and yet they also often informed decision-making. Martina described these cultural norms affecting the experience of pregnancy as “fearmongering and scolding and silliness,” and explained that this was why, in particular, she had enjoyed Emily Oster’s book *Expecting Better* (2018) so much, because of Oster’s calculated risk/benefit approach with uses economics to debunk some of the common cultural myths around pregnancy. Certainly, it is clear from Martina’s above comment, as with many others, that many had negotiated reactions to the information they gathered during pregnancy. However, medicalized information still clearly carries weight with many pregnant people. There is clearly an interplay between medical advice and cultural norms, with medical disciplinary recommendations informing cultural norms and vice versa (e.g., Savage, 2007). In the next section, I offer a few examples of sites of information-gathering used by participants, including *Expecting Better*, because these examples demonstrate how the supposedly neutral and scientific information pregnant people seek out can significantly contribute to the discourses of disability as a burden, and also has a profound effect on cultural norms and expectations.

Other Discursive Sites

It is perhaps quite unsurprising that many participants appreciated Oster's *Expecting Better* (2018), which offers a differing point of view on many of the restrictions commonly followed by pregnant people, especially in North America. For instance, it "allows" for a much higher consumption of caffeine and alcohol as compared to the guidelines offered by Health Canada and most Canadian doctors (Oster recommends moderation, rather than abstinence, which is actually in line with the recommended guidelines in many other countries). It also, more importantly, takes an approach of "here are the known risks, decide for yourself" which is surely refreshing to many pregnant people, accustomed as they are to both overtly paternalistic comments, as well as assumptions that are likely not meant maliciously, but still assume a "correct" way for pregnant people to behave.

While I am not offering a comparative analysis of pregnancy books, Oster's book is worth a small digression, since it is so popular and was praised by several of the participants in this study for its approach. Oster is tapping into the zeitgeist in which pregnant people are tired of being subject to an extended and growing list of everything that is forbidden, and of having everything from smoking to pesticides to high mercury fish conflated as though they were all equally risky. For example, Mila described getting dirty looks for being at a Nordic spa with hot tubs while pregnant, despite staying in the moderate temperature areas, and very generously attributed this to a sense that "people kind of want the best for you. And maybe think that you don't know." Oster's (2018) approach, conversely, is to provide the studies, offer the known risks and benefits, and tell the reader what her own decision was, as well as sometimes the different decisions made by her friends. While this is an improvement on top-down guidelines in

some ways, there is still an aura of the authority figure offering permission about this, since many people will feel emboldened to act by having read the advice in a pregnancy book.

I also noticed, reading this book, that while I cannot speak to Oster's evaluation of studies on things like alcohol or caffeine consumption during pregnancy, I found the chapter on prenatal testing to be sorely lacking. Throughout the chapter, Oster uncritically uses a healthy/abnormal binary, in which I found the language strongly ableist and very simplistic. She uses words like "abnormality" and "mental retardation" uncritically, and on the other side, constantly refers to fetuses without Trisomies as "healthy" or "normal," continually using a dichotomy of "bad" and "good" results (Oster, 2018, pp. 98–121). There is a very brief acknowledgement in the chapter that some women may prefer to risk having a "special needs child" to the risk of losing a "healthy baby" through miscarriage caused by testing. Oster's uncritical use of the binary fails to account for the possibility of parents who have children with Trisomies considering that as a "good" result, and it fails to acknowledge that simply lacking a Trisomy does not necessarily equate to "healthy." I also found it quite telling that Oster uses quotation marks around "bad" and "good" test results the first few times she uses that terminology, as though reluctantly acknowledging that these are value judgements, but then drops the quotation marks throughout most of her chapter.

I include this brief review of Oster's prenatal testing chapter because it speaks to something I have noticed about the discourses around prenatal testing and disability: That even as there is a slow, cultural shift towards a greater exercise of questioning popular top-down restrictions on pregnancy behaviour such as moderate alcohol or caffeine consumption, there is a continued responsabilization of pregnant people for producing "healthy" babies that is making prenatal testing more routine, if anything, not less. It is less easy than it ever has been to opt out

of these tests. It is more expected, it is more culturally normalized as the “responsible” thing to do, and this expectation is a significant influence over pregnant people’s decisions about whether to test and terminate. Julia said that keeping a child with a prenatally diagnosable disability could create stigma towards the mother for this reason alone:

I think the only thought that I had may have been people wondering if I had thought about keeping it or not. Because that’s an option we now have to know things in advance.

Whereas in the past, you wouldn’t have had the option of knowing.

Certainly, the idea that people were constantly wondering if a mother had considered terminating her pregnancy, due to their judgements about disability, could act as a powerful motivating influence for mothers wanting the best for their children.

Non-invasive prenatal testing (NIPT) also surfaced as a new behavioural pressure on participants, in part because of the number of participants who paid out of pocket for this testing, many of whom spoke to the financial burden imposed by this testing. (Pricing varies between labs, but participants reported paying between \$500 and \$700 CDN.) It was clear that despite the financial burden, refusing this test did not feel like an option to many participants—they had already internalized the discourse that getting it constituted responsible parenting, and also they felt very strongly that the results would provide them with relief from anxiety over and above what they could get from the free Integrated Prenatal Screening. The normalization of NIPT as responsible parenting is, I would argue, no accident, but in large part due to marketing efforts by the makers and distributors of this for-profit test. As mentioned in the section on communication about tests, the websites for these tests have also become a primary information source not only about the actual test, but also about topics such as Advanced Maternal Age and the conditions caused by Trisomies.

The fact that these websites are being frequently used as a source of information is feeding into biopolitical discourses, considering the profit incentives of these companies and their economic vested interest in maintaining status quo discourses around Trisomy 21 and other chromosomal abnormalities. Consider Figures 1 and 2, which appear under Appendices. Figure 1 is a screenshot from the Panorama website, which shows a (white) mother's hands checking off items on a pregnancy checklist, highlighting this very expensive prenatal test as part of the correct and responsible way to be pregnant. Juxtaposing "order Panorama" with items like "buy prenatal vitamins" clearly paints this test as a responsible medical choice, and also including elements such as "research baby names" and "pick colours for nursery" also situates the Panorama test as part of a certain type of (probably white, upper/middle class, privileged) cultural experience of parenting.

The second figure is a screenshot of a Dynacare ad that appeared in my Facebook mobile newsfeed in February 2020. This ad shows a visibly pregnant woman (which is actually an incorrect representation, since NIPT is done in early pregnancy, but it provides a clear visual code of "pregnant"). The woman would probably read as able-bodied and could easily be read as white, is wearing a wedding ring, and is sitting on a pristine white sofa with a dining room table behind her—these are class markers. She is smiling serenely above a caption that reads: "The Harmony Prenatal Test: Get Answers to Questions That Matter." This vague language avoids mentioning unpleasant or taboo topics such as termination, while still carrying a strong implication that Trisomy 21 is not part of the lifestyle the test is selling in this ad.

It was clear from my participant interviews that these advertisements and the broader discourses they engender appeal to a broad demographic—the representations of class and whiteness are read aspirationally, with many participants thus paying out of pocket for NIPT

tests which constitute a financial sacrifice. The advertising here is a significant factor in reproducing an ableist norm which associates ability with the “good life.”⁷¹

Visual Knowledge

The last area of experiences of pregnancy to which I will briefly speak is the construction of visual knowledge through ultrasound. As mentioned in Chapter 1, ultrasound has been shown to tie into the experience of tentative pregnancy, with many pregnant people feeling the pregnancy is not “real” until it is observable on the ultrasound. Tying into this, there is a long history of coercive use of ultrasound as an anti-abortion tactic, with many jurisdictions in the US requiring ultrasounds for access to abortion (Bailey, 2010; Hartouni, 1997; L. M. Mitchell & Georges, 2000; Upadhyay et al., 2017). One feminist critique of ultrasound is that it tends to displace other forms of knowledge production during pregnancy, especially the embodied knowledge of the pregnant person. Sadie mentioned that she had seen this in her capacity as a healthcare provider, where, “One of the things of prenatal testing and prenatal surveillance that we don’t talk about is how much it deprioritizes knowledge like that [how the baby feels inside the pregnant person.]” Interviews often showed how the participants’ embodied experiences were disregarded, not only by their healthcare providers, but by themselves, and in fact one of the only people who spoke about embodied knowledge was Alexandra, who said that “in my non-expert judgement, it seemed like the baby was fine.” Alexandra, who had opted out of testing for Trisomies, had fewer ultrasounds than most participants.

⁷¹ The examples I have provided are a small representation of the ones that have appeared in my social media feeds—I am sure I get many of these advertisements because of both my personal and professional Google search history (from writing this dissertation and from three pregnancies since 2017). It is worth noting that any pregnant person would be likely to get a lot of these ads because of social media microtargeting capabilities as well as tie-ins to Google search.

As mentioned above in the section on medical authority, Tanya also spoke to her experience of being in the high-risk clinic, where ultrasounds were very frequent, and there were no belly measurements or manual checks of the pregnant body, something that she found much more striking after seeing a midwife in her second pregnancy. The midwife was much less reliant on ultrasounds, and used other methods to glean knowledge, such as touch, and asking many more questions of the pregnant person. For Tanya, this was significant and logical; it increased her trust of her midwife. She also pointed out some of the weaknesses of ultrasound and other technologies as a method of knowledge acquisition. For instance, she pointed out that often the ultrasounds were difficult to read, and she was told they would just try again the following week. She had frequent blood tests, and said often her veins were too small and the bloodwork had to be skipped. These technology failures suggested to her that knowing other methods to understand the pregnancy, that were more reliant on physical touch or asking about embodied experience, were still important. She also gave the example of exercise monitoring. During her first pregnancy, the high-risk clinic outfitted her with a heart rate monitor and told her not to do exercise in which her heart rate went over 120 beats per minute. She experienced this method as a strict restriction, forcing her to significantly curtail her activity level from what it had been pre-pregnancy. Whereas, in her second pregnancy, her midwife did not use a heart rate monitor, but simply told her, “Pay attention to how red your face is, how hard your body’s working, and monitor from there.” For Tanya, this was a more reasonable approach, taking technology out of the equation and instead trusting the pregnant person to be the authority on her own body.

Which is not to suggest that ultrasound does not have an important role to play, not only in scientific diagnostic but also in emotional experience of pregnancy. For instance, many studies I looked at had found that some of the pros of ultrasound were the way it helped partners and

fathers feel like more active participants in pregnancy (Draper, 2002), and the sense of excitement and joy often experienced by mothers during pregnancy ultrasounds (Clement et al., 1998; Saetan, 2000; Williams et al., 2005). What I found from the participants in this research, however, was that actually the routine overuse of ultrasounds was too pervasive for this to be commonly felt—while many participants expected to feel joy in ultrasounds, their reports were that the experience often actually came up short of their expectations. Julia said:

Yeah, I sort of hesitate because it wasn't like in the movies or anything. It was a relief, I suppose, and happiness and sort of a bit of a feeling of something miraculous, but it wasn't this overwhelming... I don't know how to describe it.

Martina described something similar, worried that saying so would make her sound “cold,” but that ultrasounds had never made her think, “Oh, that’s my baby.” Many participants used words like anxiety or relief to describe their experiences, and a few did enthusiastically report loving it. However, many found the experience overwhelming simply because the high number of ultrasounds began to impose a burden. There were several participants whose pregnancies were flagged as high-risk, mostly due to pre-existing medical conditions, and for these participants especially, ultrasounds were often bi-weekly or even weekly during the last trimester. For these participants, ultrasounds lost much of their ‘magic,’ they were often uncomfortable, and partners usually stopped accompanying them at a certain point.

Certainly, for those participants who had any test results that caused them anxiety, subsequent ultrasounds became a deep source of stress. One important finding here was that across the board, not one participant in the study was at any point offered any resources to cope with the anxiety and stress they might experience due to having prenatal tests or while waiting for results. Only two people reported being offered any resources to cope with their own

feelings, at any point. The first was Sam, whose midwife called her after her 6-week miscarriage to check on her. The second was Grace, who was offered a counsellor once she decided to terminate, an offer she accepted, and the counsellor called her *five months later*.⁷² At this point Grace was pregnant again, and declined the appointment, and then had to convince the counsellor that her services were no longer required. The lack of resources offered for stress and anxiety related to undergoing ultrasounds and waiting for results is a striking commonality between experiences, especially considering that anxiety was routinely experienced, and that it is well documented in the literature about these tests. It speaks to the expectations of pregnant people functioning merely as vessels to produce ‘perfect’ babies, and to the lack of care for the impact this may have on their feelings and experience. Mila, who is a healthcare provider and also experienced a false positive on her Integrated Prenatal Screening, said that experiencing prenatal tests firsthand made her understand for the first time how the anxiety produced by them constitutes a “real harm” which is “less easy to dismiss,” and she recommended that healthcare providers should discuss this anxiety with their pregnant patients and provide them with mental health resources.

I end this chapter, therefore, with these brief recommendations from Sadie and Mila, the two healthcare providers who were interviewed during the course of this study, who both had concrete ideas for improving healthcare based on their own experiences of pregnancy. In the following chapter, I will further discuss these recommendations and offer some of my own. Sadie suggested that the way we inform pregnant people about what prenatal tests actually do is incorrect. She commented that in her experience, most health care providers preface the IPS by

⁷² Not only is the long wait for care astounding, but I also observe that the only cases of mental health supports being offered to pregnant people were in cases of poor outcomes, which reinforces my argument that the effect on the mental health of the mother is often brushed aside when the only measure of a positive outcome is a “healthy” baby.

saying that it will have a look at the baby to see if it has Down syndrome. She took issue with this description, and suggested a shift to explaining that the test looks for the statistical likelihood of Trisomy 21, which can tell us that the baby would share some characteristics with other people who also have Trisomy 21. Both Sadie and Mila recommended that parents should be advised of the potential for these tests to cause anxiety, and that it be phrased as a risk of the test (a recommendation that does not seem likely to be adopted in a context in which the tests are being marketed as a way to assuage anxiety, but which is consistent with the evidence). Sadie advised that prenatal care should also include much more frequent questions about embodied knowledge, and that these be employed to help the pregnant person make decisions with the same respect that is given to knowledge acquired through ultrasound.

Mila recommended that a list of resources be compiled for family doctors which could be given to all pregnant people if they choose to undergo prenatal testing, and that this list should include support groups composed of parents with their own recent experiences—whether in person, or online. She felt that the creation of local support groups on this topic, especially with parents who had experienced false positives, would be especially beneficial. This was a finding that seems practicable, since some other participants such as Martina had mentioned that they would have liked the opportunity to share their experience with other parents and provide support.

Findings in Brief

Communication around testing failed pregnant people in a number of ways: Often what the test specifically looks for was unclear, or it was framed to participants as “getting a look at the baby” or “making sure the baby is growing properly,” without any clear indication that Integrated Prenatal Screening searches for soft markers that would indicate chromosomal

conditions or fetal abnormalities. Opting out of prenatal screening turned out to be complicated not only because of discursive pressures, but also because on occasion the participant needed other information and the chromosomal testing was integrated into the process. Many tests are offered without explaining the potential risk that they could be inconclusive and cause severe anxiety, as with participants who were told that tests could show potentially life-threatening conditions or could be perfectly normal. The meaning of results is also not always clear, which can cause significant stress. This stress seems to be underestimated by medical care, since doctors do not seem to be informing pregnant people that it is a risk, but everyone who dealt with uncertain results described this anxiety as a concrete and tangible issue. Some recommended that mental health supports be offered to pregnant people who are waiting for test results, or dealing with inconclusive or unwelcome results, or support groups be offered composed of parents who have already experienced this. Many, without these supports, turned to the types of online communities explored in Chapter 3.

Many participants also highlighted the role of ultrasound technicians in communicating, with ultrasounds significantly contributing to stress. Specific suggestions included more communication, not of results, but of what to expect in terms of time, turning over, etc. Reassuring pregnant people that variances of time or needing more pictures is normal would help alleviate anxiety. Some also noted the importance of the way positive results are communicated, with a need for clearer explanation of what they mean. The ableist attitudes that people who have a diagnosis of Trisomy 21 (Down syndrome) will likely terminate are also pervasive throughout the medical profession and they influence outcomes.

Many of the sources of information pregnant people turn to, including baby books and pregnancy forums abound with ableism and misinformation. Many also reported using the

websites for for-profit companies such as Dynacare, Harmony and Panorama, which offer Non-invasive prenatal testing (NIPT), which are incredibly biased and openly trying to paint NIPT, which is an out-of-pocket expense for many pregnant people, as a critical part of responsible motherhood. The result is many pregnant people paying for this test, even when it is a serious financial burden.

The overall experience of pregnancy seriously affects prenatal testing, and in turn is also affected by it. Participants often reported a sense of “tentative pregnancy,” where early pregnancies did not feel real until the screening cleared them of the potential for disability or illness, or the ‘magic’ 12-week mark had passed. Culturally, the governmentality of the pregnant body was noted by most participants, who faced second-guessing of their decisions by family, friends, and sometimes strangers, and a clear lack of respect for their own knowledge and agency in this regard. Pregnant people often felt the behavioural pressures were not indicated by the evidence, but only sometimes had the wherewithal to push back against these deeply entrenched cultural norms. Cultural norms were reported around exercise, eating, gaining weight, “natural” childbirth, choice of care provider, consumption of alcohol, taking medication, and bedrest. Although participants did occasionally push back against medical recommendations that lacked evidence, when they feared a serious impact on their own quality of life, for the most part, they reported that the greatest pressures on their behaviour came from within and their own expectations of themselves, or fear of something being “wrong” and being to blame. It was clear that medical disciplinary recommendations and cultural norms were mutually self-reinforcing.

Chapter 6:

Motherhood and Quality of Life: Explaining the Imperative to Test

As we have seen, under biopower, and in the context of continually increasing biomedicalization (A. E. Clarke et al., 2003), the importance placed on population health has extraordinary implications for the operation of pregnancy care, prenatal testing technologies, and fundamentally, for the experience of pregnancy. Over time, medical disciplinarity and entrenched reliance on technological knowledge have taken on the status of cultural imperatives for pregnancy care, making opting “out” of them very difficult or impossible. This dissertation has shown many of the impacts of this for pregnant people: Among others, the anxiety that is caused by the testing, the overwhelming sense of having our behaviour regulated and needing to self-regulate, and the failure to adequately support pregnant people or disabled children and adults. In the introduction, I asked two research questions:

- 1) How does the medicalized process of prenatal testing instil the pregnant person with a sense of responsibility (to the fetus/baby, partner, family, community, or population health)?
- 2) How do pregnant people negotiate with the implicit marginalization of disability in the discourses surrounding prenatal testing?

As I conducted both the analysis of online pregnancy forums, and the interviews with recently pregnant people, it became clear that the answers to these questions function together: Pregnant people’s negotiations with ideas around disability usually included internalization of a sense of social responsibility to not reproduce disability, which greatly contributed to their acceptance of medicalized pregnancy, often at the expense of their own birthing experiences.

We saw how the ubiquity and pervasiveness of discourses of disability, including seemingly benign expressions of them such as the phrase “As long as it’s healthy...,” can have significant influence over both experience and decision-making. In this chapter, I begin by discussing the relationship between ableist discourse and the experience of motherhood and pregnancy. Following this, I consider how biopower and governmentality continue to operate through ableist discourses that saturate both culture and medical discipline. I then further explore the relationship between the social model of disability and embodied impairment, considering the implications of this dynamic for prenatal testing. I then also speak to the role of technology and its entrenchment in biomedicalization. I offer a brief discussion of the role of language and communication in ableism, drawing on some of the findings about the way language is deployed both medically and in everyday settings. One of these, of course, is the idea of “quality of life,” which recurred throughout this work, and which I juxtapose in the next section with motherhood because of my impression that one of these ideas (life) effectively erases the importance of the other (motherhood).

Quality of Life and Quality of Motherhood

As noted above, the phrase “quality of life” emerged often throughout this dissertation: In Chapter 3, through the Down syndrome termination discussion boards where commenters insisted that there was no ‘quality of life’ for people with Trisomy 21; in Chapter 4, where many interview participants stated that they would terminate a pregnancy due to disability diagnosis, especially if they felt that medical intervention would not yield improvements to ‘quality of life’; and finally in Chapter 5, where participants noted that they sometimes opted out of medical pregnancy recommendations if they feared these would seriously encroach on their own ‘quality of life’. Quality of life appears as a shared human value, one which often serves to reinforce the

biopolitical notion that some lives are worth fostering, while others may be permitted to fall by the wayside.⁷³ The Foucauldian phrase to explain biopower is: “The power to foster life or disallow it to the point of death” (1990, p. 138) and the discourse of quality of life is instrumental to ableist norms which construct only able-bodied and neurotypical lives as worth growing and nurturing—essentially, as being worthy of parenting (especially in Western culture where people have fewer children, often later, and they are largely planned.)

In the findings from both online forums and participant interviews, we have seen that the idea of quality of life is deeply interconnected to cultural norms which frame “health” as the pinnacle of normalcy, and the good life, and which place disability and illness in opposition to this norm. This view of “health,” whilst it certainly has roots in medical evidence, is also constructed through biomedicalization,⁷⁴ the framing of pregnancy as ever-more risky, and the socially constructed maternal responsibility for ableist outcomes. Ableism and the attendant fear of disability, or fears about quality of life, have thus come to pervade the experience of pregnancy, leading to the routinization of prenatal testing technologies (compounded by fear and anxiety throughout pregnancy). They have also augmented the power of medical disciplinary authority. Discourses that disabled lives are of poorer quality than able ones permeate culture (Garland-Thomson, 2001; McRuer, 2006; Swain & French, 2000); they are entrenched throughout the institution of medicine (Cardin, 2020b; Gentile, 2013; Sauer, 2015), and they are deeply internalized by the time most people become pregnant as my research has demonstrated. As I have shown, these discourses influence mothers in a vulnerable and affective state, because

⁷³ The Nazis used the horrific phrase “life unworthy of life” to describe these populations (Wikipedia, 2020b).

⁷⁴ As noted in previous chapters, biomedicalization goes beyond medical evidence—Clarke et al. (2003) define it as the overreach of medicine into every aspect of human life. That being said, medical evidence is also constructed through a positivist scientific framework which has its own series of biases and is certainly not foolproof (Ginzberg, 1987; Higginbottom & Lauridsen, 2014; Nind et al., 2013).

of course mothers want the best for their children. Without even speaking to ‘nature’ or the power of affective experience, mothers are culturally conditioned to be self-sacrificing and even to find solace in our own suffering, so long as it is in service of our children, and in pursuit of what we might term the ‘good life,’ for them, and for ourselves. The ‘good life’ is also socially constructed—and, as we have seen in examples ranging from advertising about prenatal tests to the medical pushes toward termination, the good life is usually white, it is framed through aspirational socioeconomic class status, and it is often heteronormative. When it comes to pregnancy, above all, it is able. Ableism remains as a value that saturates our culture, with disability operating as a silent taboo (Fritsch, 2015; Garland-Thomson, 2001; Rapp, 2011; Swain & French, 2000). We do not always name disability or illness, but our prejudices against them are there, quietly understanding disability as that which must not be. Disability is perpetually left implied through the ellipsis at the end of the phrase, “As long as it’s healthy...” The implication that something “must” be done if it were not healthy has led to widespread chromosomal screening, causing significant anxiety. It has produced a sea change in the experience of pregnancy, over a time period of basically one generation, as I found through both interviews and online pregnancy forums.

Biopower, Governmentality and Gender Norms around Motherhood

As noted in Chapter 1, Foucault defines biopower as a productive mode of power, largely centred on ideas of choice, which operates visibly as the production of vitality (life). Death is therefore perceived as unintentional under biopower. Under these logics, biopower is not a centralized actor causing death; death occurs through the exercise of individual choices and liberties. This is fundamental to the operation of prenatal testing—there is no centralized control through which the state is overtly prescribing a eugenics program. Rather, biopower depends on

the perception of individual choices which are underpinned by discourses of ableism and responsible motherhood; these are both so constant and pervasive, saturating both culture and medical discipline (Foucault, 1990), that there is no need for biopower to directly prescribe death. Power is seen to foster life, and discourses continually remind us of both which lives are deemed valuable and the burden we will face, as mothers, if we produce children who do not fit this ableist norm. Responsible motherhood is therefore framed as the key to the “good life,” for ourselves, for our children, and for society at large—we are aware that by producing disabled or ill children, we may be perceived as creating a drain on society.

Biopower is effective in part because it operates on multiple fronts—some of the forms of power which Foucault describes include disciplinary power, which centres on the individual body as a machine, which is exercised institutionally, and which cements its authority through the production of knowledge and discourses (1990, pp. 138–139). This power was evident through many of the online findings; for instance, the prevalence of the medical definitions of various conditions or abnormalities—in other words, the total authority which medicine is granted by everyday people to define health and illness, and the lack of interrogation from online commenters of these narrow definitions. This medical knowledge is clearly built away from the context of lived disabled experience, with very little or no consultation with disabled people or their communities, and yet goes virtually unchallenged (Hamraie & Fritsch, 2019; Piepzn-Samarisinha, 2018). Medical discipline also was evident through interview participants who described the weight they placed, or would place, on medical suggestions about what to do, based on their assumptions of the doctor’s greater knowledge. It was evident when participants described wavering in their decisions after being faced with comments from their healthcare providers (for instance, Martina’s comment about termination from Chapter 4: “She’s just

assuming that's what we'll do, so does that mean this is so dire that that's absolutely what we should be doing?"). It was also sometimes evident in the support that medical providers demonstrated for their patients, especially through decisions to undergo prenatal testing or termination. These decisions, congruent with biopolitical expectations, were routinely well-supported.

Biopower also operates through governmentality, or a dispersed form of power that regulates our conduct; Foucault describes it as the "conduct of conduct" (2007b, p. 193). As Foucault explains, while individual people do have agency, we are extraordinarily influenced in our decisions by forces outside of ourselves, especially discourses. The idea of 'self-care,' which places a biomedicalized morality over each of us, is already omnipresent in our culture; we are placed under enormous pressure to exercise due care of our bodies, out of duty to public health, family and friends, even concerned strangers, as part of the ethic of biopower, in which we are meant to be fostering and nurturing life (Foucault, 2007b; Murray, 2007). Pregnancy amplifies these discourses because of the discourse that our bodies are now containers for the most vulnerable and precious humans, placing the conduct of mothers under a (often self-imposed) microscope. It also, as Bordo (2004) argues, creates a powerful sense of individual responsibility for fostering life and preventing harm in mothers that is highly gendered, and totally leaves out the role of fathers and other caregivers, not to mention society at large.

Participants in this research, as in other studies, described many of the ways these pressures to modify their behaviour manifested—examples included pointed comments or questions from family members about appropriate weight gain or consumption of certain foods, remarks from strangers about exercising while pregnant, and recommendations from doctors that they take greater care and avoid working too hard, among others (Ayers, Crawley, Webb,

Button, & Thornton, 2019; Barker, 1998; Jette, 2011; Murkoff, 2008). The fact that these suggestions are sometimes based in (or tangentially refer to) clear medical evidence gives them greater power; if they were all nonsense, they would be easier to dismiss. This policing is grounded in the medical disciplinary power/knowledge structures from which they arose, and they have taken on new life as cultural norms which are incredibly difficult to shift, even once they are questioned. One example from my interviews was with medical guidelines such as bedrest, which continues to be offered as a sort of panacea (or, most likely, a protection from liability for the doctor), despite no medical evidence that it does anything, to women who simply cannot take months off to lie in bed, because they have jobs and families to support and other children to care for (a significant barrier to rest for some participants in this study).

Despite the negotiation with medical guidelines like bedrest, which are incredibly disruptive, this research showed that, largely, pregnant people want to comply with medical guidelines, and often governmentality is centred from within. Many participants spoke not about pressure from other people to conform with norms, but a desire to do so that felt logical and personal. This was true despite the fact that many people recognized the strictness of the guidelines they were following more as cultural norms than medical evidence. One example was when Catherine reported (in Chapter 5) being told by her doctors in England that she could drink alcohol moderately, but said that for herself, as a Canadian, she didn't feel it was culturally appropriate to drink any alcohol while pregnant. Or, also in Chapter 5, when Sadie said, "I want this baby so bad, that I can't take the chance, of whatever universal power selects people for parenting will pass me over, in favour of somebody who didn't eat any Brie." I found this comment heartbreaking because it shows how cultural norms of correct conduct for pregnant people are in fact respected, not only as physical best practices for health, but as a form of moral

code. The unspoken narrative is that if we adhere successfully, then motherhood is deserved; if we adhere successfully, then negative outcomes will not be our fault. But, these morality tales also ensure that we will blame ourselves if something goes “wrong,” and wonder what we could have done differently (Deveaux, 1994; Greene, 1999; Lupton, 2011; Roberts, 2015).

Given the power of the governmentality of pregnancy, I come back therefore to a question I posed in Chapter 1: Are people inclined to refuse prenatal tests? In brief, I think the answer is no. For most participants, prenatal tests were either welcome, or they were so routine in the process of pregnancy that they went unquestioned. It was clear to me that prenatal testing has been internalized as a new type of requirement for responsible pregnancy—and in fact, many went the extra mile to request NIPT and pay out-of-pocket for it, despite many also describing this as a significant financial burden. However, many felt the information they were offered about tests was insufficient and experienced a higher degree of anxiety related to tests than they expected. There was often an expectation that tests would assuage fears, but despite all the recent advances, testing is still too rudimentary for this. There are so many things that cannot be tested for, and so in fact perhaps part of becoming a parent is actually about learning to live with uncertainty, despite the way prenatal tests are sold to us as a way to manage and control outcomes.

The findings of this research also demonstrate that prenatal testing has been routinized in part because it is the newest invention in a line of normalized technological advances, and it is packaged with other important advances that have been instrumental to preventing maternal and infant mortality. In Canada, thankfully, we no longer face high levels of maternal and infant mortality, which is largely due to widespread improvements in hygiene (Barker, 1998), but is

often attributed to the medicalization of birth more generally.⁷⁵ However, we do still deal with high levels of miscarriage and termination of previously wanted pregnancies (both of which I would characterize as loss), and although this is something medicine does not have a solution for, my impression from interviews is that the high levels of prenatal testing are connected to our desire to put our faith in medicine to improve our outcomes. Several people I interviewed used prenatal testing because their previous miscarriages might have been caused by chromosomal abnormalities, and getting more information related to this in their current pregnancy felt like a sort of insurance policy against further miscarriages. This, despite knowing that if a pregnancy is going to be lost due to chromosomal abnormality, there is really no medical intervention to change that outcome. Still, miscarriages weighed on many participants' minds, and prenatal testing seemed to manifest for many people as something they could "do" when so many other elements were beyond their control. As mentioned in Chapter 1, it was clear from participant interviews that when pregnant people exercised agency in refusing a medical recommendation, their feelings about this lack of compliance, later, were very much tied to outcomes. Poor outcomes tended to produce self-blame, whether or not compliance would have changed anything. Positive outcomes tended to mean that exercising agency was experienced as empowering.

I also observed that the potential for maternal and infant mortality, as well as disability, are discourses that work in tandem to place the "worst case scenario" at the forefront of pregnant peoples' minds, and to reduce the medical and cultural importance placed on the mother's experience. Quality of life, or seeking the "good life," is a value of biopower that is thus placed

⁷⁵ It is important to note that this is not quite as true in the US, which is the only country in the Global North with a rising rate of maternal and infant mortality, and which has much higher rates of mortality in Black communities.

in opposition to quality of motherhood, even though it is framed as in the mother's interest. Quality of life is, in this way, measured biopolitically; biopolitics, as Foucault tells us, is focused not on the individual, but on the species body. As stated in Chapter 1, it is concerned with "propagation, births and mortality, the level of health, life expectancy and longevity" (1991, p. 139). Quality of life is measured as the production of lives that have a high level of "health," and that are long-lasting, and the mother's experiences—the anxiety caused through prenatal testing as a biopolitical classification technique,⁷⁶ the potential trauma of termination, the birth experiences lost through fear of negative outcomes—none of these are important under biopower.

On this level, I think there is a great deal to be learned from feminist literature around pregnancy and motherhood (D.-A. Davis & Craven, 2012; Draper, 2002; Shaw, 2013; Worman-Ross & Mix, 2013), as well as from Critical Disability Studies (Aulagnier et al., 2005; Isgro, 2015; Landsman, 2005; Titchkosky & Michalko, 2009). For one, as mentioned in the introduction to this dissertation, the Foucauldian view of power has been criticized by many scholars for being too narrow in that it treats power as though it applies to everyone equally and does not recognize the gendered nature of power relations (Sawicki, 1991). This is why it was important to inform my work with feminist studies (e.g., Deveaux, 1994; Ells, 2003; Morrow, Hawkins, & Kern, 2015; Roberts, 2015; Scott, 1992; Shaw, 2013; Yuill, 2014). This research clearly shows the vestiges of the patriarchal development of obstetric medicine at work today, through the continued valorization of observational and technologically-based epistemology over embodied or client-led methods of knowing. It is also clear in the way that women's desires

⁷⁶ Foucault defines the techniques of biopolitics as those which allow us to classify and sort between different populations; those which do and do not benefit the body politic (Foucault, 2005).

for their birth experiences are nearly always overlooked in the service of biopower, and their anxiety and fears around prenatal testing are treated as if they do not exist or are of minor import, and are not a significant risk/outcome of the process. I would go so far as to argue that we are using a great deal of language of medical “consent” in a rote fashion. The pregnant person is asked to consent to treatment, but the more doctors are concerned about the worst-case scenario, the more asking for consent is routinized, and becomes much more about avoiding liability than actually offering people meaningful opportunities for understanding and exercising critical agency.

Furthermore, as we think about what constitutes the “idealized” population which we are working so hard to achieve, it is essential to apply an intersectional lens. We do see a particularly white, educated, and well-resourced vision of families through our state-funded prenatal testing communication, information and advertisement, and this definitely impacts our cultural discourses of what lives are worth fostering. The impact of cultural acceptance is incredibly significant and cannot be minimized: I saw this especially through the users of prenatal testing forums on Down syndrome termination and their justification of their decisions. The existence of this public sharing and seeking of reassurance, or seeking to reinforce their decision through the approbation of strangers points to choices not made in isolation but in a strong discursive context, and the importance of feeling that one’s choices are backed by community.

This research showed that a Critical Disability Studies lens very much applies to the imagined child and mother in prenatal testing as it asks us to re-consider the meaning of the phrase “quality of life,” to end the assumption that disability exists only as an opposite to health, as well as the assumption that health equates to happiness (and is the responsibility of the mother), and to recognize not only the spectrum of ability, but also the legitimacy of

neurodiversity and disability (Fritsch, 2015; Garland-Thomson, 2011; Swain & French, 2000). The pressures women felt to test and to terminate were clearly grounded in their impressions of disability as a hard life; moreover, the increasing imperative to test fetuses cannot be extricated from the many “better dead than disabled” narratives that are rampant throughout our culture (Swain & French, 2000). Challenging these narratives is integral to the social and affirmation models of disability (Oliver, 2013; Swain & French, 2000) and they have ripple effects that were clear to me in the findings of this research. The idea of seeking health at all costs had serious repercussions for parents as they coped with prenatal testing, and after their children were born, when they were raising children with heart conditions, neurodivergent children, and other children whose needs differed significantly from their preconceived expectations, in part because of the ubiquitous discourses of normalcy. In the next section, therefore, I wish to further interrogate the social model of disability and the way it is sometimes placed in opposition to thinking about disability as a form of impairment, and why this matters for prenatal testing.

The Social Model of Disability vs. Impairment and Prenatal Testing

As explained in Chapter 1, the social model of disability was originally put forward in the mid-1970s, and argued that people were not disabled by their physical impairments but by the barriers and lack of accommodation they faced in society (Oliver, 2013). The social model became a fairly mainstream way of thinking about disability, with government action to create legal frameworks to accommodate disability, and organizations and workplaces actively aiming to remove barriers to access (though certainly, these measures have been routinely criticized as afterthoughts, or retrofits, rather than true accessibility [Dolmage, 2017]). The social model has been critiqued as a limited and only partial way to think about disability, and one of the major critiques of the model has been its failure to adequately account for physical impairment. As

Garland-Thompson points out, in our rush to defend disability from being framed as abnormality, disfunction, or restriction, we have sometimes failed to acknowledge the ways that disability is embodied (Garland-Thomson, 2012). Disability is not always uniquely constructed from social barriers that can be removed, nor is it only physical impairment. Our very adherence to the idea that there is a typical or correct type of human is wrong—and it is continually challenged as we develop prenatal testing further and find a plethora of minute and various ways that humans can and will diverge from whatever we define as normal. When we see something which we define as an “abnormality,” and then that genetic code produces what we see as a “normal” child, we tend to read that either as a failure of the testing or as lucky, instead of reconsidering our definition of normal entirely, as inclusive of diverse genetic codes.

Despite this, we run into issues when we try to deny the embodied or physical realities of disability and illness, when it comes to prenatal testing. For one, this research shows clearly that it is not only fear of disability that is a driving force behind the movement to test prenatally, but fear of fetal and infant mortality. Certainly, individual decisions to terminate occur within a cultural background of ableism and are influenced by ableist discourses, but it does not follow that all terminations are therefore uniquely rooted in ableism, to the exclusion of all other reasons. When we look at situations like Grace’s, who terminated due to a diagnosis of Monosomy X, this decision is reflective of parents wanting to avoid the pain of losing a child.⁷⁷ While the decision to terminate a fetus with Monosomy X may not be produced so much from fear of disability as from fear of pregnancy or infant loss (though I am not dismissing ableism as a factor), if we terminate most fetuses with Monosomy X, that affects the lived experiences of

⁷⁷ It is of course worth noting that some of these terminations are also based in many other reasons, such as protecting the pregnant person’s life.

teenagers and adults with Monosomy X. It reinforces the discourse that their lives are a preventable burden, and it also has the potential to reduce the supports available to them, as the total numbers go down at a population level, as I was told by some participants.

The influences on parents also matter for prenatal testing because not only these life-and-death situations but any diagnosis of prenatal disability can represent an ethical dilemma for the parent. Moreover, these are often situations where parents are making the hardest decision of their lives, often with extraordinarily few supports, which this research showed is sometimes why they turn to online forums like WhatToExpect.com. This research, both online and through interviews, showed that these parents often have a high level of medical understanding of the conditions their fetuses have been screened for or diagnosed with, and it showed that the financial burden of disability continues to be a major influence over what they decide. That alone is evidence of the social construction of disability, because the state's decision to pay for widespread prenatal testing, instead of better resources for disabled people and their supports, reflects implicit cultural values, and can absolutely be altered. The importance for mothers to provide financial support for their disabled children, without drawing all attention away from their non-disabled children, not only through childhood but also as adults, is an important factor in their decision-making. It is also a critical reason that we cannot dismiss terminations due to fear of (re)producing disability as merely the product of individual ableist thinking; they are the result of systemic ableist and classist biopolitical policies that favour eradication over support.

As in the example of financial supports, I do think there is enormous merit in continuing to consider the discourses that surround disability, because this research demonstrated certain clear-cut cases where it is the marginality associated with disability, and the divergence from the “norm,” that was the deciding factor. One example from Chapter 3 was the online commenter

whose fetus had been diagnosed with achondroplasia (dwarfism) and who was seriously concerned about the effect on the baby's potential 'quality of life' living in the world while being visually "deformed." This example reinforces findings from earlier studies that the visually observable facial differences associated with Down syndrome and other chromosomal abnormalities are a major reason people abort (Rapp, 1999).

New Technologies, Medicalization, and Pregnant Experience

Another central finding of this dissertation is that Non-Invasive Prenatal Testing (NIPT) is a critical new technology, one which is changing the landscape of prenatal testing experience in important ways. The responses to NIPT were significant in both online communities and through participant interviews. In the former, it was clear that NIPT was important to pregnant people and that there was a high level of faith in its results. In the latter, it was clear that NIPT is quickly becoming an integral part of the definition of what constitutes "responsible" pregnancy, and it is providing pregnant people with a way to test that is much less nerve-wracking. It was clear throughout the research, however, that the perceived⁷⁸ miscarriage risk with amniocentesis, prior to the advent of NIPT, was also providing a sort of "out" for people who did not want to do further testing. Because of the risk, they could refuse, still feel they were taking care of their fetus, and have what was perceived as an acceptable medical reason to justify their decision to their doctors. Now, I observe that the advent and increased routinization of NIPT has increased the socialized imperative to test. This also clearly demonstrates the need for a discursive shift over a technological one; while NIPT is a much more reliable test than Integrated Prenatal

⁷⁸ I use the word "perceived" not because there is no risk, but because my impression throughout the research was that pregnant people perceive this risk as much higher than it is made out to be by medicine, for example, in anecdotal evidence such as the post in Chapter 3 where the mother mourned the death of her fetus following amniocentesis.

Screening, people undergoing it are still experiencing stress and anxiety because of the continued cultural pressure to produce “perfect” children.

There was a clear connection throughout this work between technological authority and medical authority vested in the personage of the doctor or other medical personnel, in that they bolster each other—and yet I observed that these two forms of authority also operate separately. For instance, there were occasions in which online commenters and interview participants reported pushing back against doctors, or questioning the evidence behind recommendations. This was also very clear through Twitter—many of the Tweets were highly critical of medicine. It is also wise to be cautious in observing criticism of medicine online and interpreting it as a challenge to medical authority, since in many cases this online commenting may provide an outlet for emotional responses to the exercise of medical authority, in place of actually challenging the doctor.

I observed by contrast that faith in technology seemed very strong. Even the examples offered by participants of medical error were mix-ups by humans, and seen that way. These were clearly seen as exceptional to the use of technology, instead of part and parcel of technology’s inherent design and use by humans, with values embedded (Noble, 2013; Wajcman, 2009). Lisa’s story from Chapter 4, of her NIPT results being mixed up with someone else’s, demonstrates this clearly. Lisa’s faith in NIPT was unshaken by the story; she saw the mix-up as an anomaly, one which should be closely guarded against due to its dire consequences. Furthermore, she was very clear in her articulation of those potential consequences: If she had been told her fetus had Down syndrome, she would have aborted, which she saw as a tragedy only if there was a mistake. This constitutes a high level of faith in the technology not only to be accurate, but to classify or identify human worthiness. And yet, at the same time, we do know

the limits. NIPT can perform a highly accurate screening for Trisomies 13, 18, and 21 (Patau, Edwards and Down syndrome) and sex chromosomes. It is not diagnostic, and it simply can't look for everything defined as disability or abnormality. (Not to mention that many disabilities are not congenital.) And yet, the decision-making that is based on these results depends on a level of faith that seems disproportionate to both its accuracy and its limits. This is where we see evidence of medical authority bolstering the technology. We trust the NIPT because the doctors tell us to do so. As we saw in Chapter 5, the information we get, even through doctors, is largely provided by the makers of the tests, and is highly biased in favour of the test, painting it as an essential part of responsible motherhood. Thus, the shock when it is revealed to be subject to human error.

Both this faith in technology, and the increased emphasis on using technology are actively promoted by medical authorities, and as this happens, there is a concurrent abandonment of embodied knowledge and epistemology of pregnancy through the senses. Medicalized findings are also often used in lieu of information provided by the pregnant person, which can feel disempowering. Whether the overreliance on technology simply happens in tandem with these or whether it is the cause of them is unclear, but the evidence from this research shows that once technology is introduced and emphasized in someone's care, it changes the way we learn about that person's pregnancy and the fundamental control the pregnant person has over their own care and choices. Many of the people I interviewed were classified as having high-risk pregnancies and spoke to the resulting erasure of embodied and sensory care; there was no asking them what was going on or feeling of the belly. All knowledge was produced externally, largely through ultrasounds. This happened even as their medical providers routinely warned them of the limits of ultrasound—for instance, Tanya's reports of failure to get a good picture on

some visits. The frequency with which pregnancies are classified as high-risk and thus subjected to high levels of technological intervention, and reduced emphasis on the mother's experiences, is clearly increasing and therefore I find that this is a systemic issue. What I mean by this is that overall, there is an increased movement in birth and pregnancy care (in Canada) towards recognizing the pregnant person as a central decision-maker for their own care, and respecting their choices (Cardin, 2020a), though of course these are couched in broader technologies and discourses as I have been arguing. We see many examples of this, even for people who have medicalized pregnancies in hospital environments: Emphasis on keeping mothers and infants together, increased assistance for lactation, skin-to-skin bonding time, etc. However, the moment the pregnant people are classified as high-risk, they are right back to experiencing higher levels of medicalization and technology with de-emphasized agency. Again, the pregnant person's experience is sacrificed in service of the biopolitical imperative to foster life (as a higher-risk pregnancy brings with it a greater risk of infant or maternal mortality or morbidity, although sometimes this increased risk is very small). When a large percentage of pregnant people are being classified as high-risk, these issues are systemic, rather than exceptional. Many participants in this research reported a high number of ultrasounds, and an overuse of other forums of testing such as urine samples, weigh-ins, and blood tests—and many felt that the large number of tests increased their stress. There was a direct connection between technology-based tests and stress, whereas hands-on tests such as measuring the height of the fundus (top of uterus), feeling the belly, and asking about how they were feeling, were perceived as caring, and reduced stress.⁷⁹ It is an incidental finding that people who had midwives often felt much better

⁷⁹ I am certainly not suggesting that ultrasound be abandoned, as mentioned in Chapter 1.

supported, felt they had more agency, and enjoyed their experiences of pregnancy much more.⁸⁰ Furthermore, in general, the people I interviewed felt unsupported during the stress caused by added surveillance due to “high-risk” classification. Relatedly, I also found in this research that medicine traffics in norms surrounding pregnant experience to a point where everyone feels as though their poor experiences are exceptional. Many participants told me that their experiences were unusual or thought they might “skew” my results, and everyone who said this had an experience that was shared by other participants.

This finding also tied back to the use of the phrase “As long as it’s healthy...,” which some participants said was about minimizing the importance of the mother’s experience. While many acknowledged the implied ableism in this phrase, others said that this phrase places the emphasis on outcomes (healthy baby) to the exclusion of what the mother experiences. It was seen as a way of dismissing trauma or obstetrical violence (Burstow, 2003; Cohen Shabot, 2016) as unimportant. This ties into another important finding from Chapter 5, which is the terrible job our medical system is doing of supporting maternal mental health. Every person I interviewed reported being offered no support whatsoever to deal with stress and anxiety related to prenatal testing, including the several who dealt with positive (abnormal) results. The only person who reported being offered counselling was Grace, and as I mentioned in Chapter 5, the offered counsellor did not call her until five months after her termination. This routine lack of support demonstrates a complete abandonment of the mothers with hyper-attention to their fetuses and it treats the effects of medicalized pregnancy as only liminal. Perhaps it also shows a cultural reluctance to admit that this is stressful for mothers, whether because this undermines the

⁸⁰ I feel the need to be cautious in reporting this, and to declare my bias having both produced research on midwifery (Cardin, 2020a) and been a midwifery client. However, I did not directly ask about which healthcare providers people used, and this finding emerged nonetheless. I think comparing healthcare providers from a client perspective would be an important avenue for further research.

biopolitical imperative to test and terminate, or because of larger cultural expectations that mental health for mothers (as for everyone, really) is an individual problem.

These findings about the mother's experience tie back to our abovementioned technological overdependence, our abandonment of embodied knowledge, and also a general reduction of the agency of the pregnant person. The issues we saw in Chapter 5 around poor communication—failure to explain what tests look for, failure to explain the risks, and failure to communicate the outcomes clearly—demonstrate an overall medical disciplinary authority that still does not see pregnant people as the decision-makers for their own bodies. Of course pregnant people do not need the full picture if we are just going to tell them what to do anyway. This also connects to the observation many pregnant people made that their care would have been improved through greater consistency, which would have allowed them to form a relationship with their healthcare provider. In many cases, having multiple specialists and many people involved in care cannot be helped, but it would not be such a problem for communication if the pregnant person themselves were seen, by all involved, as the central decision-maker for their own care, and the principal repository of information about their own experience. Nonetheless, several people commented that they did not appreciate remaining with their family doctor until 12 weeks, before being transferred to their OB-GYN; for them, this constituted the medical institution framing the pregnancy as tentative on their behalf and meant that they went through a difficult stage of prenatal testing without support from their primary pregnancy provider. It also means that when pregnant people do miscarry in the first 12 weeks (in which most miscarriages occur), this happens without much support, an experience that was routinely described as very lonely and difficult. Much like pregnant people further along, a person having a miscarriage may have a lot of questions and having immediate access to an expert who is on

call more than the hours of a family doctor, and who specializes in pregnancy, seems like a good idea. When pregnant (or recently pregnant) people have these experiences unsupported, that contributes to further mistrust of doctors down the road.⁸¹

One final point in terms of considering the treatment of mothers within the medical system is that the way I observed pregnant people educating themselves, throughout this research, may in part be caused by this inconsistency of healthcare providers. There are other potential reasons for pregnant people to be so well informed, but through both participant interviews, and online comments, I observed people taking a great deal of agency in their own health and educating themselves both through their medical providers and through other sources of information including Google searches, pregnancy books and medical articles. They were evaluating the literature they were presented with and using advanced medical vocabularies to describe screening results and diagnoses. While all of this can be reflective of privilege, education, and/or being a healthcare worker oneself (or having access to healthcare workers), and is certainly positive, I think it is also definitely worth considering that the reason this savviness happens is that women, especially, feel they must be comfortable using medical jargon, or risk having their concerns dismissed. This, coupled with many participant experiences of being ignored by healthcare providers, or a failure to adequately provide them with the information required to assess their situations, is a reminder of the continued sexism prevalent

⁸¹ It also treats the entire process of pregnancy very mechanistically, with women being transferred to the care of the OBGYN at 12 weeks, unless there is a miscarriage, in which case they are no longer identified as pregnant, with their mental health never considered unless there is a problem. There is a failure to recognize the holistic effects of pregnancy on a person's health and identity.

throughout medical institutions, and perhaps of a neoliberal model of healthcare complete with self-responsibilization.⁸²

Views about Disability, Language, and Prenatal Testing Results

While qualitative interviewing provides an unparalleled opportunity to understand and extrapolate from personal experience (Angel, 2013; Higginbottom & Lauridsen, 2014; Murray-Davis et al., 2012; Nind et al., 2013), it generally does not provide us with a significant enough sample size to draw broad demographic conclusions. Nonetheless, the impression I was left with from participant interviews was that previous experiences of disability have an important role to play in normalizing disability, and generally leave people with positive attitudes about disability. Despite the limitations of the study method in terms of drawing this conclusion, I think it is a remarkable finding in that it flies in the face of everything that has been socially entrenched in us through the tragedy discourse (Garland-Thomson, 2012; Swain & French, 2000). Widespread media representations tell the story that personal experiences of disability will leave us depressed or perhaps even suicidal (and that state is painted as a natural response to the tragic disability which has befallen us). We are taught through discourse that being disability-adjacent (having a close friend or family member with a disability) will be experienced as a burden. In this research, aspects of this were occasionally manifest for parents of disabled children, but nearly all of their stress and burden was either mostly produced or significantly exacerbated by the failure of society around them to provide adequate support, and their normalized, ableist expectations about parenthood. Isabelle, who described her situation of parenting an intellectually disabled child in the most catastrophic terms of anyone, was seriously impacted by the financial toll of her

⁸² I did not ask about the genders of the physicians, but anecdotally there seemed to be enough stories about female/ women physicians dismissing concerns for me to conclude that sexism is also sometimes internalized by women providers.

child's therapies, which were unsupported by funding, and by the impression she had that the time it took to care for her child was taking away from her ability to parent her other child. How different might her experience have been with adequate help and resources and proper supports that might alleviate some of the economic, physical and emotional labour? Leah, who was a single parent of an autistic child, was very clear that one of the biggest challenges was the lack of roadmap, and the failure of popular discourse to provide strategies for parenting in the way that exists for neurotypical children. She spoke, for instance, about parenting books on common topics like toilet training, that all assume a neurotypical child in their approaches. On the other hand, she had a generally more positive experience than Isabelle, in part because she had been able to access resources such as trained specialists to contact when she had questions. The fact that some parents were better able to access resources than others also may speak to a generalized failure to communicate what is available, and the amount of time and labour one is able to dedicate to research while also balancing care and other responsibilities.

Meanwhile, I really want to highlight that those people who described themselves as disabled or chronically ill were much more receptive to the idea of having disabled children, although Tanya did note that she worried her illness could interfere with her ability to care for a child with a need for more support. It is also worth pointing out that experiences of being disability-adjacent did not always translate to higher comfort with having a disabled child, but when people spoke about experiences of temporary disability (e.g. broken limbs) or of disabled people they had known well (former teachers, former students, friends, neighbours), I heard very few tragic descriptions. I heard descriptions of love, resilience, and of themselves as able-bodied people learning from others who were disabled. Sam's voice was excited as she described her daughter's experiences of being able to communicate with her non-verbal friend through the use

of technology. Tanya and Sadie, both experiencing chronic illnesses, were both positively glowing as they imagined a better future for people with disability and illness. The fact that these experiences do not always translate to a greater level of comfort with potential disability in children is indicative of the profound normalization of ableism—countering this discourse is not simple. Ableist discourse is widespread and constant. It does not happen all at once, it happens through thousands of messages and conversations and micro-aggressions—but there is space for counter-discourses to enter.

Another finding of this project about the way ableist discourse was clearly constructed was through small uses of language. As mentioned in Chapter 1, one of the serious ways this happens in medical institutions and literature is through the constant use of the word “risk” to describe disability. When we continually use the word “risk,” throughout the information we provide to pregnant people, we have already framed this situation negatively—we speak of the risk of getting hepatitis, we do not speak of the risk of winning the lottery. We can improve this communication through use of words like “chance” or “probability” which are much less value-laden (Cardin, 2020b), and a more accurate description of what the test is actually indicating. This research also showed the use of euphemistic language to normalize and disassociate from termination. Without commenting on the ethics of abortion, I would argue that even the word “termination” does this—throughout this work, I have never seen an instance of a person who aborted for reasons of disability using the word abortion. It is always referred to as termination, and this matters, because the word abortion carries strong negative connotations (Bailey, 2010; Greasley, 2012; Kimport, 2012). No matter our position on abortion, euphemistic language is clearly used to cover or distance from discomfort. In discussion forums, euphemistic language is frequent, and as I wrote in Chapter 3, very noticeable through the use of “Dx” to mean

“diagnosis” and “Tx” to mean “termination.” (I do wish to put this in a context that these forums are very prone to using acronyms for everything, which I think is part of community-building in that one needs to learn the language to get comfortable in the space.) In another example, when Grace was describing her termination, the use of euphemistic language was very striking, from using the term “medical termination,” which implies there is really no other choice (it is framed as a medical decision, not one based on values), to her colleague using the term “interrupted pregnancy.”

I think this type of indirect language has a dual function of easing discomfort with what is happening (which, again, is not just abortion—it is biopolitically-based, ability-selective abortion), and also of easing our failure to support mothers above fetuses. We minimize what is happening, and then what do mothers have to feel anxious or traumatized about? In this, I want to come back to my point about trauma from Chapter 2; that trauma often occurs even in the absence of regret. We can make a decision that we feel is the correct one for ourselves and our families and still experience trauma as a result of that decision (Burstow, 2003; Cohen Shabot, 2016). Grace’s case is a powerful example of this. She made an informed and thought-through decision—and yet she talked about how she had invested her hopes and dreams in that pregnancy, and this was something she had to cope with during her termination. Many of the examples from the Down syndrome forums reflect this also; the words used by the commenters never showed regret exactly, but they did show guilt, shame and trauma. These decisions were carefully considered, because they did not feel adequately supported to have a disabled child, and because they had deeply internalized that Down syndrome is incompatible with “quality of life,” but nonetheless many experienced dissonance with the idea of selecting fetuses for ability. In other words, they were clear that in the case of a diagnosis of Down syndrome, they would

terminate, but also several expressed discomfort with the idea, even though this discomfort would not necessarily change their decision. This also ties back to discourse—although I have spent less time on this, it is discourse that shrouds abortion in shame and guilt, and places pregnant people between a rock and a hard place—placing responsibility on us to produce perfect babies and also damning us if we terminate.

Relatedly, one final word I would like to address, especially as it came up throughout the discourse I analyzed on Twitter, is “eugenics.” I think this word is worth some further examination because it has taken on very strong connotations of Nazism, and because even without that connection it is still deeply interconnected with the history (which continues to the present) of abuse of disabled people and others whose reproduction has been deemed unwanted, in Canada and throughout the “eugenic Atlantic” (D. Mitchell & Snyder, 2003). I do think some of the findings in this research push us to *slightly* complicate these connotations. The original definition of eugenics was essentially selective reproduction to produce an ‘idealized’ version of the human race (Sanger, 2007; Savage, 2007). This results in the biopolitical technique which Rapp (2011) calls stratified reproduction, in which essentially a powerful minority decides what human life was worthy to reproduce, and fosters this life. People who do not fit this model (most particularly through poverty, disability, and race) are discouraged or prevented from reproducing. I wish to vehemently argue against this (eugenics) as a practice, and yet also consider again Julia’s story of selecting for embryos that did not carry her husband’s autoimmune disorder. This decision really clearly fits the model of eugenics I have just outlined. It is an instance, essentially, of selecting against disease (as Savage notes, the language of disease has historically been used as the justification of eugenics [2007]). I am sure, based on the fervour with which many of the Twitter commenters fought the idea of eugenics, especially as it

perpetuates ableism, that there are many who would find this decision ethically abhorrent. It is a decision modelled on eugenic logic, and yet it is also an individual decision, not one intended to influence populations. However, we cannot assume it is unimportant on this ground; Foucault's argument is that biopower operates through individuals, at the behest of individuals, influenced by discourse. In this case, and many others, they were also influenced by experience. I cannot possibly make a final pronouncement as to the ethics of anyone else's individual circumstance, but I return to the argument that all of these decisions are complicated. The decision may be individual; it is also very likely ableist.

And again, ableism was clear throughout this research, and communication around test results was one of the best indicators I saw of the operation of rampant ableism in medicine. It was there in Grace's doctor saying, "This is not going to be your baby," as though her decision was a foregone conclusion. It was there in the concern and immediate talk of termination with Martina's Down syndrome positive screening, and in the online forums, with the reports of insurance refusing to cover anything for a fetus that had been diagnosed as disabled, or reports of doctors telling pregnant people to terminate. It was also there in more subtle ways, such as Sadie being unable to opt out of knowing her disability-related test results, once the test had been run. This tells us about the medical biases around disability, because people frequently get ultrasounds and ask not to be told the sex of the fetus, a request that is granted because medical providers do not consider this information medically important (in Canada). But knowing about health or dis/ability cannot be refused.

I have brought up comparisons to learning the sex of the baby in a few places, in part because of the parallels between sex- and disability-selective abortions, in that they are both based in our sociocultural constructions of human value. One unexpected finding of this research

that I also wish to re-highlight is the cross-section of gender/sex bias and disability that came up. First off, it is clear that sex diversity (various types of what is known as being intersex, or having less frequently found sex chromosomes) is popularly understood and communicated by medicine as disability. Intersex types are named as “syndromes,” much like Trisomies, and they are part of dis/ability selective terminations. This is not baseless: Some of them do include forms of physical impairment or higher likelihood of illness, and some do have lower than average life expectancy. Still, this produces an overall fear of diversity in sex chromosomes (in other words, fear of conditions produced by chromosomes that vary from XX and XY) (Rapp, 1999).

Second, there is an ongoing cultural discourse that boys are more likely to be autistic or have intellectual disabilities, which more than likely dates back to early definitions of autism by people like Hans Asperger and Leo Kanner (Wikipedia, 2020a), who were among the first to describe autism with a set of diagnostic criteria. More recent literature has debunked this, pointing to the underdiagnosis of girls for many reasons (Simone, 2010). This stereotype is certainly geared to culture and gendered expectations, and also comes back to our social conceptions of gender and sex. We saw that there is a cultural stereotype that boys are more likely to be disabled that is based on the way boys are acculturated to behave when overstimulated, and based on this there were participants who preferred to have babies classified as girls, and were nervous about producing male-sexed babies, despite the fact that this is actually a gender stereotype, not a sex stereotype, and gender cannot be tested for. There are a lot of holes in the reasoning behind this phenomenon, clearly, but nonetheless it is quite noteworthy that the aversion to disability is also being reproduced as a gender norm which surfaced in more than one interview and requires further investigation.

A Final Word on “Quality of Life”

Through participant interviews, I heard such varied expressions of love, even in the midst of ableist comments, and read so much love in the comments from parents online. I have come to the conclusion that strangely, love is at the crux of the biopolitical project of prenatal testing, that is convincing so many of us that we must not have disabled or ill children. The pervasive discourses around quality of life are incredibly effective in producing pregnant people’s conformity with cultural and medical norms, in part because of love, but also because we have been deeply conditioned towards the importance of health for fetuses. Love for our potential children combines with deeply felt norms around motherhood as self-sacrificing, creating a powerful desire to give them the best quality of life that we can imagine. Biopower works due to norms that place the responsibility for perfection on mothers, in a highly gendered way. It also works because of our normalized ideas of love and who is worthy of the investment of our love. In a society that treats disability as a burden and individuates that burden, it is no surprise that prenatal testing has come to constitute a system of classification and elimination, as it has. I do not think these uses are an inherent feature of the technologies—as I mentioned earlier, I think there are good and important uses for prenatal testing, many of which can be in the service of reducing maternal and infant mortality. It is no small thing to ask our culture, with its deeply rooted ableism, to abandon the tragedy model of disability, but that essentially is where we go from here. We can imagine a different way to define quality of life; a different way to decide who is worthy of life; a different way to think about who gets to decide.

References

- Abel, E., & Browner, C. H. (1998). Selective compliance with medical authority and the uses of experiential knowledge. In M. Lock & P. A. Kaufert (Eds.), *Pragmatic women and body politics* (pp. 310–326). Cambridge, UK: Cambridge University Press.
- Ahmed, S. (2010). Happy objects. In M. Gregg & G. J. Seigworth (Eds.), *The affect theory reader*. Durham, NC: Duke University Press.
- Alder, J., Fink, N., Bitzer, J., Hösli, I., & Holzgreve, W. (2007). Depression and anxiety during pregnancy: A risk factor for obstetric, fetal and neonatal outcome? A critical review of the literature. *Journal of Maternal-Fetal and Neonatal Medicine*, *20*(3), 189–209.
<https://doi.org/10.1080/14767050701209560>
- Angel, S. (2013). Grasping the experience of the other from an interview: Self-transposition in use. *International Journal of Qualitative Studies on Health and Well-Being*, *8*(1), 1–8.
<https://doi.org/10.3402/qhw.v8i0.20634>
- Aulagnier, M., Verger, P., Ravaud, J. F., Souville, M., Lussault, P. Y., Garnier, J. P., & Paraponaris, A. (2005). General practitioners' attitudes towards patients with disabilities: The need for training and support. *Disability and Rehabilitation*, *27*(22), 1343–1352.
<https://doi.org/10.1080/09638280500164107>
- Ayers, S., Crawley, R., Webb, R., Button, S., & Thornton, A. (2019). What are women stressed about after birth? *Birth*, *46*, 678–685.
- BabyCenter.com. (2019). Terms of Use. Retrieved from <https://www.babycenter.com/help-aboutus-terms>
- Bailey, J. E. (2010). Ethics case: Mandated ultrasound prior to abortion. *American Medical Association Journal of Ethics*, *16*(4), 240–244.

- Barad, K. (1998). Getting real: Technoscientific practices and the materialization of reality. *Differences: A Journal of Feminist Cultural Studies*, 10(2).
- Barcelos, C. A. (2014). Producing (potentially) pregnant teen bodies: biopower and adolescent pregnancy in the USA. *Critical Public Health*, 24(4), 476–488.
<https://doi.org/10.1080/09581596.2013.853869>
- Barker, K. K. (1998). A ship upon a stormy sea: The medicalization of pregnancy. *Social Science and Medicine*, 47(8), 1067–1076. [https://doi.org/10.1016/S0277-9536\(98\)00155-5](https://doi.org/10.1016/S0277-9536(98)00155-5)
- Berube, M. (2018, April 6). This Pa. abortion bill has nothing to do with helping kids with Down syndrome or their families. *Penn Live Patriot News*. Retrieved from https://www.pennlive.com/opinion/2018/04/this_pa_abortion_bill_has_noth.html
- Booth, R. (2019, September 25). Transgender man loses court battle to be registered as father. *The Guardian*. Retrieved from <https://www.theguardian.com/society/2019/sep/25/transgender-man-loses-court-battle-to-be-registered-as-father-freddy-mcconnell>
- Bordo, S. (2004). *Unbearable weight: Feminism, Western culture and the body*. Berkeley, CA: University of California Press.
- BORN Ontario: Better Outcomes Registry Network. (2016). 2014-2016 Biennial Report. Retrieved from <https://www.bornontario.ca/en/publications/annual-and-biennial-reports.aspx>
- Botelho, A. (2014, April 7). Women with Turner syndrome tell their stories. *Boston Globe*. Retrieved from <https://www.bostonglobe.com/lifestyle/health-wellness/2014/04/07/women-with-turner-syndrome-tell-their-stories/Y0z0o6X5K162vLjqt0907J/story.html>
- boyd, d., & Crawford, K. (2012). Critical questions for Big Data: Provocations for a cultural,

- technological and scholarly phenomenon. *Information, Communication and Society*, 15(5), 662–679.
- Browne, S. (2015). *Dark matters: On the surveillance of blackness*. Durham, NC: Duke University Press.
- Browner, C. H., & Preloran, H. M. (2000). Para sacarse la espina (To get rid of the doubt): Mexican immigrant women's amniocentesis decisions. In *Bodies of technology: Women's involvement with reproductive medicine* (pp. 368–383). Columbus, OH: Ohio State University Press.
- Browner, C. H., & Press, N. (2017). The production of authoritative knowledge in American prenatal Care. *Medical Anthropology Quarterly*, 10(2), 141–156.
- Burstow, B. (2003). Toward a radical understanding of trauma and trauma work. *Violence Against Women*, 9(11), 1293–1317. <https://doi.org/10.1177/1077801203255555>
- Butler, J. (1993). *Bodies that matter: on the discursive limits of sex*. New York, NY: Routledge.
- Canadian Down Syndrome Society. (n.d.). Anything but sorry. Retrieved from <https://cdss.ca/family-support/anything-but-sorry/>
- Cardin, M. (2020a). Midwives in Ontario hospitals: The mainstreaming of “alternative” childbearing. In R. Pisco Costa & S. L. Blair (Eds.), *Childbearing and the changing nature of parenthood: The contexts, actors, and experiences of having children (Contemporary perspectives in family Research)* (Vol. 14, pp. 97–119). Bingley, UK: Emerald. <https://doi.org/10.1108/S1530-353520190000014005>
- Cardin, M. (2020b). Reconsidering “Advanced Maternal Age”: Communicating about pregnancy, disability risk and ageing. *Feminist Media Studies*, 20(8), 1073–1087.
- Carroll, K. (2013). Infertile? The emotional labour of sensitive and feminist research

methodologies. *Qualitative Research*, 13(5), 546–561.

<https://doi.org/10.1177/1468794112455039>

Charter, R., Ussher, J. M., Perz, J., & Robinson, K. (2018). The transgender parent: Experiences and constructions of pregnancy and parenthood for transgender men in Australia.

International Journal of Transgenderism, 19(1), 64–77.

<https://doi.org/10.1080/15532739.2017.1399496>

Cheek, J. (2004). At the margins? Discourse analysis and qualitative research. *Qualitative Health Research*, 14(8), 1140–1150. <https://doi.org/10.1177/1049732304266820>

Clare, E. (1999). *Exile and pride: Disability, queerness and liberation*. Cambridge, MA: South End Press.

Clarke, A. (1998). *Disciplining reproduction: Modernity, American life sciences and the “problems of sex.”* Oakland, CA: University of California Press.

Clarke, A. E., Shim, J. K., Mamo, L., Fosket, J. R., Fishman, J. R., Mamo, L., ... Fishman, J. R. (2003). Biomedicalization: Technoscientific transformations of health, illness, and U. S. biomedicine: American Sociological Review. *American Sociological Review*, 68(2), 161–194. <https://doi.org/10.2307/1519765>

Clement, S., Wilson, J., & Sikorski, J. (1998). Women’s experience of antenatal ultrasound scans. In S. Clement (Ed.), *Psychological perspectives on pregnancy*. Edinburgh, UK: Churchill Livingstone.

Cohen Shabot, S. (2016). Making loud bodies “feminine”: A feminist-phenomenological analysis of obstetric violence. *Human Studies*, 39(2), 231–247.

<https://doi.org/10.1007/s10746-015-9369-x>

College of Physicians and Surgeons of Ontario. (2019). Managing tests. Retrieved from

<https://www.cpsso.on.ca/Physicians/Policies-Guidance/Policies/Managing-Tests>

- Crenshaw, K. W. (1995). Mapping the margins: Intersectionality, identity politics and violence against women of color. In *Critical Race Theory. The Key Writings That Formed the Movement*, 43(6), 1241–1299.
- Darke, P. (1998). Understanding cinematic representations of disability. In T. Shakespeare (Ed.), *The Disability Reader: Social Science Perspectives* (pp. 181–200). London, UK and New York, NY: Cassell.
- Darke, P. A. (1994). The Elephant Man (David Lynch, EMI Films, 1980): An analysis from a disabled perspective. *Disability & Society*, 9(3), 327–342.
<https://doi.org/10.1080/09687599466780371>
- Davis, D.-A., & Craven, C. (2012). Revisiting Feminist Ethnography: Methods and Activism at the Intersection of Neoliberal Policy. *Feminist Formations*, 23(2), 190–208.
<https://doi.org/10.1353/ff.2011.0018>
- Deveaux, M. (1994). Feminism and empowerment - A critical reading of Foucault. *Feminist Studies*, 20(2), 223–247.
- Dolmage, J.-T. (2017). *Academic ableism: Disability and higher education*. Ann Arbor, MI: University of Michigan Press.
- Dolmage, J. (2014). *Disability Rhetoric*. Syracuse, NY: Syracuse University Press.
- Douglas, A. (2011). *The mother of all pregnancy books: The all-Canadian guide to conception, birth and everything in between*. Victoria, BC: Page One.
- Down syndrome facts and frequently asked questions. (n.d.). Retrieved February 17, 2020, from <https://cdss.ca/resources/facts-questions/>
- Draper, J. (2002). “It was a real good show”: The ultrasound scan, fathers and the power of

- visual knowledge. *Sociology of Health and Illness*, 24(6), 771–795.
<https://doi.org/10.1111/1467-9566.00318>
- Dreger, A. D., & Herndon, A. M. (2009). Progress and politics in the intersex rights movement: Feminist theory in action. *GLQ: A Journal of Lesbian and Gay Studies*, 15(2), 199–224.
<https://doi.org/10.1215/10642684-2008-134>
- Dubriwny, T. N., & Ramadurai, V. (2013). Framing Birth: Postfeminism in the Delivery Room. *Women's Studies in Communication*, 36(3), 243–266.
<https://doi.org/10.1080/07491409.2013.830168>
- Ells, C. (2003). Foucault, feminism, and informed choice. *Journal of Medical Humanities*, 24, 213–228.
- Erevelles, N. (2011a). *Disability and difference in global contexts: Enabling a transformative body politic*. New York, NY: Palgrave Macmillan.
- Erevelles, N. (2011b). The color of violence: Reflecting on gender, race and disability in wartime. In K. Q. Hall (Ed.), *Feminist Disability Studies*. Bloomington, IN: Indiana University Press.
- Foucault, M. (1972). *The archaeology of knowledge and the discourse on language*. New York, NY: Vintage Books.
- Foucault, M. (1980). *Power/knowledge: Selected interviews & other writings*. New York, NY: Pantheon Books.
- Foucault, M. (1982). The subject and power. *Critical Inquiry*, 8(4), 777–795.
- Foucault, M. (1990). *The history of sexuality: Vol 1: An introduction*. New York, NY: Vintage Books.
- Foucault, M. (1991). Governmentality. In G. Burchell, C. Gordon, & P. Miller (Eds.), *The*

- Foucault Effect: Studies in governmentality* (University). Chicago, IL.
- Foucault, M. (2005). Society must be defended. In M. Bertani & A. Fontana (Eds.), *Lectures at the Collège de France, 1975-76* (pp. 239–264). New York, NY: Vintage Books.
- Foucault, M. (2007a). *Abnormal: Lectures at the collège de France, 1974-1975 (Vol. 2)*. London, UK: Macmillan.
- Foucault, M. (2007b). *Security, Territory, Population: Lectures at the collège de France, 1977-1978*. New York, NY: Palgrave Macmillan.
- Fox, M. (2008). *Ten little fingers, ten little toes*. San Diego, CA: Harcourt.
- Fritsch, K. (2015). Gradations of debility and capacity: Biocapitalism and the neoliberalization of disability relations. *Canadian Journal of Disability Studies*, 4(2), 12–48.
- Garland-Thomson, R. (2001). Seeing the disabled: Visual rhetorics of disability in popular photography. In P. K. Longmore & L. Umansky (Eds.) *The new disability history, American perspectives*, (pp. 335–374). New York, NY: New York University Press.
- Garland-Thomson, R. (2005). Feminist disability studies. *Signs*, 30(2), 1557–1587.
- Garland-Thomson, R. (2011). Integrating disability, transforming feminist theory. In K. Q. Hall (Ed.), *Feminist disability studies* (pp. 13–47). Bloomington, IN: Indiana University Press.
- Garland-Thomson, R. (2012). The case for conserving disability. *Journal of Bioethical Inquiry*, 9(3), 339–355. <https://doi.org/10.1007/s11673-012-9380-0>
- Gaskin, I. M. (2003). *Ina May's guide to childbirth*. New York, NY: Bantam.
- Gentile, K. (2013). Biopolitics, trauma and the public fetus: An analysis of preconception care. *Subjectivity*, 6(2), 153–172. <https://doi.org/10.1057/sub.2013.2>
- Gibson, M. F. (2015). Intersecting deviance: Social work, difference and the legacy of eugenics. *British Journal of Social Work*, 45(1), 313–330. <https://doi.org/10.1093/bjsw/bct131>

- Ginzberg, R. (1987). Uncovering gynocentric science. *Hypatia*, 2(3), 89–105.
- Glaser, B. G., & Strauss, A. L. (1967). The Discovery of Grounded Strategies for Qualitative Research. *International Journal of Qualitative Methods*, 5(1), 271.
<https://doi.org/10.2307/2575405>
- Global Down Syndrome Foundation. (2018). Down syndrome human and civil rights timeline. Retrieved from <https://www.globaldownsyndrome.org/about-down-syndrome/history-of-down-syndrome/down-syndrome-human-and-civil-rights-timeline/>
- Goodley, Dan, Lawthom, R., & Runswick-Cole, K. (2014). Posthuman disability studies. *Subjectivity*, 7(4), 342–361. <https://doi.org/10.1057/sub.2014.15>
- Goodley, Daniel, & Runswick-Cole, K. (2016). Becoming dishuman: thinking about the human through dis/ability. *Discourse*, 37(1), 1–15. <https://doi.org/10.1080/01596306.2014.930021>
- Government of Canada. (2017). Down syndrome surveillance in Canada 2005-2013. Retrieved from <https://www.canada.ca/en/public-health/services/publications/healthy-living/down-syndrome-surveillance-2005-2013.html>
- Greasley, K. (2012). Abortion and regret. *Journal of Medical Ethics*, 38(12), 705–711.
- Greene, R. (1999). *Malthusian worlds: U.S. leadership and the governing of the population crisis*. Boulder, CO: Westview Press.
- Hacking, I. (1991). How should we do the history of statistics? In *The Foucault effect: Studies in governmentality* (pp. 181–196). Chicago, IL: University of Chicago Press.
- Hall, K. Q. (2009). Queer breasted experience. In L. Shrage (Ed.), *You've changed* (pp. 121–134). Oxford, UK: Oxford University Press.
- Hall, K. Q. (2011). Reimagining disability and gender through feminist studies. In K. Q. Hall (Ed.), *Feminist disability studies* (pp. 1–10). Bloomington, IN: Indiana University Press.

- Hall, S. (1997). Introduction. In S. Hall (Ed.), *Representation: Cultural representations and signifying practices* (pp. 1–11). London, UK: Sage Publications.
- Hamraie, A., & Fritsch, K. (2019). Crip technoscience manifesto. *Catalyst: Feminism, Theory, Technoscience*, 5(1), 1–33. <https://doi.org/10.28968/cftt.v5i1.29607>
- Hartouni, V. (1997). *Cultural conceptions: On reproductive technologies and the remaking of life*. Minneapolis, MN: University of Minnesota Press.
- Higginbottom, G., & Lauridsen, E. I. (2014). The roots and development of constructivist grounded theory. *Nurse Researcher*, 21(5), 8–13. <https://doi.org/10.7748/nr.21.5.8.e1208>
- Hughes, B., & Paterson, K. (2006). The social model of disability and the disappearing body: Towards a sociology of impairment. In *Overcoming disabling barriers: 18 Years of disability and society* (pp. 101–117). Abingdon, UK: Routledge.
<https://doi.org/10.1080/09687599727209>
- Irish Health. (2006). Down syndrome. Retrieved February 17, 2020, from <https://downsyndrome.ie/support-detail/health/>
- Isgro, K. (2015). From a caretaker's perspective: Mothers of children with Down syndrome as advocates. *Women & Language*, 38(1), 63–83.
- Jack, J. (2014). *Autism and gender: From refrigerator mothers to computer geeks*. Urbana, IL: University of Illinois Press.
- Jette, S. (2011). Exercising caution: The production of medical knowledge about physical exertion during pregnancy. *Canadian Bulletin of Medical History*, 28(2), 293–313.
- Kafer, A. (2003). Compulsory bodies: Reflections on heterosexuality and ablebodiedness. *Journal of Women's History*, 15(3), 77–89.
- Kaposy, C. (2018, April 16). The ethical case for having a baby with Down syndrome. *New York*

- Times*. Retrieved from <https://www.nytimes.com/2018/04/16/opinion/down-syndrome-abortion.html?module=inline>
- Keating, A., & Fleming, V. E. M. (2009). Midwives' experiences of facilitating normal birth in an obstetric-led unit: a feminist perspective. *Midwifery*, *25*(5), 518–527.
<https://doi.org/10.1016/j.midw.2007.08.009>
- Kim, M.-H., Park, S., Cho, H., Choi, J., Kim, J., Ahn, H., ... Yang, J. (2006). Threshold of nuchal translucency for the detection of chromosomal aberration: Comparison of different cut-offs. *Journal of Korean Medical Science*, *21*(1), 11–14.
- Kimport, K. (2012). (Mis)Understanding Abortion Regret. *Symbolic Interaction*, *35*(2), 105–122.
- Kuppers, P. (2014). Crip time. *Tikkun Magazine*, *29*(4), 29–31.
- Kvande, L. (2000). Screening through the media: The public presentation of science and technology in the ultrasound diagnostic controversies. In A. R. Saetnan & N. Oudshoorn (Eds.), *Bodies of technology: Women's involvement with reproductive medicine* (pp. 309–330). Columbus, OH: Ohio State University Press.
- Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities*, *26*(2–3), 121–139. <https://doi.org/10.1007/s10912-005-2914-2>
- Lawson, K. L. (2006). Expectations of the parenting experience and willingness to consider selective termination for Down syndrome. *Journal of Reproductive and Infant Psychology*, *24*(1), 43–59. <https://doi.org/10.1080/02646830500475351>
- Lorde, A. (1984). *Sister outsider: Essays and speeches*. Trumansburg, NY: Crossing Press.
- Lupton, D. (1999). *Risk and sociocultural theory: new directions and perspectives*. *Ris* (Vol. XXXIII). <https://doi.org/10.1007/s13398-014-0173-7.2>
- Lupton, D. (2011). “Precious cargo”: Foetal subjects, risk and reproductive citizenship. *Critical*

- Public Health*, 22(3), 329–340. <https://doi.org/10.1080/09581596.2012.657612>
- Macleod, C., & Durrheim, K. (2002). Foucauldian feminism: The implications of governmentality. *Journal for the Theory of Social Behaviour*, 32(1), 41–60. <https://doi.org/0021-8308>
- Magnet, S. (2013). Identity and the new eugenics in the Newborn Screening Saves Lives Act. *Media, Culture and Society*, 35(1), 71–77. <https://doi.org/10.1177/0163443712464560>
- Magnet, S., & Watson, A. (2017). How to get through the day with pain and sadness: Temporality and disability in graphic novels. In E. Ellcessor & B. Kirkpatrick (Eds.), *Disability Media Studies* (pp. 247–271). New York, NY: New York University Press.
- Maguire, A. (2016). *War on autism: On the cultural logic of normative violence*. Ann Arbor, MI: University of Michigan Press.
- Mayo Clinic. (n.d.). Turner syndrome. Retrieved from <https://www.mayoclinic.org/diseases-conditions/turner-syndrome/symptoms-causes/syc-20360782>
- Mayo Clinic. (2021). Forceps delivery. Retrieved from <https://www.mayoclinic.org/tests-procedures/forceps-delivery/about/pac-20394207>
- McKercher, C. (2019). *Shut away: When Down syndrome was a life sentence*. Fredericton, NB: Goose Lane Editions.
- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York, NY: New York University Press.
- Million, D. (2009). Felt theory: An indigenous feminist approach to affect and history. *Wicazo Sa Review*, 24(2), 53–76. <https://doi.org/10.1353/wic.0.0043>
- Mills, C. (2001). *Futures of reproduction: Bioethics and biopolitics* (Vol 49). Springer Science & Business Media.

- Mitchell, D., & Snyder, S. (2003). The eugenic Atlantic: Race, disability, and the making of an international eugenic science, 1800-1945. *Disability and Society*, 18(7), 843–864.
<https://doi.org/10.1080/0968759032000127281>
- Mitchell, L. M., & Georges, E. (2000). Cross-cultural cyborgs: Greek and Canadian women's discourses on fetal ultrasound. In A. R. Saetnan & N. Oudshoorn (Eds.), *Bodies of technology: Women's involvement with reproductive medicine* (pp. 331–354). Columbus, OH: Ohio State University Press.
- Moore, S. E. H. (2010). Is the healthy body gendered? Toward a feminist critique of the new paradigm of health. *Body and Society*, 16(2), 95–118.
<https://doi.org/10.1177/1357034X10364765>
- Morgan, L. M. (2000). Magic and a little bit of science: Technoscience, ethnoscience, and the social construction of the fetus. In A. R. Saetnan & N. Oudshoorn (Eds.), *Bodies of technology: Women's involvement with reproductive medicine*. Columbus, OH: Ohio State University Press.
- Morrow, O., Hawkins, R., & Kern, L. (2015). Feminist research in online spaces. *Gender, Place and Culture*, 22(4), 526–543. <https://doi.org/10.1080/0966369X.2013.879108>
- Murkoff, H. (2008). *What to expect when you're expecting*. New York, NY: Workman.
- Murray-Davis, B., McNiven, P., McDonald, H., Malott, A., Elarar, L., & Hutton, E. (2012). Why home birth? A qualitative study exploring women's decision making about place of birth in two Canadian provinces. *Midwifery*, 28(5), 576–581.
<https://doi.org/10.1016/j.midw.2012.01.013>
- Murray, S. J. (2007). Care and the self: Biotechnology, reproduction, and the good life. *Philosophy, Ethics, and Humanities in Medicine*, 2(1), 1–15. <https://doi.org/10.1186/1747->

- Murray, S. J. (2016). Afterword: Care, giving: An ethical critique. In *The ethics of care: Moral knowledge, communication, and the art of caregiving*. Abingdon, UK: Routledge.
- National Centre for Biotechnology Information. (2007). Understanding human genetic variation.
- Natoli, J. L., Ackerman, D. L., Mcdermott, S., & Edwards, J. G. (2012). Prenatal diagnosis of Down syndrome: A systematic review of termination rates (1995-2011). *Prenatal Diagnosis*, 32(2), 142–153. <https://doi.org/10.1002/pd.2910>
- Nicolaides, K. H. (2004). Nuchal translucency followed by second-trimester ultrasonography. *American Journal of Obstetrics and Gynecology*, 191(1), 1–2. <https://doi.org/10.1016/j.ajog.2004.03.091>
- Nind, M., Wiles, R., Bengry-Howell, A., & Crow, G. (2013). Methodological innovation and research ethics: Forces in tension or forces in harmony? *Qualitative Research*, 13(6), 650–667. <https://doi.org/10.1177/1468794112455042>
- Noble, S. (2013). Google search: Hyper-visibility as a means of rendering Black women and girls invisible. *InVisible Culture: An Electronic Journal for Visual Culture*, 19(Fall), 1–34. <https://doi.org/10.1039/b817639f>
- O’Grady, H. (2004). An ethics of the self. In *Feminism and the final Foucault* (pp. 91–117). Chicago, IL: University of Illinois Press.
- Oliver, M. (1996). Defining impairment and disability: Issues at stake. In *Exploring the divide* (pp. 29–54). Leeds, UK: The Disability Press.
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability and Society*, 28(7), 1024–1026. <https://doi.org/10.1080/09687599.2013.818773>
- Oster, E. (2018). *Expecting better: Why the conventional pregnancy wisdom is wrong - and what*

- you really need to know*. New York, NY: Penguin.
- Parizeau, L. (2007). Appropriate use of technology : A key element in the Ontario midwifery model of practice. *Allied Health*, 4(1), 43–45.
- Parry, D. C. (2008). “We wanted a birth experience, not a medical experience”: Exploring Canadian women’s use of midwifery. *Health Care for Women International*, 29(8–9), 784–806. <https://doi.org/10.1080/07399330802269451>
- Paterson, S. (2011). Midwives, women and the state: (De)constructing midwives and pregnant women in Ontario, Canada. *Canadian Journal of Political Science*, 44(3), 483–505. <https://doi.org/10.1017/S000842391100045X>
- Pegoraro, L. (2015). Second-rate victims: the forced sterilization of Indigenous peoples in the USA and Canada. *Settler Colonial Studies*, 5(2), 161–173. <https://doi.org/10.1080/2201473X.2014.955947>
- Phillips, A. (2010). What’s wrong with essentialism? *Distinktion*, 11(1), 47–60. <https://doi.org/10.1080/1600910X.2010.9672755>
- Piepzna-Samarisinha, L. L. (2018). *Care work: Dreaming disability justice*. Vancouver, BC: Arsenal Pulp Press.
- Prenatal Screening Ontario. (2018). Screening Choices. Retrieved from <https://www.prenatalscreeningontario.ca/en/ps0/about-prenatal-screening/about-prenatal-screening.aspx>
- Puar, J. K. (2009). Prognosis time: Towards a geopolitics of affect, debility and capacity. *Women and Performance*, 19(2), 161–172. <https://doi.org/10.1080/07407700903034147>
- Rabinow, P., & Rose, N. (2006). Biopower Today. *BioSocieties*, 1(2), 195–217. <https://doi.org/10.1017/S1745855206040014>

- Rapp, R. (1999). *Testing women, testing the fetus: The social impact of amniocentesis in America*. New York, NY: Routledge.
- Rapp, R. (2011). Reproductive entanglements: Body, state, and culture in the dys/regulation of child-bearing. *Social Research: An International Quarterly*, 78(3), 693–718.
- Richmond, Z., Fleischer, R., Chopra, M., Pinner, J., D’Souza, M., Fridgant, Y., & Hyett, J. (2017). The impact of non-invasive prenatal testing on anxiety in women considered at high or low risk for aneuploidy after combined first trimester screening. *Prenatal Diagnosis*, 37(10), 975–982. <https://doi.org/10.1002/pd.5110>
- Roberts, D. E. (2015). Race, gender and genetic technologies: A new reproductive dystopia? In R. E. Dubrofsky & S. Magnet (Eds.), *Feminist surveillance studies* (pp. 169–186). Durham, NC: Duke University Press. <https://doi.org/10.1590/S1516-18462008000300012>
- Rose, N. (2007). *The politics of life itself*. Princeton, NJ: Princeton University Press.
- Roser, M., & Ritchie, H. (2013). Maternal mortality. Retrieved from <https://ourworldindata.org/maternal-mortality>
- Rushing, B. (1993). Ideology in the Reemergence of North American Midwifery. *Work and Occupations*, 20(1), 46–67.
- Saetnan, A. R. (2000). Thirteen women’s narratives of pregnancy, ultrasound, and self. In A. R. Saetnan & N. Oudshoorn (Eds.), *Bodies of technology: Women’s involvement with reproductive medicine* (pp. 331–354). Columbus, OH: Ohio State University Press.
- Sampson, H., Bloor, M., & Fincham, B. (2008). A price worth paying? Considering the “cost” of reflexive research methods and the influence of feminist ways of “doing.” *Sociology*, 42(5), 919–933. <https://doi.org/10.1177/0038038508094570>
- Samuels, E. (2017). Six ways of looking at cripp time. *Disability Studies Quarterly*, 37(3).

- Sanger, A. (2007). Eugenics, race and Margaret Sanger revisited: reproductive freedom for all? *Hypatia*, 22(2), 210–217. <https://doi.org/10.2979/HYP.2007.22.2.210>
- Sauer, M. V. (2015). Reproduction at an advanced maternal age and maternal health. *Fertility and Sterility*, 103(5), 1136–1143. <https://doi.org/10.1016/j.fertnstert.2015.03.004>
- Savage, R. (2007). “Disease incarnate”: Biopolitical discourse and genocidal dehumanisation in the age of modernity. *Journal of Historical Sociology*, 20(3), 404–440. <https://doi.org/10.1111/j.1467-6443.2007.00315.x>
- Sawicki, J. (1991). *Disciplining Foucault: Feminism, power and the body*. Hove, UK: Psychology Press.
- Saxton, M. (2006). Disability rights and selective abortion. In *The disability studies reader* (pp. 105–116). New York, NY: Routledge.
- Scott, J. (1992). Experience. In *Feminists theorize the political* (pp. 22–40). New York, NY and London, UK: Routledge.
- Sears, W., Sears, M., Sears, R., & Sears, J. (2013). *The baby book: Everything you need to know about your baby from birth to age two*. Boston, MA: Little, Brown.
- Seigworth, G. J., & Gregg, M. (2010). An inventory of shimmers. In G. J. Seigworth & M. Gregg (Eds.), *The affect theory reader* (pp. 1–28). Durham, NC: Duke University Press.
- Shakespeare, T. (2006). The social model of disability. In L. J. Davis (Ed.), *The disability studies reader* (pp. 197–204). New York, NY: Routledge.
- Shaw, J. C. A. (2013). The medicalization of birth and midwifery as resistance. *Health Care for Women International*, 34(6), 522–536. <https://doi.org/10.1080/07399332.2012.736569>
- Sheppard, M. E., Vitalone-Raccaro, N., Kaari, J. M., & Ajumobi, T. T. (2017). Using a flipped classroom and the perspective of families to teach medical students about children with

- disabilities and special education. *Disability and Health Journal*, 10(4), 552–558.
<https://doi.org/10.1016/j.dhjo.2017.03.012>
- Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity*. New York, NY: Penguin.
- Simone, R. (2010). *Aspergirls: Empowering females with Asperger syndrome*. London, UK: Jessica Kingsley Publishers.
- Sinclair, J. (2013). Why I dislike person first language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2).
- Smith, D. (1992). Sociology from women's experience: A reaffirmation. *Sociological Theory*, 10(1), 88–98.
- Sobnosky, M. J. (2013). Experience, Testimony, and the Women's Health Movement. *Women's Studies in Communication*, 36(3), 217–242. <https://doi.org/10.1080/07491409.2013.835667>
- Sugiura, L., Wiles, R., & Pope, C. (2017). Ethical challenges in online research: Public/private perceptions. *Research Ethics*, 13(3–4), 184–199.
<https://doi.org/10.1177/1747016116650720>
- Surkan, K. J. (2015). That fat man is giving birth: Gender identity, reproduction and the pregnant body. In N. Burton (Ed.), *Natal signs: Cultural representations of pregnancy, birth and parenting* (pp. 58–72). Bradford, ON: Demeter Press.
- Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability and Society*, 15(4), 569–582. <https://doi.org/10.1080/09687590050058189>
- Taylor-Phillips, S., Freeman, K., Geppert, J., Agbebiyi, A., Uthman, O. A., Madan, J., ... Clarke, A. (2016). Open accuracy of non-invasive prenatal testing using cell-free DNA for detection of Down, Edwards and Patau syndromes: A systematic review and meta-analysis. *BMJ*

- Open*, 6(1), 1–12. <https://doi.org/10.1136/bmjopen-2015-010002>
- Taylor, K.-Y. (2017). *How we get free: Black feminism and the Combahee River Collective*. Chicago, IL: Haymarket Books.
- Thompson, C. (2005). *Making parents: The ontological choreography of reproductive technologies*. London, UK: The MIT Press.
- Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. Toronto, ON: University of Toronto Press.
- Titchkosky, T., & Michalko, R. (2009). Introduction. In T. Titchkosky & R. Michalko (Eds.), *Rethinking normalcy: A disability studies reader* (pp. 1–14). Toronto, ON: Canadian Scholars Press Inc.
- Tremain, S. (2005). Foucault, governmentality, and critical disability theory: An introduction. In S. Tremain (Ed.), *Foucault and the government of disability* (pp. 1–26). Ann Arbor, MI: University of Michigan Press.
- Tremain, S. (2006). Reproductive freedom, self-regulation, and the government of impairment in utero. *Hypatia*, 21(1), 35–53. <https://doi.org/10.2979/HYP.2006.21.1.35>
- Twitter. (2018). Twitter Terms of Service. Retrieved from <https://twitter.com/en/tos>
- U.S. National Library of Medicine. (2018). Noonan syndrome. Retrieved from <https://medlineplus.gov/genetics/condition/noonan-syndrome/>
- U.S. National Library of Medicine. (2020). Achondroplasia. Retrieved from <https://medlineplus.gov/genetics/condition/achondroplasia/#frequency>
- Umansky, L. (1996). The body as a holy land: Feminism, childbirth and the imprint of the counterculture. In *Motherhood reconceived: Feminism and the legacies of the sixties* (pp. 52–76). New York, NY: New York University Press.

- Upadhyay, U. D., Kimport, K., Belusa, E. K. O., Johns, N. E., Laube, D. W., & Roberts, S. C. M. (2017). Evaluating the impact of a mandatory pre-abortion ultrasound viewing law: A mixed methods study. *PLoS ONE*, *12*(7), 1–23.
<https://doi.org/10.1371/journal.pone.0178871>
- Vedam, S., Schummers, L., Stoll, K., Rogers, J., Klein, M. C., Fairbrother, N., ... Kaczorowski, J. (2012). The Canadian Birth Place Study: Describing maternity practice and providers' exposure to home birth. *Midwifery*, *28*(5), 600–608.
<https://doi.org/10.1016/j.midw.2012.06.011>
- Wajcman, J. (2009). Feminist theories of technology. *Cambridge Journal of Economics*, *34*(1), 143–152. <https://doi.org/10.1093/cje/ben057>
- Warren, S., & Brewis, J. (2004). Matter over mind? Examining the experience of pregnancy. *Sociology*, *38*(2), 219–236. <https://doi.org/10.1177/0038038504040860>
- Weir, L. (1996). Recent developments in the government of pregnancy. *Economy and Society*, *25*(3), 373–392. <https://doi.org/10.1080/03085149600000020>
- Weir, L. (2006). *Pregnancy, risk and biopolitics: On the threshold of the living subject*. New York, NY: Routledge.
- Wendell, S. (1989). Toward a feminist theory of disability, *4*(2), 104–124.
- What to Expect. (2017). Abnormal NIPT screening results. Retrieved from
<http://www.whattoexpect.com/>
- WhatToExpect.com. (2017). Terms of Use. Retrieved from
<https://www.whattoexpect.com/terms-of-use/>
- Wikipedia. (2020a). Hans Asperger. Retrieved from
https://en.wikipedia.org/wiki/Hans_Aasperger

- Wikipedia. (2020b). Life unworthy of life. Retrieved from https://en.wikipedia.org/wiki/Life_unworthy_of_life
- Williams, C. (2006). Dilemmas in fetal medicine: Premature application of technology or responding to women's choice? *Sociology of Health and Illness*, 28(1), 1–20. <https://doi.org/10.1111/j.1467-9566.2006.00480.x>
- Williams, C., Sandall, J., Lewando-Hundt, G., Heyman, B., Spencer, K., & Grellier, R. (2005). Women as moral pioneers? Experiences of first trimester antenatal screening. *Social Science and Medicine*, 61(9), 1983–1992. <https://doi.org/10.1016/j.socscimed.2005.04.004>
- Worman-Ross, K., & Mix, T. L. (2013). “I wanted empowerment, healing, and respect”: Homebirth as challenge to medical hegemony. *Sociological Spectrum*, 33(5), 453–481. <https://doi.org/10.1080/02732173.2013.818509>
- Wylie, A., Okruhlik, K., Thielen-Wilson, L., & Morton, S. (1989). Feminist critiques of science: The epistemological and methodological literature. *Women's Studies International Forum*, 12(3), 379–388. [https://doi.org/10.1016/S0277-5395\(89\)80014-7](https://doi.org/10.1016/S0277-5395(89)80014-7)
- Yuill, O. (2014). Feminism as a theoretical perspective for research in midwifery. *British Journal of Midwifery*, 20(1), 36–40. <https://doi.org/10.12968/bjom.2012.20.1.36>

Illustrations

Figure 1

Alt text: Image shows a “Pregnancy Checklist,” being held by a pair of white, female looking hands. The first two items are ticked off: Book Doctor’s Appointment and Order Panorama. The remaining list items are: Buy Prenatal Vitamins, Research Baby Names and Pick Colours for Nursery



Figure 2

Alt text: The below image is an ad for Dynacare, a company which offers the Harmony brand Non-Invasive Prenatal Testing (NIPT). We see a woman with white skin and brown hair, in her late twenties or early thirties, about six months pregnant, sitting on a white couch, reading on her tablet. The text reads “Get safe and accurate results with this prenatal test. Download Free Guide Now!” Text below the image reads “The Harmony Prenatal Test: Get Answers to the Questions that Matter.”

 **Dynacare** Sponsored ·  ...

Get Safe & Accurate Results With This Prenatal Test.
Download Free Guide Now!



DYNACAREHARMONY.CA/PRENATAL-TEST/
The Harmony Prenatal Test: Get Answers to Questions that Matter. Download

Appendix: Interview Questions

This list is a guide for a semi-structured interview. Questions may be added or omitted depending on the answers given by the participant.

Researcher: Hello. Thank you for agreeing to speak with me today. Before beginning, I would like to remind you that you have the right to skip any question, or end the interview at any time.

I would also like to remind you that your identity will be kept confidential.

Thank you again. I am going to begin with some questions that get at your previous experience with pregnancy and your own identity. You are quite welcome to skip these if you don't feel comfortable sharing.

Demographic Information

- First off, are you currently pregnant?
- How many times have you been pregnant?
- Do you have what you would consider to be a disability?
- Do you have family members or close friends who have disabilities?
- Do you have children? How many children do you have?
- Do you have any children with disabilities?
- What is your gender identity?
- What is your sexual orientation?
- For your child or children, are there any co-parents, and if so what is their sexual orientation/ gender identity?
- Do they have a disability?
- If you feel comfortable sharing, what is your racial or ethnic background?
- What languages do you speak in your home?

Decision-making

1. Can you tell me about your experience of pregnancy? Is this recent or current? When were you pregnant?
2. What prenatal tests did you undergo?
In the case of no prenatal tests:
 - Can you speak about why you decided not to undergo any prenatal tests?
 - i. Did you worry about your fetus potentially having an illness or disability?
 - Did you feel that your decision not to do any testing was supported by your health care providers?
 - Was there anyone involved in your pregnancy care whom you felt did not support your decision? If so, who?
 - If you have a partner, did you feel like they supported your decisions?
 - Did you feel that your decision was supported by your family and friends? If not, then what kind of pushback did you experience?
 - Was your decision difficult for any other reason?

- Did you at any point feel compelled to make any other decision? Why or why not?

In the case of prenatal tests:

- Which tests did you undergo?
- Why did you choose to undergo these tests? Were some of them recommended by your health care providers, or did you ask for them?

In the case of asking for tests:

- Was there any specific reason you asked for this test/ these tests?
- Did you want to do (all) of these tests? If not, did you feel comfortable saying no?
- Were there any tests you refused?
- Did you feel like your decisions about which tests to do were supported by your health care providers?
- If you have a partner, did you feel like they supported your decisions?
- Did you feel like your decisions were supported by your family and friends?
- Did you feel any other pressures to undergo tests?
- If you did tests you didn't wish to, what were the main reasons you chose to do them?
- Did you feel pressure while pregnant to change your behaviour, such as by avoiding alcohol, quitting smoking, avoiding certain foods, or avoiding strenuous exercise?
- Did other people pressure you to do or not do certain things while pregnant?
- Are there any traditions or rituals around pregnancy you observed?
- Did you feel pressured to behave a certain way?

Knowledge about Prenatal Testing/ Pregnancy

1. Before undergoing prenatal testing, what did you know about the tests?
2. What sources of information did you consult to find out information about tests? (Doctor, midwife, nurse, friends, Google search?)
3. What resources did you use to learn about the results?
4. Did you feel that any source of information was better than any other?
5. Did you feel you had adequate access to information?

Knowledge about / Attitudes about disability

1. Prior to getting pregnant, were you nervous about the potential to have a child with a disability or illness?
2. Do you have experience of disability in your own life?
3. Were you thinking about disability or illness in terms of your decision about when to get pregnant?
4. Were you thinking about disability or illness in terms of your decision about whether to get tests?
5. Did you think about what you might do if there was a diagnosis of illness or disability?
6. Do you think it is generally harder to parent a child with an illness or disability?
 - a. If yes, what makes it harder?

7. Did you worry that you would experience stigma or exclusion if you had a child with an illness or disability?
8. Did you worry that if you had a child with an illness or disability, they would suffer?
9. Did you have any positive associations with disability? Were you ever inspired by a person with a disability, either someone you knew or someone you were aware of through media?
10. What did you imagine for the potential future of a child with a disability?
11. What resources are you aware of to learn about disability, or to parent a child with a disability?
12. Have you heard pregnant people, either your acquaintances or in the media say the phrase “As long as it’s healthy...” to refer to their fetus? What does that phrase mean to you?

Experience—these questions would have to be slightly altered if the participant is still in the process of prenatal testing, to reflect where they are in the process.

1. Do you remember how you felt while making decisions about whether or not to undergo prenatal tests?
2. What did you think about or consider?
3. Did your healthcare providers prepare you sufficiently for the tests? What information or assistance was provided? Was there anything that should have been included but was not?
4. Can you describe how you felt during:
 - Ultrasound
 - Did you feel anything about the visual aspect of seeing your fetus during ultrasound?
 - Blood tests
 - Amniocentesis
5. Did anyone accompany you to your tests?
6. At what point in your pregnancy did you tell other people in your life that you were pregnant? Did you feel you should wait until after the results of prenatal tests?
7. After the testing, how did you feel when waiting for the results?
8. What were the results of the test?
9. How did you feel about the results?
10. Did you feel the results were presented in a positive or a negative light?
11. Did your feelings about the results change at any point?
12. *If you experienced anxiety/stress:*
 - What resources did your healthcare providers offer you to cope with anxiety or stress related to the waiting period/ the results?
 - Did you turn to any personal resources such as friends, family, or online communities?
 - Did you do any research?

In the case of results that caused anxiety:

- This may be a difficult question to answer, and so I’d like to remind you that you have the right to skip a question. Did you consider whether to continue or terminate the pregnancy? Did you terminate or continue the pregnancy?

Follow-ups are the same regardless of decision:

- Did you feel you had sufficient resources to make this decision?
- What factors did you consider to make this decision?
- Did you feel this decision was influenced by anyone else?
- Did you feel your decision was respected?
- Did you face any difficulties after making this decision?
- Have your feelings about your decision remained the same or changed over time?
- Do you feel able to speak to your partner, friends and family about your pregnancy?

Is there anything else I haven't asked, or that you would like to add?

Thank you so much for your time.

I'd like to remind you that if you have anything you would like to add or remove from your interview, you are welcome to get in touch with me for the next two weeks.