

**Rhetoric, Disability, and Prenatal Testing: Down Syndrome as an Object of
Discourse**

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ABSTRACT

This project considers how disability studies and rhetorical studies—specifically the area of medical rhetoric—might usefully inform one another. In particular, this project examines prenatal testing for Down syndrome as a rhetorical situation that initiates and circulates many different discourses about Down syndrome. Chapter One begins by examining a frequently cited statistic in critiques of prenatal testing—the estimated pregnancy termination rate after a prenatal diagnosis of Down syndrome. It explores the validity of this statistic and uses this discussion to suggest that the effects of prenatal testing on social understandings of Down syndrome are complex and largely unknown. Chapter Two argues that intellectual disabilities, like Down syndrome, are underrepresented in disability studies literature and that their absence can be partially attributed to models of disability used in the field. Chapter Three argues that rhetorical analysis provides a means of examining how Down syndrome is discursively constructed. Chapter Four describes the events of prenatal testing for Down syndrome and analyzes the events as a rhetorical situation. In addition, it reviews feminist, disability, and cultural critiques of prenatal testing demonstrating the strengths of each strand of scholarship and suggesting where rhetorical analysis might provide new information. Chapters Five and Six provide analysis of two commentaries on the rhetorical situation of prenatal testing—genetic counseling discourse and parent discourse. These chapters find that ideal genetic counseling discourse offers pregnant women some opportunities to resist medicalization but also exhibits tension between what counselors say they do and what their rhetorical practice affords, especially regarding disability. In addition, analysis shows that users of prenatal testing are concerned with several factors of decision-making that are either not emphasized or ignored entirely in genetic counseling discourse. This project concludes that although different discourses about Down syndrome are available, elements of the prenatal testing situation make it easier for participants to draw on some discourses rather than others. Furthermore, it appears that certain events in the prenatal testing situation—such as the offer of amniocentesis—operate rhetorically in tacit ways, obscuring the relationship between the choice to undergo genetic screening and perceived meanings of Down syndrome.

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CHAPTER ONE: INTRODUCTION

The genesis of this project stems from the discovery of one startling statistic in Rayna Rapp's book, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. In it, she states that nearly 90% of fetuses prenatally diagnosed with Down syndrome are aborted (223). The high number of pregnancy terminations is startling considering that, according to the National Down Syndrome Society (NDSS), the situation has never been better for people with Down syndrome. Among other things, its fact sheet proclaims:

- Life expectancy for people with Down syndrome has increased dramatically in recent decades—from 25 in 1983 to 60 today.
- People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives. (“Down

Syndrome Fact Sheet”)

Recent decades have seen not only medical advancements relevant to people with Down syndrome but also social advancements in the form of deinstitutionalization, disability rights legislation, funding for special education, and a seeming shift in public attitudes. In particular, mainstreaming—the practice of educating students with intellectual disabilities alongside their peers—has ensured that most people growing up in America have contact with disabled people at a young age. The public presence of persons with Down syndrome has certainly done much to correct inaccurate stereotypes stemming from ignorance. Furthermore, although Down syndrome is still considered to be a significant disability in the medical professions, persons with Down syndrome generally do not suffer pain from their condition, are able to communicate and have meaningful relationships with others, and have the potential for a high quality of life. However, despite shifts in political, medical, and social arenas, Rapp's (2000) claim that after a prenatal diagnosis of Down syndrome close to 90% of pregnancies are terminated suggests that many people, perhaps most people, are unwilling or consider themselves unable to raise a child with Down syndrome.

Rapp's statistic also suggests that users of prenatal testing are making the decision to terminate based on a different discourse about Down syndrome than the one represented in the NDSS fact sheet. While conducting a thorough rhetorical analysis of the fact sheet is not the aim here, it is fair to say that the fact sheet presents Down syndrome in a fairly positive light. It presents Down syndrome as a condition that is not medically significant by emphasizing that most medical conditions association with Down syndrome are treatable. Perhaps more importantly, it also presents people with

Down syndrome as being perfectly capable of leading independent and fulfilling lives and of making worthwhile contributions to their families and society. At the risk of simplifying the discourse, it appears that the main message of the NDSS is that people with Down syndrome are more like nondisabled individuals than they are different. In fact, a second advocacy group, the National Down Syndrome Congress, recently launched a campaign with the slogan “We’re More Alike than Different.”

The discourse of the advocacy groups provides one representation of Down syndrome; however, if this discourse were the only one being considered after a prenatal diagnosis of Down syndrome, we might expect there to be a lower percentage of terminations. Rapp’s statistic suggests that other representations of Down syndrome are being considered and perhaps that the advocacy groups’ representations are not convincing to pregnant women. In this dissertation, I am interested in tracing, through rhetorical analysis, different representations of Down syndrome that are circulated in the prenatal testing situation. Rhetoric is an apt lens through which to study these representations because it affords the researcher an analytic perspective that attends to discourses in use in particular situations. A rhetorical lens acknowledges that discourses are contextual, targeted to particular audiences and constrained by situational factors. Furthermore, it aims to trace the particular effects of discourse both within the immediate situation and beyond. My aim is to understand Down syndrome as an object of discourse that is constructed in the prenatal testing situation in relation to other circulating discourses and in the context of a variety of persuasive forces.

Before discussing Rapp’s statistic further, a brief word about prenatal screening and testing is necessary. These procedures will be discussed in greater detail during later

chapters. Since Down syndrome is most often caused by a person having three twenty-first chromosomes instead of the usual two, it can be detected prenatally through two common *diagnostic* tests, amniocentesis and chorionic villus sampling (CVS). Each of these tests yields a sample of fetal cells from which laboratory technicians can isolate a karyotype or a picture of the number and appearance of chromosomes. These tests are considered to be invasive and carry a very small (0.2 -1%) chance of miscarriage (“Prenatal Testing: Your Guide to Common Tests”). However, amniocentesis and CVS are currently the only tests that are widely available that can also provide a definitive diagnosis of Down syndrome prenatally. In contrast, prenatal *screening* tests can indicate whether or not the fetus is at a greater risk for Down syndrome. Screening practices such as a maternal blood test or fetal ultrasound provide little to no risk to the pregnancy but vary in their degree to accurately predict an incidence of Down syndrome. No screening test can provide a definitive diagnosis of Down syndrome. In the United States, pregnant women may choose whether or not to undergo prenatal screening or testing. Until very recently, only women who were thirty-five or older or women who received positive screening results were routinely referred for prenatal counseling about testing options (“Screening for Fetal Chromosomal Abnormalities”). The incidence of Down syndrome increases with the age of the pregnant woman: at age thirty-five, the chances of having a baby with Down syndrome are roughly equivalent to the chances of miscarriage due to amniocentesis, about one percent. If a diagnostic test indicates that the fetus has Down syndrome, the woman can decide to terminate the pregnancy. The statistic that Rapp cites refers to the termination rates pregnancies that have been prenatally diagnosed, either by amniocentesis or CVS, with Down syndrome.

It turns out that statistical information regarding prenatal diagnosis and rates of termination for Down syndrome is suspiciously insufficient. The statistic that is most frequently cited comes from Mansfield, Hopfer, and Marteau's 1999 retrospective study that summarized previous research on the termination rates for Down syndrome and other conditions. They found ten earlier studies, published between 1980 and 1998, that provided Down syndrome termination rates for specific locales. In the earlier studies, most of the data came from a single hospital or clinic—the aim of the Mansfield, Hopfer, and Marteau study was to summarize that information. In total, they were able to determine the rate of termination for 5035 pregnancies that were prenatally diagnosed with Down syndrome. They found that throughout the 1980s and 1990s, the rates of termination remained fairly consistent at above 90% (810-811).

However, there are some concerns with this data. First, the study is now over a decade old. While the researchers found consistency between the 1980s and 1990s, there is no guarantee that termination rates will continue to stay the same. In 2007, the American Congress of Obstetricians and Gynecologists (ACOG) released new recommendations for pregnant women concerning screening and diagnostic testing for Down syndrome. Previous guidelines recommended genetic counseling, screening, and diagnostic testing only to pregnant women over 35, since older women have a greater chance of having a child with Down syndrome. With new populations undergoing testing, it is possible that termination rates have changed. In addition, the previous research in the Mansfield article came from five different countries, including Great Britain, France, New Zealand, Singapore, and the United States. In fact, only three of the previous studies were conducted in the United States, and all of those were published in the 1980s,

making this particular data set more than twenty years old.

In addition to the Mansfield article, I am aware of three other studies of termination rates following a prenatal diagnosis of Down syndrome. A second article published in 1999 determined the termination rates in the state of Hawaii between 1987 and 1996 and found that 84% of cases with a prenatal diagnosis were terminated (Forrester and Merz 137). Another article published in 1998, found an 86% rate of termination between 1979 and 1994 at one urban hospital (Caruso, et al. 27). Finally, a third article published in 2012 aimed to update the Mansfield et al. review. It analyzed three different types of studies—population-based, hospital-based, and anomaly-based—and found that the mean rates of termination found ranged from 50%-85%, much lower than those determined by Mansfield, Hopfer, and Marteau (Natoli et al. 150). The authors suggest that their data indicates that rates of termination for Down syndrome have actually decreased in recent years in the United States (Natoli et al. 150). While the Centers for Disease Control and Prevention (CDC) keep track of all live births of babies with Down syndrome, there is no national record of prenatal diagnoses or the number of terminations following such diagnoses. As the above studies show, however, individual hospitals and clinics may keep records of this information.

It seems that up-to-date information on termination rates after a prenatal diagnosis of Down syndrome is simply unavailable. Individual health practitioners who work in prenatal care may have a good idea about what percentage of pregnant women choose abortion, but I can find no systematic studies of prenatal care provider opinions either. Even if this information were readily available, however, it might not tell us the full story about attitudes towards birthing and raising a child with Down syndrome. For example,

there is some argument that the high termination rate following a prenatal diagnosis of Down syndrome does not account for the population at large. For example, Rapp points out that many healthcare professionals in Europe assume that women who are interested in prenatal testing are fairly sure that they will want to terminate an affected pregnancy (33). In other words, women who believe they would not want to terminate a pregnancy based on a Down syndrome diagnosis do not get testing in the first place. Thus, the high percentage of terminations may simply reflect the fact that women who are unsure choose not to get a prenatal diagnosis. However, numerous online consumer health guides suggest that there are benefits to knowing about a genetic condition prenatally. For example, the American Pregnancy Association lists four reasons, in addition to being able to make a decision to terminate the pregnancy, about why prenatal diagnostic information might be helpful. They suggest a prenatal diagnosis could offer parents the chance to:

- Pursue potential interventions that may exist (i.e. fetal surgery for spina bifida)
- Begin planning for a child with special needs
- Start addressing anticipated lifestyle changes
- Identify support groups and resources (“Amniocentesis”)

If women in the United States are reading these guidelines or receiving similar advice from their doctors, many or most women may choose to undergo prenatal testing regardless of their inclinations towards termination, and Rapp’s cited termination rates may be accurate.

We also know that although the 90% termination rate statistic would indicate that the numbers of people being born with Down syndrome should have decreased since the routinization of amniocentesis and CVS, in fact, the numbers have increased. According

to news reports, “Data from 10 regional registries of birth defects show that the incidence of Down syndrome among U.S. children increased by 31 percent between 1979 and 2003, from 9.0 to 11.8 per 100,000 live births” (“U.S. Records Increase in Kids with Down Syndrome”). However, this increased number does not necessarily mean that fewer women are choosing to continue pregnancies after prenatal diagnosis or to simply forego prenatal testing in the first place. Researchers think that the increase is likely due to the increased number of women getting pregnant at older ages, making them more likely to have a child with Down syndrome (“U.S. Records Increase in Number of Children with Down Syndrome”). Furthermore, the increased use of prenatal screening and testing procedures indicates that the procedures are being received favorably by pregnant women.

Research into Rapp's cited statistic generates other questions. First, why do we keep track of live births of people with disabilities, but not prenatal incidences of disabilities? Such statistics would not only give us a more accurate picture of incidences of Down syndrome in our population, which have been relatively static to date but may not always be so. Great Britain, for example, has a National Cytogenic Register for this purpose. Recently, the Register published data showing that although incidences of Down syndrome in pregnancies have increased, actual live births of children with Down syndrome have decreased (“Down’s Syndrome Trend Examined”). The study suggests that the increased rate of pregnancies affected with Down syndrome is due to the increase of women getting pregnant later in life, while the decreased rate of live births is a result of prenatal screening and testing.

In addition, at a time when the ethics of genetic screening practices are being

debated in many arenas and the first law has been passed preventing genetic discrimination, we seem to be in need of data that can tell us what the effects of genetic screening and testing procedures are and have been. Amniocentesis was the first prenatal test that was widely available, and research on it would thus yield the farthest reaching data on the subject. Second, in the United States, women may choose to undergo prenatal testing and screening, but they may also choose to refuse such measures. The available statistics can tell us little about the percentage of women who avail themselves of prenatal testing, or how women make choices about these tests. Rapp's book is the most comprehensive treatment of this subject, and her work indicates that the choices are complex and can vary between different populations. More work needs to be done, especially to determine whether, as some professionals believe, only women who intend to abort for a Down syndrome diagnosis decide to undergo testing. If this is not the case, it could mean that many women receive counseling from health practitioners who assume they will want to terminate. Such assumptions could have troublesome consequences for women who were not planning to terminate or decide to go against the practitioner's suggestions.

Finally, even if the statistics on prenatal diagnosis and termination for medical reasons were readily available, what would they tell us about attitudes towards birthing and raising a child with Down syndrome? Beyond that, what might these statistics mean for people who are currently living with Down syndrome and their families? Can a society that embraces prenatal genetic testing and endorses the parents' right to terminate a pregnancy for Down syndrome also be a society that promotes disability rights and treats all citizens fairly regardless of their able-bodiedness?

It is this last question which motivates the research of this project. At the very least, the statistic that ninety percent of fetuses prenatally diagnosed with Down syndrome are aborted looks somewhat paradoxical next to the assertion by Down syndrome advocates that people with Down syndrome are very capable of leading healthy and happy lives within our communities. In writing this dissertation, I seek to unpack this apparent contradiction by investigating and interpreting the contexts in which pregnant women and their partners seek information and make decisions about Down syndrome.

In order to begin investigating these issues from a rhetorical perspective, I was initially interested in speaking directly with women who were in the process of prenatal testing and following them through the decision-making process if they received a prenatal diagnosis of Down syndrome. I wanted to know what types of information women had access to as they made their decisions, who they relied on for support, and what factors had the greatest impact on their choices. What did they identify as the exigence for their behavior and how did they characterize what they were doing? Interviews, I assumed, would be the best tool to get women to explain their choices, whether the choice was to get an amniocentesis or to continue a pregnancy after prenatal diagnosis.

The first stumbling block I ran into was getting access to patients at a prenatal clinic. Prenatal testing that can lead to abortion is not only a private matter of health but a political minefield for clinics offering these services. The hospital staff I worked with for over six months eventually became concerned that my research could expose the clinic to anti-abortion fanatics, potentially putting staff and patients at risk. While I readily

acknowledge that abortion is still an inflammatory subject in the United States, I suspect that it is becoming more difficult to talk about in a public arena rather than less. However, when some researchers and advocates allege that prenatal testing that can lead to terminating a pregnancy because the fetus has a disability amounts to eugenic practice, abortion becomes a subject that we cannot ignore.

In fact, one of the objectives of this project is to demonstrate the importance of allowing social science and humanities scholars access to studying communication between prenatal healthcare providers and their patients. I firmly believe that just as the risk of giving an experimental drug to patients can be justified in some cases, so can the risks to privacy be justified when communication practices can have such important effects. We should never forget that although the right to patient confidentiality is important, patients should also have the right to waive that confidentiality for themselves. When they do not, patient confidentiality laws also serve to protect healthcare providers from political and social critique.

I encountered a second stumbling block with this research when I began conducting interviews with parents of children with Down syndrome—the second population I thought it appropriate to work with to assess decision-making in the prenatal period. After conducting the first of these interviews, I realized that the types of questions I was asking were moving me too far away from my original interests. While it was a wonderful privilege to hear the narrative of how parents learned the diagnosis of their children, how they managed their reactions, and where they turned to for support, I had questions that parents were unable to answer directly. A practical problem that I faced was that with a population of parents who were raising children with Down syndrome, a

significant amount of time was likely to have passed since they received the diagnosis. In addition, as the parents pointed out, I was asking them to remember a time when they were upset and overwhelmed with the information they were receiving. In comparison to later moments of child-raising, the moments of diagnosis and communication with doctors could become a blur. Furthermore, as I began reading more in the areas of medical rhetoric and disability studies, I became more interested in the cultural aspects of women's decisions about prenatal testing. By definition, cultural influences are more difficult for us to name as direct influences because they appear to be natural or common sense reasons for decision-making.

Thus, the restructured version of this project does not include any explicitly include any observational or interview data, partly because I did not have access to the correct populations and partly because I became interested in cultural factors better studied through tracing discourse patterns through various contexts than asking direct interview questions. This project then is an analysis of Down syndrome as an object of discourse in a prenatal setting.

The second chapter provides a rhetorical reading of the prominent models of disability in disability studies in order to determine why intellectual disabilities are historically underrepresented in disability studies literature. This chapter concludes by suggesting that rhetorical methods offer one way of studying the situatedness of particular disabilities—such as Down syndrome—separate from other disabilities.

The third chapter describes the theoretical orientation of this project which relies heavily on discourse theory from Fairclough and cultural theory from Foucault, followed by a fourth chapter that is primarily a literature review of cultural critiques of prenatal

testing. The remaining chapters provide analysis and discussion of two separate arenas where Down syndrome becomes an object of discourse.

The fifth chapter discusses Down syndrome in a professional, medical arena, focusing on prenatal genetic counseling. Finally, the sixth chapter explores how new and expectant parents discuss prenatal testing and Down syndrome in online forums. While these online forums are public, they provide a different perspective than researchers typically get when conducting interviews or surveys with parents. Whereas during interview or survey research, parents are aware they are “talking” to a researcher, on online forums they are talking to each other. The information gathered from the online forums thus represents a powerful way of examining personal discourse.

Taken together, this dissertation seeks to intervene in the debate about the ethics of prenatal screening and testing for Down syndrome in at least two ways:

1. First, this project analyzes how the ethics of prenatal testing are being framed discursively in academic scholarship, medicine, and the personal accounts of pregnant women. Rhetorical analysis illuminates the differences between these groups, including what types of actions are being encouraged or discouraged by each.
2. Second, in contrast to biomedical ethics or disability studies arguments which tell us what women ought to do and anthropological studies which tell us what women choose to do in certain contexts, rhetorical analysis can tell us how women justify their choices and to what contextual or cultural constraints they are responding.

CHAPTER TWO

A RHETORICAL READING OF INTELLECTUAL DISABILITY'S PLACE IN DISABILITY STUDIES

Historically, intellectual disabilities have been underrepresented in disability studies' literature. For example, a conservative reading of the second edition of *The Disability Studies Reader*, published in 2006, shows that at least fourteen out of the first thirty-three chapters focus exclusively on physical disability. In contrast, only one chapter focuses on a cognitive disability, and this chapter concerns psychiatric rather than intellectual differences. Disability studies sections of the library are populated with books specific to deaf culture, environmental challenges for persons with physical impairments, and illness narratives. Of course, several exceptions to the exclusion of intellectual disabilities exist—primarily James Trent's *Inventing the Feeble Mind* and Michael Berube's *Life As We Know It*—two excellent works on the historical development of mental retardation as a category and Down syndrome, respectively. Nevertheless, works devoted to intellectual disability are few and far between.

A similar gap exists in the field of rhetoric. Perhaps one of the earliest forays into disability issues in the field of rhetoric was McCarthy and Gerring's essay, "Revising Psychiatry's Charter Document: DSM-IV." McCarthy and Gerring's work demonstrates the rhetorical processes by which definitions of mental illness were negotiated in professional discourse. While emerging from a research agenda focused on scientific communication, the essay must necessarily engage with issues of disability as a result of its subject matter. "Revising Psychiatry's Charter Document" essentially draws attention to the ways that disability can be socially constructed—in this case, to the way in which

charter documents obscure the complexity of making a psychiatric diagnosis. A disability studies reading of McCarthy's article would note that the classifications of psychiatric illness developed for the DSM require interpretation and thus are subject to error and cultural bias.

McCarthy and Gerring's article proved to be only the beginning of rhetorical studies' interest in psychiatry and mental illness. Following them, such work as Prendergast's (2001) "On the Rhetorics of Mental Disability," portions of Segal's (2005) *Health and the Rhetoric of Medicine*, Berkenkotter's (2008) *Patient Tales: Case Histories and the Uses of Narrative in Psychiatry*, and, most recently, Price's (2011) *Mad at School: Rhetorics of Mental Disability and Academic Life* suggest that psychiatric disorders have continued to be a primary area of focus in disability rhetoric.

Other major figures in disability rhetoric include Ellen Barton, Brenda Brueggeman, Jay Dolmage, Patrician Dunn, Cynthia Lewiecki-Wilson, and James C. Wilson. Their combined works span a broad variety of disability issues from visual representations of disability to rhetorical constructions of deafness to teaching students with learning disabilities. Perhaps because many of these scholars are also teachers of writing, much of this work has focused on populations of disabled students that are present in college classrooms. In their particularly important collection *Disability and the Teaching of Writing: A Critical Sourcebook*, for example, Lewiecki-Wilson and Brueggemann include an interesting essay on deaf students in the writing center. The essay, like many in disability rhetoric, draws attention to our able-bodied biases in writing theory and practice. In this instance, the author points out that asking students to read their papers out loud and listen for mistakes is obviously a writing center practice

that is unsuited to students with hearing impairments.

Despite the broad range of disability topics and populations represented in rhetorical studies, I am aware of only one article that takes intellectual disability as its major object. Lewiecki-Wilson's article, "Rethinking Rhetoric through Mental Disabilities" takes severe mental retardation and facilitated communication as its objects of study. The arguments presented in this piece are important and will be discussed in more detail later; for now, however, it will suffice to say that Liewicki-Wilson's work was published in 2003 and the topics she raises as well as the attention she gives to intellectual disability are in need of continued research.

A growing area of interest in rhetoric that relates to intellectual disability is the developing concept of neurorhetorics. In the introduction to a special issue of *Rhetoric Society Quarterly*, Jack defines neurorhetorics as the study of "the rhetorical appeal, effects, and implications of [the] prefix, neuro—" (406). She continues, "Drawing on the increasingly interdisciplinary nature of rhetorical study, neurorhetorics would question how discourses about the brain construct neurological difference" (406). The articles in this special issue examine how we talk about the brain including our choice of gendered terms, metaphors, and common narratives; the articles also problematize the concept of neurological difference. This RSQ special issue and the concept of neurorhetorics is indebted to an earlier *College English* essay entitled "Neurodiversity," by Jurecic. Jurecic uses the term neurodiversity in this article to refer exclusively to people with autism. She suggests that "because of the nature of their differences, [students with autism] will raise urgent questions about how to teach them" (423). Jurecic is concerned with a new—or perhaps simply more visible—population of students entering her writing classes since,

as she says, “Writing [...] will be a particular challenge for some students on the [autism] spectrum because it does not tap into their typical strengths” (423). Essentially, Jurecic argues that autism is not a developmental condition whose effects can be “fixed” by remediation—such as a requirement to pass a basic writing class—but rather it is a neurological difference requiring our adaptation rather than the student’s.

In contrast, only one of the four articles in the RSQ issue discusses autism in any depth. Two others focus on psychiatric disability, indicating that mental illnesses may also constitute a form of neurological difference. However, there is a rising interest in rhetorical studies to examine autism as a rhetorical phenomenon—a neuroretoric. As an example, a recent issue of *Disability Studies Quarterly* that centered on disability and rhetoric included five articles devoted exclusively to issues involving autism as a specific condition. Although the concept of neurodiversity has a lot of potential to be applied to Down syndrome and other intellectual disabilities—and, indeed, I will discuss its applicability to Down syndrome later—literature reviews suggest that it has primarily been applied to autism.

I point out the gaps in disability scholarship with respect to intellectual disability and, in particular, Down syndrome not to suggest that physical and psychiatric disabilities are unimportant, but rather to draw attention to an area that has been previously neglected. Such a gap, I will argue, is indicative of the particular models of disability that are most often forwarded in disability studies theory. Thus, the rest of this chapter will address the question: Why is there a lack of scholarship on intellectual disability? I will first review the major theoretical orientations of disability studies—which certainly spill over into rhetorical studies of disability—then, I will provide a rhetorical reading of these

theories suggesting that particular theories invite particular research questions. Finally, I will argue that a rhetorical approach to disability, rather than existing paradigms in disability studies, might better allow for examination of intellectual disabilities as distinctly different both biologically and contextually from physical disabilities and psychiatric disabilities.

Theoretical Orientations of Disability Studies

Disability studies is a diverse interdisciplinary field whose “common root,” according to Williams, is “rejection of the medical model [of disability] as the foundation for any effective understanding of impairment or disability” (124). The medical model, he goes on to explain, presumes “it is the individual body within which illness is situated” (125). Siebers similarly describes the medical model arguing that it “situates disability exclusively in individual bodies and strives to cure them by particular treatment, isolating the patient as diseased or defective” (173). While the medical model of disability takes it for granted that disability is an individual, biological, and undesirable reality, disability studies theorizes that at least some aspects of disability are socially constructed. As evidence, disability scholars argue that “disability” is a contested term; different cultures and populations define it differently. Fujiura and Rutkowski-Kmitta, for example, found that rates of disability in the population are higher in North America and Western Europe than they are in the Middle East and South Asia (79). They attribute this difference not to actual differences but to the different representations of disability on national questionnaires. Disability studies, including rhetorical studies of disability, take representations seriously as evidence of meaning-making about disability.

An additional part of disability studies' tension with medical models of disability

may be medicine's historical relationship to the practice and theory of eugenics. Disability scholars have long emphasized that the eugenic movement—which included the institutionalization and sterilization of thousands of “undesirable” people including people with both physical and intellectual disabilities—was a product of mainstream science and medicine. It is common knowledge that Nazi Germany committed genocide against a European Jewish population, but it is less well known that their first target was a disabled population. Some 240,000 of disabled people were murdered in Nazi Germany, and disability scholars point out that these actions were carried out according to rationales and arguments made popular by American and British geneticists (Snyder and Mitchell 124). American laws regarding forced sterilization of the feeble-minded were in place well before the atrocities taking place in Germany were known. Condit argues that eugenic practices would likely have continued to be popular in America, if WWII had not shown what horrific conclusions they could lead to (52-53).

All this to say that disability studies has an uneasy relationship with the field of medicine. Theoretically, it argues that medicine's model of disability does not take a strong enough position on the social conditions which can greatly contribute to the challenges a person with a disability faces. It also argues that historical accounts have demonstrated that mainstream medicine is perfectly capable of contributing to the oppression and discrimination of people with disabilities though its practices masquerade as technological or ethical advancements. The field of disability studies is in some senses a corrective against a blind faith or uncritical stance towards medicine and its treatment of people with disabilities.

If Disability is Not a Medical Condition, What is It?

There is no uniformly agreed upon definition of disability even within disability studies, but this section will review two major models that are prevalent in the field: the social model and the material model. As might be expected, social models of disability emphasize aspects of disability that are socially constructed, whereas material models emphasize the material realities of an impaired body. It is probably safe to say that material models are a response to the perceived over-emphasis on social construction but also that most disability scholars would allow that at least some degree of social construction is evident in any disabling condition.

Social Models of Disability

Social models of disability include the Social Construction Model, the British Social Model, and the Minority Rights Model. These models are similar in that they emphasize the social construction of disability, but they differ with respect to the degree they consider social construction to be all-encompassing. Social models of disability emphasize that disability is located in cultural preconceptions of what it means to be able-bodied or “normal.” Such a model assumes that those with disabilities are given that label on the basis of their deviation from a statistically typical—and thus fictional—human. Davis’s work, *Enforcing Normalcy: Disability, Deafness, and the Body*, demonstrates that the concept of the “normal” is a social construction, an idea that came about in response to the developing field of statistics which started keeping track of biological characteristics such as height, weight, or intelligence. Davis's work shows the unique cultural context that led to viewing the average as normal or typical and those who were different as deviant or undesirable. In particular, one end of the spectrum, lower than

average intelligence or shorter than average height, came to be viewed as especially defective.

Davis's main argument is that the concept of normalcy and, by extension, disability, relies on a certain ideological framing. For Davis, modern constructs of “normal” and “disabled” rely on value judgments about people's differences as opposed to any inherently negative deficiencies. Wilson makes a similar point when analyzing the discourse and motivations of the Human Genome project. Whether the scientists working on sequencing the genome intended to or not, Wilson finds that their work is being translated to the public in particular ways. Descriptions assume that scientists are deciphering a “correct” genome in order to determine where “textual irregularity,” in the form of disease or disability, occurs (69). Wilson argues that this particular way of talking about the genome promotes the idea that there is one typical human genome, a false idea. Furthermore, rather than being viewed as natural variation or even valuable hybridity, non-typical genetic material is automatically seen as defective.

In addition to demonstrating value-laden concepts about ability, social models of disability can also demonstrate how identity is constructed. Another example of the social construction of disability can be found in Lane's article, “Constructions of Deafness.” Focusing specifically on the deaf population, Lane points out that deaf people struggle to construct a deaf identity that is different from the deaf identity constructed by, what Lane terms the “troubled-persons professions” (81). People who are deaf and grow up in deaf culture (i.e. a group of other sign language users) often don't consider themselves to be disabled—that is they don't consider their deafness to be an impairment. Lane argues that instead people who are deaf may prefer to be constructed as a linguistic minority (84-85).

On the other hand, Lane argues that “the troubled-persons professions serve not only their clientele but also themselves, and are actively involved in perpetuating and expanding their activities” (81). Lane argues that professionals' work “is guided by a genuine belief in their exclusive construction of the social problem and their ability to alleviate it” (81). In other words, professionals have invented a certain construction of deafness that requires intervention, rehabilitation, and integration—notably different from the provisions a linguistic minority would require.

In sum, scholars working from a social constructionist model of disability tend to analyze the mechanisms by which both disability and health are conceived. Social constructionists have demonstrated that there is a relationship between the two concepts and that the definition of one often relies on the other. Furthermore, a social constructionist view of disability allows scholars to consider how identity is constructed from both outsider and insider perspectives. Lane is just one scholar who works in this area. A significant portion of disability studies has been devoted to studying disability identity or, indeed, identities. And while in recent years the notion of a disability identity has been questioned (for example, Davis questions the concept of disability identity in his 2002 article on disability and identity politics), some disability scholars have found it politically powerful to imagine a disability identity that could exist outside of medical and rehabilitation models of disability.

Strong and Weak Versions of Social Models of Disability

Historically, disability scholars have debated the role of the social with respect to disability. Strong models of social constructionism presume that all aspects of disability are “historically specific [effects] of knowledge/power,” while weaker versions make a

distinction between impairment and disability (Tremain 185). In other words, a strong social construction position views disability as an entirely social process in which society, by virtue of its intolerance, disables certain individuals. Perhaps the most common example is that of a person in a wheelchair. The social constructionist argues that this person is only disabled if she encounters steps or other obstacles that prevent her from accessing other public areas. The British social model agrees with this assessment, but also concludes that it is inadequate. This model argues that there is a distinction between a biological difference (for example, paralysis of the legs), and social disability, in which social conditions (such as an absence of wheelchair ramps) create oppression and discrimination. Shakespeare lists three key aspects of the weaker social model—what he refers to as the British social model. The first, as mentioned, is the distinction between impairment and disability which he terms “social exclusion” (Shakespeare 198). The second characteristic is its separation from the medical model, which is viewed as reactionary in contrast to the progressive agenda of the British social model. The third characteristic is the belief that disabled people are an oppressed group and, therefore, able to organize for civil rights.

Two things strike me as interesting regarding Shakespeare's definition of the British social model. First, in distinguishing impairment from disability, those working within this model can both distinguish themselves from medicine while at the same time giving themselves room to work with doctors. In other words, by acknowledging that biological impairments are not mere social constructs, they leave themselves open to the possibility of collaborating with medical and rehabilitation professionals interested in reducing the effects of impairment. However, by insisting on an identity that is separate

from a medical identity, they give themselves the authority to create a social agenda which might include campaigning for more individual autonomy in institutional settings.

A second note here concerns Shakespeare's rejection of person-first language. Person-first language is favored by many disability advocacy groups including the National Down Syndrome Society. However, many in the disability studies community and many people with disabilities who are involved with civil rights work prefer to use phrases such as “disabled people” to demonstrate that a certain population is oppressed. Some disability scholars claim that person-first language, such as the phrase, “the girl with Down syndrome,” is actually a product of the medical model in which the disability exists within the individual (Linton 163). Referring to a “disabled population” then supposedly reflects the idea that disability is a condition of society and that society needs to change as opposed to the individual needing to change. Although I understand Shakespeare and Linton's views, I remain unconvinced by their argument against person-first language. I think that another consequence of person-first language is that it can emphasize humanity rather than impairment. Yes, the disability may be located in the individual rather than society, but it also becomes but one characteristic or trait out of many that that person may possess. However, because I am undecided on this issue and because I wish to respect both language preferences, I use both types of language throughout this dissertation. Some sections may use one type more than the other. For example, in the chapter in which I analyze parents’ discourse, I tend to emphasize person-first language simply because most of the parents use it and many emphasize the importance of using it in their discussions.

What Shakespeare terms the British social model is similar to what others term

the American Minority Rights model. Both models emphasize the political potential of disabled people when they form a group. Braddock and Parrish argue,

Our central thesis is that changing social and political perspectives on poverty during the seventeenth and eighteenth centuries, coupled with the development of increasingly medicalized interpretations of disability during the nineteenth and twentieth centuries, contributed to increasing segregation and stigmatization of persons with disabilities. However, a related thesis is that the congregation of people with similar disabilities for treatment and services also made possible the development of group identities, which ultimately facilitated the rise of political activism in the modern era. (11)

In other words, disability historians can trace the formation of a minority culture of disabled people back to social oppression, in particular social services that threw a highly varied and disparate group of people into similar economic, medical, and educational locations. With reference to the British social model, Shakespeare notes that like all the models being discussed, it has gone in and out of fashion. He sees its strengths as the following: first, it is easily explained and understood; second, it has been effective in pointing out, and in some cases removing, social forms of oppression and discrimination against disabled people; and third, it has allowed disabled people to “[build] a positive sense of collective identity” (199). The main point here is that the British social and the American Minority Rights models have been politically effective and resulted in some concrete changes in mainstream society.

On the other hand, social models of all types have their detractors, some of whom are in disability studies. Again Shakespeare lists four objections with regards to the

British social model in particular: first, it discusses social means of oppression to the exclusion of material accounts of the body. In other words, the physical realities of living with a disability have been largely ignored or trivialized in past scholarship that favors full analysis of social oppression. To return to our earlier example, scholars have focused on adding more wheelchair ramps without allowing people in wheelchairs to talk about the physical condition of paralysis in the legs. The other objections are, I think, related to the first in that they all point out that the model's strength—its easily understood principles—is also a weakness because the model is not nuanced enough. For example, a universally accessible city full of wheelchair ramps would still not address the issue of making beaches or steep mountain trails accessible. Also damning have been the criticisms of the impairment/-disability distinction. Shakespeare cites Tremain's 2002 work where she suggests “that the social model treats impairment as an unsocialized and universal concept, whereas, like sex, impairment is always already social” (Shakespeare 201). While social models of disability have been useful both theoretically and politically, they are beginning to lose their explanatory power because they have not proved flexible enough to account for more complex understandings of the relationship between the individual and society.

Material Realities of the Disabled Body

The major response to social theories of disability—including social construction, the British social model, and minority or cultural models—has been a return to the study of materiality and the body. Siebers argues, “Disability scholars have begun to insist that strong constructionism either fails to account for the difficult physical realities faced by people with disabilities or presents their body in ways that are conventional, conformist,

or unrecognizable to them” (175). Thus, one focus of material models of disability is to describe pain and suffering. However, these models try to describe pain and suffering in a way that avoids the conclusion that pain ultimately leads to personal tragedy or the opposite, that pain is a gift that leads to enlightenment. These two oversimplifications “are not only unrealistic about pain; they contribute to an ideology of ability that marginalizes people with disabilities and makes their stories of suffering and victimization both politically impotent and difficult to believe” (Siebers 178).

Like social models of disability, material models have also been criticized. Siebers suggests, “Advocates of reality risk appearing philosophically naïve or politically reactionary,” and, indeed, one can easily imagine a strong social constructionist contesting the existence of a physical and bodily reality that is not mediated by social ideologies. One example of language that could suggest this naivety occurs in Williams’s criticism of social constructionism and justification of material models. He writes, “To theorize disability wholly in terms of ‘social oppression’ seems to be profoundly limited,” and “To say that disability is social oppression and that the body has nothing to do with it is curiously solipsistic and clearly not the whole story” (135). The language used here, especially in the phrases “profoundly limited” and “clearly not the whole story,” is strong even though Williams provides no further evidence. Audience members are required to supply their own, readily available narratives about disability in order to determine whether they agree or disagree with Williams. This is not to say that Williams’s argument is invalid, only to say that it has become difficult to argue about material reality, even the material reality of the body.

Although this review of disability models may suggest that these models have

developed chronologically towards ever more sophisticated models, such is not the case. These models are still very much in discussion with one another. As a newcomer to the field of disability studies, I find it somewhat unsettling because it seems that no two individual scholars define disability in quite the same way. The above models are not absolute categories but rather reflect my best attempt to create graspable frameworks out of some common themes and methods.

Outcomes of Common Theoretical Models of Disability

Despite the numerous and nuanced differences among social models of disability, we might tentatively say that there are two major theories at work—those that emphasize social aspects of disability and those that emphasize the body and material reality. I have already discussed some of the major objections to each of these approaches, but perhaps it is important to add what both of these philosophies have accomplished. Social models of disability have provided justification for civil rights action, as mentioned earlier; however, it is doubtful that that articulation of these theories actually provided the impetus to bring disabled people together as a minority group. Instead, there is evidence that the common experience of oppression and placement in local institutions likely caused groups of similarly oppressed people to form. However, it seems fair to say that social theories of disability may have contributed to political actions such as the passing of the Americans with Disabilities Act (1990) in two ways:

- through observing and documenting the formation of disability culture, therefore making disabled groups and activities worthy of study and giving them legitimacy, and
- by articulating arguments that could be used by disabled groups to advocate for

equality and civil rights.

It would seem that, thus far, material theories have been less useful for direct political action. However, theories of the body have probably done much to fight stereotypes or take away the mystery of illness and disability. For example, a new literary genre, pathography, or the personal story of illness, is a good example of body theory in action. “Locked-in” syndrome, a condition in which a person becomes nearly totally paralyzed unable to speak or write, might have remained a relatively obscure syndrome known only to physicians and a few members of the public if *The Diving Bell and the Butterfly*, a memoir of a French man with this disability, had not been published to great success first in Europe and then in North America. The book became a best-seller and then a movie. Although the movie was criticized by some close friends of the author’s as falsifying some of the biographical details of the author and his family members, I have not found any criticism accusing the filmmakers of inaccurately representing Locked-in syndrome. We can imagine that disability scholars might worry about the potential for pathography to slip into either a trope of personal tragedy or disability as a gift, the popularity of this genre suggests that at least some in the disabled community believe their experiences are worth sharing and many in the nondisabled community find these narratives worth reading. The genre is a way of stating, “I am here!” More research may need to be done to determine what messages audiences take away from these memoirs.

Alternative Views of Disability

While the above synthesis represents my current understanding of some of the main trends in disability studies, there were certainly outliers and alternative viewpoints that were not as well represented or developed. I wouldn't necessarily call these

viewpoints models, because I don't think a substantial body of scholarship has been developed around them yet. However, in terms of rhetorical studies, it is clear that these viewpoints could be developed further and would have a different set of social functions and limitations should they gain traction.

Disability as Natural

At least one scholar, Wilson, suggests conceiving of disability as a natural state. Wilson arrives at this perspective by analyzing the human genome project in comparison to the rhetoric of other biological endeavors. Whereas in evolutionary theory, for example, heterogeneity—the differences in DNA even within the same species—is said to promote the vigor of that species, in contrast, the human genome project posits DNA as a monolithic, homogeneous code in which a biological “defect” is the result of an “error.” This viewpoint, Wilson points out, contradicts the widely known fact that “no two human genomes are or can ever be alike: all exhibit mutations, deletions, and other genetic variants” (69). In other words, Wilson argues that the rhetoric of the human genome project explicitly contradicts other biological rhetoric by suggesting that diversity is defective rather than evolutionarily beneficial. While Wilson's work focuses on explaining what this monolithic view of the genome achieves rhetorically, he does not develop an alternative model. Yet, we can imagine that if disability were viewed as being a natural part of life, something that happens on a regular basis to every person with different effects, there could be a radical shift in the way society approaches disability. An orientation towards disability as a natural variation could go a long way towards removing the stigma of disability. On the other hand, it could be used to justify eliminating treatment options for disabled or ill persons if interventions came to be seen

as unnatural.

Disability as Neutral

A second alternative view sees disability as neutral—that is, as a factor which ought not to be considered at all. One articulation of this view comes in a short personal narrative included in a volume about the ethics of prenatal testing. In “Somewhere a Mockingbird,” Kent remembers learning that her blindness is hereditary around the time that she and her husband were determining whether to try to have children. While the news that her future children could be blind was not upsetting to her, it was upsetting to her husband. Kent was disappointed in her husband's reaction since he had always been supportive and tolerant and had never treated her differently just because she was blind. A few weeks after their daughter was born, her husband observed the daughter following his hand movements with her eyes and was overjoyed. Kent, meanwhile, struggled to understand what appeared to be a contradiction in his emotions. How could he treat her blindness as insignificant, but relish their daughter's ability to see? For Kent, blindness was a neutral and insignificant trait. Of her daughter's vision, she writes, “I know her vision will not spare her from heartbreak. She will still meet disappointment, rejection, and self-doubt as all of us must” (62).

Kent articulates disability as something “neither to be prized nor shunned” (62). Kent's article suggests that it may be possible to consider disability as simply unimportant as a category. One obvious question makes this model extremely difficult to engage with: would the author feel the same way if she had a different disability? Blindness, deafness, and minor physical impairments are all relatively easy to adapt to in modern Western society in comparison to severe cognitive disabilities or physical conditions such as

quadriplegia. Western notions of independence and self-sufficiency are more compatible with blindness than with quadriplegia, for example. Would the author feel the same way about passing Huntington's disease—a condition that shortens the lifespan in addition to causing severe pain and personality changes—to her daughter? At the very least, we know that some persons with Huntington's disease choose not to have children. Still, the author might argue that life holds hardships for everyone, and the potential for suffering, whether physical or mental, does not make a life less valuable.

It is difficult to imagine scholarship that embraces disability as a fully neutral category—could a disability studies field even exist in this scenario? While pure social constructionist models have tried to minimize the biological elements of disability, they do acknowledge disability's presence as a social category. Perhaps a truly neutral view of disability embraces an opposite view in which disability is considered a biological difference and reality, but an unimportant difference. Disability exists, but it is not a cause for despair. This view strikes me as being somewhat fatalist. It acknowledges challenges, obstacles in a disabled person's life, but does not see these as meaningful. Or perhaps, a better way to say it would be that they are no more meaningful than the significant obstacles and challenges that occur in able-bodied persons' lives—financial strain, divorce, a particularly demanding boss. A neutral view of disability might be what Siebers is trying to articulate when he writes that there “is the temptation to view disability and pain as more real than their opposites” (180).

Disability as Unstable

Finally, a third divergent view of disability sees disability as an unstable category (End 231). The best articulation of this viewpoint occurs in Davis's exceptional article,

“The End of Identity Politics and the Beginning of Dismodernism: On Disability as an Unstable Category.” This article is in some ways a reconsideration of the social model of disability which relies on a broad conception of “the disabled” in order to construct a large minority identity with considerable political power. However, in Davis's view, all identities, including those based on race, gender, and sexual orientation, are becoming less stable. For example, he cites attempts to study race genetically, which have not been able to prove that race exists at a cellular level. Although he sympathizes with arguments suggesting that “while there may be no basis in theory for being X, large numbers of people are nevertheless X and suffer even now for being so” (what we might recognize as a social constructionist argument), he argues from a non-essentialist position (235). For Davis,

The idea of maintaining a category of being just because oppressive people in the past created it so they could exploit a segment of the population, does not make sense. To say that one wants to memorialize that category based on the suffering of people who occupy it makes some sense, but does the memorialization have to take the form of continuing the identity? (235)

Rather than relying on disability as an inherently unified category then, Davis proposes that we view it as “malleable” (239). He believes this model offers a better explanation for the tremendous amount of variability within a category of disabled people—from those who are blind to those who are obese. Under older social models, such “minor” disabled conditions may force us to ask the question, “Who will get to claim the definition of disability or the lack of one?” (238).

However, an unstable model of disability identity, according to Davis, will allow

us flexibility to comprehend this large, diverse group and can account for cures or technological advancements that reduce the effects of impairment. Davis's goal seems to be a theory of disability that can account for the extreme amount of diversity within any group of people who are labeled as disabled, and indeed, everyone comes to fall under this category. Or, as he writes, "Impairment is the rule, normalcy is the fantasy" (241). For Davis, the function of this model is to produce an ethics of care in which difference is valued and acknowledged as worthy of receiving services. A model of disability identity as unique and particular separates people who cannot identify with the category, whereas a model of disability identity as flexible and unstable could attract everyone.

Davis's model of disability would emphasize the diversity of disabled people in order to unseat disability as a reliable category. It would demonstrate how current political practices, even those supposedly in the service of disabled people, actually serve to further segregate and encourage us to make divisions and classifications between disabled and nondisabled or between more disabled and less disabled.

Rhetorical Implications of Disability Models and Their Approach to Intellectual Disability

The above section has, I hope demonstrated the complexity of the question "what does disability mean in society?" A review of disability studies theory shows that there are multiple models in use, each with different functions. In rhetorical terms, we might say that different theoretical models afford the scholar different opportunities in terms of methods of analysis, units of analysis (topic), or even options for political advocacy. These models can also constrain or limit these same areas. Throughout the above discussion, I have tried to indicate where each model is limited, and what each model is

useful for. Later chapters will explore on a microlevel public, professional, and private representations of Down syndrome and whether these representations coalesce with the models of disability put forward by disability scholars.

However, in the rest of this chapter, I will analyze how the more popular disability models have afforded and constrained our opportunities talk about Down syndrome within disability studies. This section risks oversimplifying some of the specific, complex arguments that exist within disability studies. The following analysis is presented with this caution. The discussion provides some specific examples of common tropes, common ways of talking, evident in disability studies discourses. There are certainly instances of scholarship which do not rely on these tropes to make their arguments. However, those I will discuss do represent trends seen across time and multiple authors. My examples come from some of the texts in disability studies that have become canonical, that is to say, they have been anthologized and create some of the foundational knowledge in the field.

An Emphasis on Physical Disabilities

There are two commonplaces in disability studies scholarship that have affected how Down syndrome is discussed in this field. The first is that there is an emphasis in disability studies on physical as opposed to cognitive or intellectual disabilities. This emphasis appears to exist for at least two reasons. First, many scholars working in disability studies are themselves disabled—deaf, paralyzed, chronically ill, etc. On the one hand, this situation is a great strength of the field. Academics with disabilities may be highly motivated to do work in this area. By this account, it is possible that disability studies would not exist if not for the personal connection that motivates some academics

to pursue this work. Yet, on the other hand, because of this tendency, disability studies works overtime to avoid being marginalized as a special interest group within the academy.

In addition, a disabled academic is a person with a certain type of disability. An obvious requirement for an academic position is a typical—or perhaps untypical but in a certain direction—intellect. Academics are rewarded for highly individualistic and expressive work, especially in the humanities where collaborative work is often regarded with suspicion. People with intellectual disabilities are unlikely to be academics. For perfectly good and legitimate reasons, academics are often motivated to write about their personal experiences or to analyze situations that interest them. This appears to be quite true in disability studies as well where first-person narratives are a popular academic genre. Breuggaman's work, "Interlude 1: On (Almost) Passing" and Krummel's work, "Am I MS?" are good examples of this tendency. Other times, disabled academics may have special access to study particular communities because of their own non-academic affiliations with these communities. Davis explains growing up in a deaf household in his important work *Constructing Normalcy*, an experience that clearly affected his scholarly interest in deafness. In the second edition of *The Disability Studies Reader*, he notes, "A fair number of articles deal with deafness. The reason for this focus is twofold: (1) personal interest, and (2) the rather large body of historical materials on the history of deafness" (xviii). So one reason for a lack of scholarship on intellectual disabilities may simply be because academics are unlikely to have intellectual disabilities and are therefore less likely to be motivated to research them.

A second reason for the emphasis on physical disabilities is the historical

development and articulation of the prominent theories of disability; they all seem to share a common bias towards physical disabilities. Some of this bias can be traced to their historical development. The British social model, for example, “emerged from the intellectual and political arguments of the *Union of Physically Impaired Against Segregation (UPIAS)*” (Shakespeare 197). Note the organizational name's emphasis on physical impairments. This group's leaders were males who took complex rational steps while forming their organization: they wrote to a newspaper, created a policy document, and lobbied to get the attention of other groups. Their distinction between impairment and disability is clearly easier to imagine in the framework of a physical disability. In the classic example of a wheelchair user, it is easy to imagine that a lack of public ramps limits accessibility. However, it is not as easy to imagine what social modifications would make the world more accessible to an intellectually disabled person.

In fact, all of the social models of disability seem to have an uneasy relationship with cognitive disabilities more broadly because it is hard to imagine how social oppression could be removed in these instances. When we speak of building more ramps, elevators, and handicapped parking, or providing American Sign Language translators and making sure signs are written in braille, these are, in theory at least, easy fixes. Moreover, environmental changes do not challenge Western society's values of citizenship, autonomy, and individualism. With these and other modifications, people with disabilities can blend in with the rest of society. They can live independently, they can work productively, and they can be responsible for their own actions. In other words, they can achieve proper citizenship.

Thus, a third outcome of prominent models of disability is that they serve to help

instantiate traditional, hegemonic views of individualism. Parmenter argues that individual independence is required for a modern state by suggesting that in order to acquire social capital “citizens must have the capacity to use [material and social goods] effectively” (290). In contrast to individualism, a means by which people can gain independence and control over their own lives, “the vast majority” of people with intellectual disabilities “will [...] remain dependent on supports” (Parmenter 289). Since they may not be able to achieve social capital, their status in the modern state is regarded as “less than full humanness,” even by some in the disability community (Parmenter 290).

I suggest that social and material models of disability actually serve to reinstate rather than challenge the conditions of citizenship which Parmenter describes. For example, the insistence on minority rights and a disabled community in both the British social model and the American minority model is problematic for disabled individuals with intellectual disabilities. While I would not wish to argue that a disability rights model has failed—after all, the Americans with Disabilities Act remains a landmark case in the history of disability discrimination—the direct application of other civil rights rhetoric and tactics to disability rights is untenable for some people with intellectual disabilities. Other civil rights movements were able to argue from a position of universality. Non-white, female, and homosexual individuals used civil rights rhetoric to assert their rights to a traditional form of citizenship, one based on individuality. They wanted more autonomy rather than less and sought forums where they could rewrite their own histories and self-advocate. Disability rights are more complex. In general, the disabled population also wants more autonomy; they also want the right to speak for

themselves. However, these goals are complicated for individuals with intellectual differences.

Lewiecki-Wilson's article, "Rethinking Rhetoric through Mental Disabilities," articulates a similar question: "How can people who have psychiatric and cognitive disabilities that interfere with communication exercise rhetorical agency?" (157). Like Parmenter, Lewiecki-Wilson criticizes individualized conceptions of agency suggesting, "We often demand some verbal response from an Other as proof of their humanness and [...] we have an impoverished language for conveying the rhetoricity inherent in embodied life" (157). She suggests that disability rights models that focus on accommodation—for example, computer programs that give a voice to speech-impaired persons—still require that an individual be responsible for his or her own speech. Furthermore, models of disability that focus exclusively on modification only reinforce traditional definitions of rhetorical agency. Lewiecki-Wilson is especially concerned with the severely impaired who may be unable to communicate on their own and instead rely on facilitated communication. Facilitated communication involves collaboration between the disabled person and a caretaker who learns to speak for the other. Lewiecki-Wilson argues that facilitated communication offers the greatest challenge to traditional models of agency because it breaks the link between self and speech.

While Lewiecki-Wilson draws our attention to the people with disabilities who exhibit the greatest differences in communicative style and cognitive difference, it is not only the severely impaired that challenge traditional models of agency and selfhood. People with Down syndrome can have mild to moderate mental retardation, but even mild retardation signals a significant difference in cognitive processing. The social rights

model of disability that has prevailed in modern America led to first the Education for Handicapped Children Act (EHA) which was subsequently revised to the Individuals with Disabilities Education Act (IDEA). The language of social construction is present in all areas of the statute, but the section describing the Individualized Education Program (IEP) requirement will serve as an example. The IEP documentation process has several strict content requirements. For example, it asks for “a statement of the child's present levels of academic achievement and functional performance”(“Topic: Individualized Education Program”). Such a statement seems like a logical and straightforward requirement. Teachers must understand the student’s current academic and intellectual level before they can determine what the student needs to learn. However, this simple requirement becomes complicated when we consider what it requires of the student. Academic achievement and functional performance are measured in specific ways in a school setting. A child with atypical cognitive processing abilities may not be able to demonstrate her achievements in the same way as typical children. Studies have shown that African American children are far more likely to be placed in special education classes than white children, but those statistics do not demonstrate that more African Americans are in need of special education but rather that cultural differences results in different testing performances. If such testing bias can be present between different races, imagine what biases might be present with people of different cognitive abilities. It seems very likely that traditional school-based testing measures do not give an accurate picture of people with innate differences in intellectual abilities. Even assuming, however, that the testing procedures give an accurate picture, there is still the problem of difference. Only certain types of thinking and processing are valued in school. A model of disability

that emphasized and respected intellectual difference might seek to find out more about how people with Down syndrome think and what types of processing they are good at, rather than focusing exclusively on remediation.

One concept that might be useful in promoting a definition of disability as difference is the concept of neurodiversity discussed earlier in the chapter. The concept of neurodiversity has thus far been used primarily to discuss autism. While autism is distinct from Down syndrome, both conditions share some important characteristics. Down syndrome, like autism, is a highly variable condition. It is defined as a conglomeration of symptoms rather than a disease—thus its label as a syndrome. All individuals with Down syndrome have some mental retardation, but the retardation can range from mild to moderate. All individuals with Down syndrome have some physical symptoms such as low muscle tone or a heart defect. However, a single person with Down syndrome could exhibit all physiological differences associated with the syndrome or only a few of them. Some children with Down syndrome are born with severe heart defects requiring immediate surgery, some are born with heart defects that are minimal, and some with completely healthy hearts. Thus, we might also talk about being on the Down syndrome spectrum in the same way we talk about the autism spectrum, but we don't.

Moreover, the concept of neurodiversity itself might be usefully applied to Down syndrome. Mental retardation and developmental disability are two terms used to describe the intellectual differences of people with Down syndrome, but neither are particularly accurate. Both imply that people with Down syndrome are delayed and that they might some day catch up with remediation. However, this portrayal is not accurate. People with Down syndrome can, of course learn new things, but their thinking

processes—their intellectual disability—will remain the same. Thus, rather than categorizing intellectual disability as a deficiency, conceiving of it as a neurological difference may be both more accurate and more helpful. For example, if we put more energy into understanding how people with Down syndrome think, we might be better able to help them learn. As a result, conceiving of intellectual disability as a difference might go a long way towards challenging the stigma associated with the condition.

With regards to the limitations of the material model, the overemphasis on physical disability means that there is a corollary overemphasis on pain and suffering which are hard to translate into the situation of mental disabilities. Suffice it to say, pain and suffering are important foci in this model and while we may conceive of mental pain and suffering with respect to psychiatric conditions it is much harder to do so for intellectual disabilities. There is no inherent pain associated with mental retardation. The material model also focuses on bodily experience, but it is not clear what this might mean for the person with Down syndrome unless they were to describe physical ailments associated with the condition such as congenital heart defects or rheumatoid arthritis. However, physical features of Down syndrome do not appear with consistent regularity; in other words not every person with Down syndrome has all or any of the physical conditions that are associated with Down syndrome. The only shared feature of Down syndrome is some degree of mental retardation, although even this feature varies widely. To describe the bodily experiences of someone with Down syndrome, it then seems that we would have to imagine a way of describing differences in thinking.

An Emphasis on Disability as a Universal Experience

A second commonplace that occurs in disability studies across all models of

disability is an emphasis on disability as something that every person could potentially experience. This commonplace shows up in several different ways. It is perhaps best articulated by Davis who explains, “Disability confounds the neat borders of identity in that it is not a discrete but rather a porous category. Anyone can become disabled, and it is also possible for a person with disabilities to be 'cured' and become 'normal'” (End 536). This definition of disability becomes useful in a number of different theoretical models of disability.

The importance of this trope is evidenced by its inclusion in the first sentences of the first chapter of *The Handbook of Disability Studies*. The anthology begins:

Disability is an enigma that we experience but do not necessarily understand.

While some people are born with or experience disability as children, most of us become familiar with disability later in life. For the majority, then, what was once deemed as foreign, something outside of our bodies and experience, frequently becomes an intimate part of our lives as we age. (Albrecht, Seelman, and Bury 1)

Defining disability as a universal concept, one that nearly every human being will experience in some form is a particular rhetorical move. It might seem strange to a general public audience that AIDS is considered a disability. A medical model might differentiate between a disease—in this case a virus that we catch—and a disability such as Down syndrome which is present at birth and unalterable. However, even to a broader public, these distinctions are being blurred. Overenthusiastic reporting on the potential for stem cell and gene therapies could alter public perceptions of what it means to be disabled and hope for which disabilities might be cured or eliminated altogether. However, in terms of a disability studies perspective, this rhetorical move does not have

to rely on technological advancements to be viable. A social definition, after all, claims that disability is caused by stigma and oppression. Surely the person with AIDS is subject to discrimination just as the person with Down syndrome is. This definition of disability calls attention to that fact.

Moreover, disability studies advocates have good reasons for wanting to expand the definition of disability; the more people who are included in the category, the more powerful a minority rights agenda becomes. In other words, “whereas postmodernists stress diversity and fragmentation and the diminished relevance of broad political projects, more 'traditional' disability theorists argue that this leads to political inaction. Can disabled people have it both ways, stressing their diversity while seeking unified political action?” (Barnes and Mercer 523).

In addition, the move towards universality is commonly used to conclude articles. The move to conclude a theoretical discussion with a nod to the common experience of disability may function in several ways. First, it could be viewed as a move to legitimize the study of disability. It is a unifying move and therefore works as an argument for why we should all, regardless of our disability status, pay attention to this work. For example, in an argument about the uses of the social model of disability, Shakespeare concludes that in addition to a social model “another [...] insight [is] that disability is not a minority issue, affecting only those people defined as disabled people. As Irving Zola (1989) maintained, disability is a universal experience of humanity” (203). Since this quotation is literally the last sentence of Shakespeare's article, it is difficult to tell exactly in what spirit he wants us to read these words. It seems to signal the importance of disability issues by reminding us even if we are non-disabled these issues could still become

personally important to it. But it also, whether intending to or not, shuts down conversation. It seems, at the same time, to both encourage and discourage conversations about types or classifications of disability. The problem of disability being such a large category is that, as Davis writes,

Also the category of disability casts quite a wide net. In consulting obesity, carpal tunnel syndrome, AIDS, deafness, dyslexia, attention deficit disorder, Down syndrome, and many other diverse conditions. Given this continuum, it is hard to imagine that any one person can be representative for this group or be a representative character in a novel. (Identity Politics 536)

On the one hand, in actually naming specific disabilities Davis invites a comparison here. What do these disabilities have in common? How are they different? Moreover, by using the word “continuum,” which is incidentally a frequently used word in this context, Davis implies that we might rank disabilities from better to worse. In other instances the word continuum is used to signal the fact that there is a chronological progression from being able-bodied to becoming disabled as we age. Such a ranking is exactly what disability scholars and advocates want to get away from, as this signals that it may be more or less justifiable to discriminate against certain groups of people. In other words, ranking disabilities from better to worse could cause society to try to justify why we should make some modifications in terms of universal design but not others or why we should pay for some disability services but not others. The move then to emphasize that regardless of the disability, we are all universally oppressed becomes an important one in terms of diverting the conversation away from differences and towards universality. An example of this move occurs in Davis's article on disability as an unstable category. Near the end

of the essay he writes:

But dismodernism argues for a commonality of bodies within the notion of difference. It is too easy to say, “We’re all disabled.” But it is possible to say that we are all disabled by injustice and oppression of various kinds. We are all nonstandard, and it is under that standard that we should be able to found the dismodernist ethic. (End 241)

In this excerpt, he seems to be indicating that he recognizes that saying disability is a universal experience is a particular kind of rhetorical move and perhaps one that has lost its meaning or impact. However, he goes on to conclude his essay with the following paragraph:

What is universal in life, if there are universals, is the experience of the limitations of the body. Yet the fantasy of culture, democracy, capitalism, sexism, and racism, to name only a few ideologies, is the perfection of the body and its activities. As Paul Gilroy writes, “The reoccurrence of pain, disease, humiliation, grief, and care for those one loves can all contribute to an abstract sense of human similarity powerful enough to make solidarities based on cultural particularity appear suddenly trivial.” It is this aspect of experience, a dismodern view, that seems suddenly to be, at the beginning of the twenty-first century, about the only one we can justify. (End 241-242)

For Davis here, the emphasis is on the difference between disability as physical category (we all experience pain) and disability as social oppression. By returning to talk about the similarities of oppression, he precludes conversation on the experiential differences of physical disability. When we talk about differences in the material reality of disability, we

can also begin to talk more specifically about how social oppression is different for different types of disability. In other words, it is difficult to talk about how a person with Down syndrome is treated fundamentally differently from a person with Alzheimer's disease, although both are intellectual disabilities. We have to first acknowledge what is different about their fundamental physical reality before we can talk about how the social aspects of their disabilities are created and why. What I am beginning to see is that there is a difference in what we want theoretically to say that disability is, and what the experience of disability already is.

What is also jarring about the excerpt from Davis is the seeming need to rely on identification or empathy in order to guarantee equality and fairness. When he refers to Gilroy's text, he emphasizes the personal connection that happens when we experience our own instances of pain, disease, and suffering. From these experiences, we should be able to extract a mindset of deep sympathy and connection with other people, no matter how different. Such a perspective seems to me an example of unrelenting humanism. Is it possible to assume that our own experience contain in them the seeds of every other human being's experiences? That seems somewhat arrogant. This sentiment is a popular one, however. Hubbard, for example, also argues, "People shun persons who have disabilities and isolate them so they will not have to see them. They fear them as though the disability were contagious. And it is, in the sense that it forces us to face our own vulnerability" (93). The argument here is that we discriminate against people with disabilities because we fear that we will end up like them. The message is, if we can acknowledge our own vulnerability and come to grips with our own experiences of suffering, we will be able to better connect with others.

Aside from the probably erroneous assumption that our own personal experiences are so closely related to anyone else's experiences, such a position also becomes more troublesome when talking about intellectual disabilities. A person's way of thinking about himself, the world, society is changed when he is disabled, but to what degree? A person with mental retardation or autism, I would argue, has a radically different cognitive process. To expect that we can somehow access this process through our own experiences of discrimination seems to me to trivialize them and subsume difference rather than to accept it.

Rhetorical Approaches to Disability

In the above discussion, I have argued that different models of disability have different functions. Each model I discussed is good at doing particular things, producing particular readings, focusing on particular topics. If they weren't useful, they would not be such popular models in disability studies. Of course, each model has its limitations and there are, as I have noted, alternative competing models at the edges of the discipline. However, across all of these models, there appears to be an absence of projects--with a few notable and important exceptions—that focus on intellectual disability. In the above section, I have tried to explain how certain models, common arguments, appeals, and tropes, make it more difficult to fit intellectual disabilities into popular and foundational models of disability work. I concluded the section by arguing that there is a need to consider specific situations of different types of disability—both as physical, material differences in the body and as differences in how they are treated socially. In this section, I will argue rhetorical methods of studying disability are necessary in order to adequately address these concerns.

Thus far I have only alluded to the differences between disability studies and rhetorical studies as two fields with very different methodologies and goals. Disability studies, at least of the type that I have been discussing, is primarily located in a humanist tradition. It is therefore closely linked with literary and cultural theory and these fields' concern with identity and group formation. The theoretical work underpinning much of disability studies suggests that disability, as a category, needs to be redefined by scholars so that gradually we might introduce new models of thinking about disability which itself will result in a paradigm shift in not only how we as a society think of disability but also how we as a society treat disabled people.

In contrast, rhetorical studies does not get so bogged down in assigning ever more precise and complex definitions to a particular phenomenon. Or rather, rhetorical studies does not assign such importance to an academic or philosophical definition of the phenomenon, at least initially. Rhetoricians study language use to determine how discourse is being used in particular texts and contexts and they assess how this discourse in use affords certain actions and limits others. In other words, rhetoricians study language to determine not how accurately it reflects reality, but to understand how people are using it to justify and accomplish certain actions. Of course this may, in the end, result in suggestions for better practice or suggestions about how to be more inclusive. This notion of language in use seems to me to be unique to rhetorical studies. This concept seems more apt to analyzing how people negotiate flexible or unstable (to use Davis's term) identities because it assumes that people may use different language strategies depending on the specific situation and its demands.

Disability scholars forward different definitions of disability in order to theorize

one that best reflects reality, to help those with disabilities achieve equal treatment, and to eliminate disability discrimination. However, the major models of disability all have a tendency to elide rather than embrace differences. Even when they address differences head on, as Davis does by forwarding a concept of disability that is “malleable,” they attempt to embrace difference while at the same time excluding judgment about the severity of different disabilities. Ultimately, I believe what Davis asks of us is impossible. Taking difference seriously requires us to examine the contexts of different disabilities. A rhetorical approach is necessary to consider disabilities on their own terms and in their own contexts, but once we take this step we will no longer be able to assert that all disabilities are equal. However, by examining the multiple contexts in which disability exists, we may eventually get back to Davis’s concept of a malleable disabled identity. Studying the contexts (including contexts where decisions or judgments are made about disability) will help broaden the definitions of disability and allows us to better assert that there is no one disabled identity. In the following chapter I will talk more specifically about a rhetorical approach and the methods used in this project.

CHAPTER THREE
INTEGRATING CULTURAL AND RHETORICAL THEORIES OF DISCOURSE
AND MEANING-MAKING

In the first chapter, I demonstrated a lack of attention to intellectual disabilities in both disability studies and rhetorical studies literature. This project, on the one hand, attempts to fill that gap by providing information about the social meanings of Down syndrome. On the other hand, this project aims to expand rhetorical and discourse theory by tracing one discursive formation, Down syndrome, through several strands of discourse in several situations that are typical in the life of a person with Down syndrome. This dissertation, then, represents the beginnings of a much larger project that asks three major questions:

- What is the meaning of Down syndrome in modern day, American society?
- How are “objects of discourse” (such as Down syndrome) produced, reproduced, and circulated through multiple, competitive and symbiotic discourses (Foucault 44)? And what role do typified, recurring, rhetorical situations play in this circulation process?
- How do the discourse practices listed above affect the social potential of people with Down syndrome and how can advocates interfere to promote alternative, expanded meanings that will enable alternative, expanded potentials?

The first question indicates the main goal of the project, to better understand the social meanings of Down syndrome, while the second and third questions arise from the methodological approach used to answer the first question. As the first question indicates, this project views Down syndrome as a social phenomenon that has rhetorical and

cultural meanings beyond its status as a medical category.

The social perspective of Down syndrome can be illustrated by the following example: new parents are informed that their baby has Down syndrome, and it is described as a biological condition in which there are 47 chromosomes present in every cell as opposed to 46. This genetic description may then move into a discussion of the consequences of the extra chromosome—a flattening of facial features, low muscle tone, and, of course, mental retardation—all “symptoms” of the disorder. However, this description portrays a medical orientation alone that does not have meaning absent of a larger, social context. It is the social implications of these symptoms which give them meaning. For example, it is the fact that other people will recognize the typical, flattened facial features that give the features significance, and it is the fact that mental retardation may prevent people with Down syndrome from accomplishing typical social actions such as living independently, operating a vehicle, or pursuing post-secondary education that creates a stigma. In the end, the new parents will be engaged with these social meanings and effects rather than concerning themselves with the number of chromosomes their child has. It is, of course, significant that a strictly medical definition of Down syndrome excludes these social meanings, but this is a discussion I will return to in a later chapter.

As has already been discussed, the field of disability studies also purports to study the concept of disability from a social rather than medical perspective. In fact, it purposefully sets itself apart from a medical model of disability which, it argues, is only capable of viewing disability as a deficiency. Thus disability scholarship is meant to serve both as an argument for an alternative view of disability and as a contribution to new knowledge about disability in society. By forwarding this first argument, disability

scholarship works as advocacy. Disability scholars and even disability advocates are the minority in society, however. And while they propose a new way of thinking about disability, they leave open the question of what the current state of the meaning of disability is in our culture. For example, despite criticism of the medical model of disability, most people with disabilities still choose to receive medical services. In fact, one probably cannot even identify as disabled until labeled as such by the medical community. In this project then, I seek not to condemn one model of disability and forward another, but to better understand the different arenas where the meanings of disability, and in this case Down syndrome, are constructed and circulated.

I view Down syndrome through the Foucauldian phrase “object of discourse” (44). By this, I mean that I investigate Down syndrome as a phenomenon whose meanings are constituted by social practice, including discourse, such that it signifies meanings, practices, and responses that are not inherently tied to the physical traits of the condition. I will further define discourse in the next section, but for now it will suffice to say that discourse is a set of language practices that are associated with particular social groups (i.e. medical discourse, disability advocacy discourse). A modern view of discourse argues that it is a social practice that both reflects the values of the group and serves to produce, reproduce, and circulate those values even as it comes into contact with other discourses.

Studying Down syndrome as an object of discourse therefore has the advantage of recognizing that disabilities are not fixed, stable categories, but rather have meanings that are negotiated and contested through discourse practices across different social arenas. This method requires studying specific instances of discursive practice with respect to

their contextual locations and in comparison with other discursive practices in other locations. Analysis of these instances will help determine where and how different discourses interact, where and when different discourses are deployed, and to what aims they are deployed. In order to accomplish a study of the social meanings of Down syndrome that is both situated in actual discourse practices and that provides comparison between multiple arenas of discourse, I will utilize a combination of rhetorical theory, specifically rhetorical genre theory, and what Fairclough refers to as social discourse theory, which is heavily indebted to Foucault's work. These theories will be discussed in more detail in the next section.

In short, the research questions listed above are intended to address some of the complications of studying a phenomenon, Down syndrome, which is an object in many different discourses. Since the social meanings of Down syndrome are played out in so many different discourses, this study extends some of the most recent, important theory on discourse in rhetorical and cultural studies. In particular, this study aims to illustrate social theory that suggests that “there is a dialectic relationship between discourse and social structure” and to extend the theory that different discourses interact with each other and combine in new ways by analyzing discourse practices (Fairclough 64). Thus, one contribution this study hopes to make is to better understand how different strands of discourse operate simultaneously, even during moments of tension, change, or struggle to afford and limit potential meanings of a discursive object and position subjects in particular ways to allow certain ways of acting. By studying multiple strands of discourse, this study aims to emphasize the sites of struggle where the potential for expanded meanings, actions, or justifications might be possible. Hence, the third question

aims to address the potential for change and the relationship between discourse and action.

Social Theories of Language: Rhetoric, Discourse, and Culture

An object of discourse as complex as Down syndrome, one whose meanings are mediated in many social arenas through many social actions and discursive practices, could no doubt be studied from many different disciplinary or theoretical perspectives with fruitful results. This study takes a primarily rhetorical perspective that encompasses multiple orientations to language, discourse, and culture. The advantage of studying Down syndrome from a rhetorical perspective is that rhetorical theory emphasizes language practices as means to an end. In rhetorical studies there is an emphasis not merely on language as communication or expression but also on language as action. Whereas language has sometimes been viewed as a transparent reflection of a speaker's inner thoughts, a rhetorical perspective views language as a social practice that rhetors use to respond to certain exigences or situations that require a response in order to accomplish certain goals. Thus, while modern rhetorical theory does acknowledge the role of contextual elements and cultural pressures that limit the possible responses to any one exigence, it also forwards a concept of agency in which the rhetor formulates a particular response in order to accomplish particular social actions. Thus, rhetorical theories can serve as a corrective to cultural theorists such as Foucault, who have been criticized for emphasizing social construction too heavily (Hacking). Using cultural theory and rhetorical theory together can help to achieve a kind of balance in the tension between the influence of individual agency and cultural hegemony that exists in arguments about meaning-making. Each perspective can serve as a check and balance

upon the other. In the following section, I will describe the specific iterations of rhetorical theory and cultural theory that I will rely on in this work. These descriptions will be followed by an analysis of the similarities and differences between the two approaches and an assessment of the contributions this particular combination of theoretical approaches can make to rhetorical studies.

Cultural Studies and Discourse: Social Discourse Theory

Broadly speaking, a cultural studies approach is “interested in problems of history (process and change throughout time), inequality, and the positioned subject” in society (Rosaldo xii). Cultural theory often takes a critical approach to analyzing various forms of power and ideology that are operating within different cultures, institutions, or communities. Such an approach is different from traditional rhetorical approaches in that it traces cultural pressures and influences across specific situations, whereas traditional rhetorical approaches focus on analysis of the immediate situational conditions at hand. Historically, we might say that cultural studies has been interested in macrolevel analysis while rhetorical studies has been interested in microlevel analysis. However, in recent years these two fields have been moving closer together with cultural studies work that takes more careful consideration of specific instances of discursive practice and rhetorical studies work that takes seriously the cultural influences beyond a material situation. Scott's 2003 work, *Risky Rhetoric: AIDS and the Cultural Practices of HIV Testing*, is one example of a primarily rhetorical text that incorporates cultural theory to consider not just the local practices of HIV testing but their cultural implications as well.

One example of a work that takes seriously the aim of studying language practices on a small, specific situational scale and a larger, cultural scale is Fairclough's *Discourse*

and Social Change. Here Fairclough, a linguist, attempts to outline a method of language analysis that takes seriously the study of language as text and practice that reflects and contributes to “wider social and cultural practices” (1). Rather than using the terms “language” or “rhetoric,” Fairclough's work centers around the word “discourse” presumably as a result of the term's use in both linguistic and cultural (what Fairclough terms “social”) theories. In linguistics, he argues, discourse can refer to conversations, written texts, speeches, or “types of language” such as newspaper discourse or medical consultations. These examples of discourse could be analyzed with respect to their organizational properties, situational contexts, or the processes of their production. In contrast, cultural theory uses the term discourse to describe “different ways of structuring areas of knowledge and social practice,” of which discursive practices are but one way (Fairclough 3). Fairclough suggests medical science and holistic medicine as two examples of different cultural discourses. These examples of discourse could be analyzed by considering how discourses position subjects, how discourses evolve over time, or what the social effects of a particular discourse are. In an attempt to combine these definitions to create a method of analysis that incorporates “language analysis and social theory,” Fairclough defines discourse in the following way:

Any discursive “event” (i.e. any instance of discourse) is seen as being simultaneously a piece of text, an instances of discursive practice, and an instance of social practice. The “text” dimension attends to language analysis of texts. The “discursive practice” dimension like “interaction” in the “text-and-interaction” view of discourse, specifies the nature of the processes of text production and interpretation, for example which types of discourse (including “discourses” in

the more social-theoretical sense) are drawn upon and how they are combined. The “social practice” dimension attends to issues of concern in social analysis such as the institutional and organizational circumstances of the discursive event and how that shapes the nature of the discursive practice, and the constitutive/constructive effects of discourse referred to above. (4)

In other words, at the heart of Fairclough's method is an attempt to analyze discourse on multiple levels: (1) as language, best analyzed by linguistic, textual methods; (2) as discursive practice, best analyzed by referencing specific, local situations; and (3) as social practice, best analyzed by cultural studies methods.

Fairclough lists four advantages to his method of analysis that I will parse in turn. First, he claims that his method “enables relationships between discursive and social change to be assessed, and detailed properties of texts to be related systematically to social properties of discursive events as instances of social practice” (8). In other words, Fairclough claims that his method takes into account the theory that the smallest linguistic features of discourse are related to the immediate situation in which they are used and to wider social conditions. He further suggests that by acknowledging this relationship, scholars have a new way of analyzing social change. The relevance of Fairclough's argument to this project can be demonstrated by recent debate over the use of the word “retarded” in federal documentation. In the federal government, this debate led to the passing of Rosa’s Law in 2010 which requires federal documentation to use the term “intellectual disability” instead of “mental retardation.” This debate spread into the public sphere through Bill Maher’s television show. Maher, a political talk show host who has repeatedly made offensive statements about people with Down syndrome,

recently hosted Tim Shriver, president of the Special Olympics, to discuss Shriver's work. During the segment, they discussed comedians' use of the word “retarded” and its prevalence in popular language. Bill Maher argues that people use the term humorously to refer to nondisabled people and entities (like “the government”) seemingly to suggest that there is no harm in doing so because the word has taken on different meanings. However, Shriver argues that this type of humor only works if the word “retard” is equated with the word “stupid.” Shriver goes on to suggest “that what you call people affects how you treat them” (“Tim Shriver on Bill Maher”). Using Fairclough's method to study the relationship between specific instances of language and wider social practice should help to clarify this debate and to help determine how using particular language might encourage certain types of social action, such as looking the other way when people with intellectual disabilities are bullied, and discourage others, such as advocating for more special education funding.

A second and related advantage that Fairclough lists is the ability to determine how discourse practices are related to “knowledge (including beliefs and common sense), social relations, and social identities” (8). Continuing with the above example, we might analyze implications of the word “retard” with respect to a social identity. This aspect of Fairclough's method allows the scholar to analyze the social construction of knowledge and identity.

However, a third advantage, the ability to study discourse historically, ensures that changes in discourse practices are attended to (9). Fairclough suggests that the concepts of “intertextuality,” how texts are related to other texts, and “interdiscursivity,” how different types of discourse are related to other types, could help scholars understand

evolution of discourse over time. Using these concepts, we could compare the language of the 1960s Civil Rights movement to the language of the 1980s Disability Rights movement to demonstrate whether the movements used similar types of language and perhaps whether the later movement borrowed inspiration from the former.

The final advantage Fairclough lists is that his method is a critical one: “Critical’ implies showing connections and causes which are hidden; it also implies intervention, for example providing resources for those who may be disadvantaged through change” (9). He further states that it is important to recognize that “people may resist or appropriate changes coming from above, as well as merely go along with them” (9).

In sum, Fairclough's method of discourse and social change greatly emphasizes the relationship between cultural ideologies and specific language practices. He takes great pains to explain both the value of linguistic analysis and cultural (what he terms “social”) theory. Coming from a linguistic perspective, Fairclough's method of discourse analysis focuses on three areas: the function, coherence, and intertextuality of a text (75). In other words, on this level he is interested in how discourse functions as discourse. For example, an analysis of a thank-you letter might determine the purpose of the text (presumably to give thanks, but there might be additional purposes), assess the cohesion of the letter by examining its various topics and transitions, and compare the letter to other thank-you letters to learn more about the genre.

Fairclough's linguistic approach is similar to a rhetorical approach in many ways. However, a rhetorical approach tends to also focus on the text as a response to a given situation. In other words, in a rhetorical approach the analyst would compare the function of the text to the exigence—or the factors that prompted the discourse. Rhetoricians may

also use the word “motive” to consider what textual evidence there is for the writer's intent. The features of the text, such as those that lead to cohesion or those that signal the text's genre would also be analyzed in terms of their effects. Although the actual effect on the audience cannot be determined by rhetorical analysis alone, a rhetorical analysis can explain how certain textual features are operating and how textual features are related to situational constraints. In other words, in a rhetorical approach, as opposed to a linguistic approach, there would be more emphasis on the speaker or author as a person who crafts discourse in specific ways in response to specific situations. Fairclough's second level of analysis, the level of discursive practice, does seem similar to a rhetorical approach since it “specifies the nature of the processes of text production and interpretation” (4).

Production and interpretation could be substituted with motives and effects; however, this level is the least attended to in Fairclough's discussion of analysis, perhaps indicating that he does not have access to a strong analytic vocabulary here. I would argue that rhetorical theory provides a much richer vocabulary and a strong research tradition with respect to a text's relationship to the immediate situation and a rhetor's language choices.

Fairclough's method also relies heavily on Foucault's work and argues that discourse analysis is incomplete without a theory that can account for the relationships between institutional discourse and subjectivity. Fairclough provides a well-written overview of Foucault's work, describing the differences between Foucault's archaeological and genealogical projects. Fairclough explains that Foucault's archaeology provides evidence that discourse helps constitute social knowledge, practice, and identity, and that discourse is produced and circulated with the help of social institutions, such as medicine or government. Genealogy, in Fairclough's words, “adds power” (49). For

Fairclough, Foucault's genealogies are more provocative because Foucault's conception of power is that it is productive. Thus, power is related to knowledge, meaning-making, and identity: "Power does not work negatively by forcefully dominating those who are subject to it; it incorporates them, and is 'productive' in the sense that it shapes and 'retools' them to fit in with its needs" (Fairclough 50). However, while Fairclough asserts that Foucault's work provides "a rich set of theoretical claims and hypotheses to try to incorporate and operationalize," he also insists that Foucault's work could be strengthened by attention to "real instances of people doing or saying or writing things" (56, 57). For Fairclough, the real advantage of bringing Foucault and other cultural theorists' work to discourse analysis methods is that it gives discourse analysis greater importance. If specific and individual instances of discourse are related to broad social movements, cultural ideologies, and social policies, then it is important to look at these everyday practices. Moreover, since everyday practices both reflect larger, cultural ideologies and reproduce and potentially change them, it is even more important to understand the mechanisms by which such production happens. Ultimately, Fairclough's theory seems to suggest that through careful discourse analysis, we might better understand how to implement large-scale changes through individual practice.

Genre Theory and the Concept of a Typified, Recurring Situation

Like Fairclough's method of discourse analysis, rhetorical theory has also been moving towards methodological approaches and theories that can account for both specific instances of rhetoric and larger, cultural ideologies. Scott's (2003) work was mentioned earlier as an example of a text that brings together rhetoric of science theories and cultural theory. Scott argues that "the methodological traffic between [cultural studies

of science and rhetoric of science] has remained strangely slow” (15). While this may be true in the particular area of rhetoric of science, I would argue that this has been less true in other areas of rhetorical study. Rhetorical genre theory, for example, has found itself to be very compatible with cultural theory. The 2002 collection entitled *The Rhetoric and Ideology of Genre* is one example of a text that utilizes cultural theory quite effectively. While most of the foundational texts in rhetorical genre theory (Miller's “Genre as Social Action”; Bazerman's *Shaping Written Knowledge*; and Berkenkotter and Huckin's *Genre Knowledge in Disciplinary Communication: Cognition/ Culture/ Power*) do not rely on cultural theorists like Foucault, they come to many similar conclusions about discursive practice and essentially lay the groundwork for the more recent work, much of which includes cultural theory. Early work in rhetorical genre theory instead built on the work of rhetorical theorists such as Burke and Bitzer, as well as borrowing from other social theories such as Vygotsky's activity theory.

The relationship between discourse and genre depends on the definition of both terms. If a discourse is made up of discursive practices, I might suggest that genre is one of those discursive practices—a practice that has become a type of practice because it gets repeated in generic form. The major contribution of rhetorical genre theory has been to move away from a definition of genre as form to a view of genre, in Miller's terms, as “social action.” Miller argues for a rhetorical understanding of genre, “an understanding of how discourse works” that “reflects the rhetorical experience of the people who create and interpret discourse” (152). Miller's argument for an understanding of genre as social reflects the impulse in rhetorical studies to see discourse as helping to achieve social goals and a desire to study language from the point of its users—in context. In fact,

Miller strongly advocates for moving genre studies away from studying public, ceremonial genres (such as the inaugural speech) to what she termed “de facto’ genres, the types we have names for in everyday language” (155). She argues, “To consider as potential genres such homely discourse as the letter of recommendation, the user manual, [...] is not to trivialize the study of genres; it is to take seriously the rhetoric in which we are immersed and the situations in which we find ourselves” (155).

There are several key concepts in genre theory that I will overview here before providing a comparison between genre theory and Fairclough's cultural discourse theory. The first key concept is the idea of form. Although rhetorical genre theory seeks to distance itself from the work of classification, there is an element of genre theory (as opposed to discourse theory) which always implicates form through analysis of textual features. Nevertheless, textual features such as organization, style, and thematic content are always analyzed with respect to rhetorical situation that calls for the generic response. The idea of genre implies a category or a type, which, in order to define, implies typical features. In other words, it is nearly impossible to talk about genre without talking about some characteristics of form.

One notable exception is Medway's article, “Fuzzy Genres and Community Identities: The Case of Architecture Students' Sketchbooks.” In this article, Medway analyzes a number of sketchbooks that many, although not all, architecture students use as “a personal resource” at his university (127). He determines that the form of these sketchbooks is highly variable—to the point where he questions whether the sketchbooks can be considered a genre at all (136). When he steps away from questions of form, however, he can state, “The decision [about whether the sketchbook is a genre] will have

to take account of the user's perceptions of the matter: do they themselves treat the sketchbook as a genre?" (141). Elsewhere he states, "The essential criteria are rather that the practitioners find themselves in a socially recognized and typified situation, and engage in a semiotic activity that is socially recognized as a response to that situation and has meaning in relation to it" (142). Medway suggests that the idea of a form recognizable to critics is less important to generic status than the classification of the users themselves. Nevertheless, so long as genre is viewed as a type, question of form will always be important.

Another reason why form remains an important concept has to do with the concept of community or the group of people using and recognizing the action of the genre. Different genre scholars have given this community different names depending on the methodology being used. The terms "discourse community" (Berkenkotter and Huckin; Swales), "community of practice" (Lave and Wenger; Wenger), and "activity system" (Russell, Spinuzzi) are all common and indicate to what degree the scholar wants to focus on discourse as the primary social action being studied. The concept of a community centered on common social practices, including discourse practices, is important in a rhetorical conception of genre that wants to take into account local practices and values. Berkenkotter and Huckin, for example, assert that "genre conventions signal a discourse community's norms, epistemology, ideology, and social ontology" (21). In other words, they see a clear relationship between a genre's conventions (or form) and the values of the community. Elsewhere they argue, "Our own research on discourse communities has led to our growing attention to the ways in which the genres of academic writing function to instantiate the norms, values, epistemologies,

and ideological assumptions of academic cultures” (22). These arguments demonstrate that there is a complicated relationship between genre form and community because genres both reflect community values and, by their very use, reinforce those values. Many scholars of writing pedagogy and professional communication are interested in genre theory because it can help them understand how academic or professional values are enculturated in genres. Rhetorical genre theory can help scholars understand why it can be so difficult for novices to become accustomed to new professional roles and the social actions they require (Beaufort; Winsor). There has been debate over the use of explicit teaching of genre conventions to novices as a way of more quickly acclimating them to a new community, discipline, or profession.

A third important concept in rhetorical genre theory is Schryer's explanation of genres as “stabilized-for-now.” As the phrase suggests, this concept reflects both an understanding of generic flexibility—different examples of the same genre look slightly different—and an understanding that genres can evolve over time. Berkenkotter and Huckin explain, “Genres are dynamic rhetorical forms that are developed from actor's responses to recurrent situations and that serve to stabilize experience and give it coherence and meaning. Genres change over time in response to their users' sociocognitive needs” (4). Thus, while old genre theory saw genres as fixed and stable entities, rhetorical genre theory views genres as only temporarily stable. Stability cannot exist in practice so genres are an approximation or heuristic that users can rely on in order to respond to social situations efficiently.

Perhaps the most important concept of rhetorical genre theory is the concept of a recurring, typified situation. The idea that textual types develop when situations recur

over and over again cements the connection between text and rhetorical situation. Miller introduced the idea that typification is not just a feature of genres, but also of situations and responses. To be sure, she was not the first one to argue this point; for example, Jamieson studied inauguration speeches as an example of a genre that developed over time. Genre conventions became typified as the situation was repeated, so that now, new presidents look back upon past speeches to guide their practice. Bitzer's definition of rhetorical situation is also important here. Miller argues,

He essentially points the way to genre study, although he does not use the term himself, in observing that situations recur: "From day to day, year to year, comparable situations occur, prompting comparable responses." The comparable responses, or recurring forms, become a tradition which then "tends to function as a constraint upon any new response in the form" (Bitzer 1968: 13). Thus inaugurations, eulogies, courtroom speeches, and the like have conventional forms because they arise in situations with similar structures and elements and because rhetors respond in similar ways, having learned from precedent what is appropriate and what effects their actions are likely to have on other people. (152)

Miller also observes that when we say situations recur, we do not mean that recurring situations are exactly alike in every material way, but rather that we interpret them as similar enough to engender a similar response. Miller calls this process "typification" and states, "It is through the process of typification that we create recurrence, analogies, similarities. What recurs is not a material situation (a real, objective, factual event) but our construal of a type. The typified situation, including typifications of participants, underlies typification in rhetoric" (157).

In sum, there are four key concepts in rhetorical genre studies:

- (1) Form or genre conventions are important. Conventions are linked to rhetorical situations.
- (2) Genres exist in communities and both reflect and reinforce community values.
- (3) Genres are flexible and evolve in response to changing circumstances.
- (4) Genres come into being when community members recognize (or typify) similar situations that recur.

As a final word to this section, I will note that more recent scholarship on genre has called into question some of these foundational concepts. I have already mentioned Medway's article that questions the importance of genre conventions. Other work is reminiscent of Fairclough in that it seeks to understand the seeming paradox between the observation that genres help reinforce social norms and are therefore highly conservative, while also coming to terms with the recognition that genres change over time. Some research suggests that genres change locally in response to situational factors such as new technology (Yates and Orlikowski) or new users (Miller and Shepherd). However, genre evolution is not well understood.

Additionally, the concept of typified, recurring situations has been reassessed. A 2002 collection entitled *The Rhetoric and Ideology of Genre*, points to a greater interest in ideology, a term associated with cultural studies. The collection primarily locates ideology in local, institutional cultures; however, Devitt's (2004) monograph, *Writing Genres*, goes a step farther by arguing, "In part, culture defines what situations and genres are possible or likely" (25). For Devitt, recurring situations are still important, but

it is not only local cultures that affect situation. On a macro level, there are cultural forces that affect local cultures, situations, and, in turn, genres. In the end, Devitt recommends a study of genres in layers, similar to Fairclough's method. She writes,

Thus, the context of situation, context of culture, and context of genres all influence the actions of writers and readers, speakers and listeners, and they do it partly through genre. Each kind of context has both a material and a constructed reality, for what makes them 'contexts' is the extent to which people give them significance [...] All three contexts interact, and at the nexus of that interaction lies genre. A genre constructs and is constructed by a notion of recurring situation, entailing participant roles, purposes, and uses of language. A genre constructs and is constructed by cultural values, beliefs, and norms as well as by material culture.

(29)

With Devitt, I see rhetorical genre studies moving towards cultural studies and trying to integrate the most important features of genre studies (local situations, local practice, local cultures) with cultural studies. Genre studies has already utilized some of the language of cultural studies, such as ideology and power. However, like Fairclough's method, the most recent genre scholarship would suggest that it is important to study multiple levels (or layers—in Devitt's terminology) that contribute to discursive practice.

Operationalizing Social Discourse Theory and Rhetorical Genre Theory

The above overviews suggest some commonalities between Fairclough's social discourse theory and recent rhetorical genre theory. The appeal of both theories is their capacity to study specific instances of language use as instances of meaning-making at both a local level and a larger, cultural level. Both theories recognize the value of specific

practice and the influence it can have on ideology. Furthermore, both theories seem to be moving towards an understanding of language practices as influenced by multiple and sometimes competing factors such as the individual rhetor, the immediate rhetorical situation, local cultures, and macro-cultures. Finally, both provide a theoretical grounding from which to account for historical changes in ideology and social practice.

Both are also subject to some of the same difficulties when trying to operationalize them in research studies. For example, if there are so many potential influences on a discursive event—agency, situational constraints, cultural ideologies—it may be impossible to design a study that can account for all of them. It would be just as difficult to determine all of the effects of the discursive event—both immediate and diffuse. What a critic can do is attempt to map out some of the influences that seem to be more important and, perhaps, to judge their relationships to one another. Although it may be difficult to know how to limit analysis, ultimately the scholar must recognize the complex network in which individual rhetors are situated but nevertheless frame the analysis like a photographer selects a scene to photograph. The photographer knows there is a world beyond the camera lens but uses the camera to showcase or focus specific scenes. By focusing, sometimes a photograph can capture aspects of the scene that are not apparent to an actual witness of the scene.

Fairclough's theory of discourse is particularly helpful in combination with genre theory for several reasons. Both study concrete examples of language (although this appears to be Fairclough's recent contribution to discourse theory) and attempt to relate them to social practice and meaning. The impression from Fairclough's work is that discourse theory studies the specific in order to get to the whole. As a linguist, it is not

surprising Fairclough's strongest analytic discourse occurs at the level of the text, on the text's own terms, isolated from context. In contrast, genre theory has been used quite effectively to ground studies of particular communities. Attention to context is one element that genre theory can lend to social discourse theory. Earlier scholarship, such as Bazerman's *Shaping Written Discourse*, focused on one genre within one particular discourse community. More recent scholarship in genre theory, such as Spinuzzi's *Tracing Genres through Organizations* and Devitt's "Intertextuality in Tax Accounting," attempts to study the numerous written genres of communication that circulate in one institutional setting. Nevertheless, barring Devitt's most recent call, the social turn in professional communication and genre theory has meant the immediate or local social. I know of no studies based in genre theory that have actually put Devitt's call for a layered analysis that incorporates cultural critique into practice. The challenge for those attempting to operationalize Devitt's suggestion will be to remain tied to an analysis that is rooted in actual practice—a traditional strength of genre studies. Thus, whereas Fairclough emphasizes the importance of the linguistic, self-contained particular, genre theory emphasizes the rhetorical, contextualized particular. This latter form of analysis is more useful for my purposes.

Moreover, since I analyze multiple data sets of different genres, the goal of this study is not to complete a traditional genre analysis, but to view these different data sets and genres as representative of different discourses about the same topic—prenatal testing for Down syndrome. Although, then, I am studying discourses as opposed to genres, the analytic vocabulary I use has more in common with genre theory than with Fairclough's discourse theory for two reasons: first, because I am not a trained linguist

and second, because, as mentioned earlier, I am more interested in the rich, contextual analysis that genre theory can provide. The elements examined from a rhetorical perspective may be similar but also different than a linguistic approach. Fairclough mentions grammar, vocabulary, cohesion, text structure, force, coherence, and intertextuality as categories that a linguist might study. These features overlap with what a rhetorical genre theorist might look for, particularly intertextuality; however, approaching the research questions from a rhetorical genre perspective will help me examine textual features with respect to their context, including the constraints and affordances of specific situations, generic conventions, and disciplinary values, among others, to see how the discourse is being used.

One particular concept that is better developed in rhetorical genre theory than in Fairclough's social theory of discourse is the concept of agency. Fairclough tries to refute readings of Foucault that criticize him for having a limited conception of individual agency. Fairclough provides a new reading of Foucault in which he points to the latter's discussions of power struggles as evidence of Foucault's attention individual resistance. Fairclough claims that although the "dominant impression [of Foucault's work] is one of people being helplessly subjected to immovable systems of power," this impression is not necessarily the full story (57). Rather, "these problems seem to be connected with the absence of a concept of practice in Foucault's analysis, including the absence of text and textual analysis" (57). Here, rhetorical genre theory provides a useful corrective to Foucault's overemphasis. A rhetorical approach assumes that rhetors are responding to some exigence and using discourse to achieve some purpose. The concept of exigence—a call—relies on the counter-concept of agency. Invention is one of the five canons of

rhetoric and refers to the ability of a rhetor to determine the way he or she should respond to a given exigence. Clearly a simplistic view of invention is not compatible with social constructionist theories, but a more nuanced version is what genre theory tries to provide. Genre theory does not relinquish the idea of agency, but instead allows that social forces and ideologies may limit the choices available to rhetors or, indeed, the response of the audience. A discursive instance that is too far from a generic response will be difficult for an audience to recognize. Nevertheless, genre theorists insist that practitioners do have some control over their discourse.

In addition to providing a framework for analyzing context and agency, rhetorical genre theory also adds the concept of a typified, recurring situation. I did not find any mention of this or a similar concept in Fairclough's methodology; however, it could be potentially helpful to this project. The concept of typified, recurring situations allows the critic to see that certain types of responses get instantiated when people perceive situations to be similar. The concept of a typified, recurring situation with an attendant typified discourse essentially provides a mechanism for Fairclough's theory that individual practices have a reciprocal relationship with larger, cultural ideologies. The concept of a typified, recurring situation also allows us to choose particular discursive practices to study. It makes sense that situations that recur might have a greater impact on the meanings of Down syndrome than those that do not.

The remainder of this dissertation focuses on one particular event—prenatal testing for Down syndrome. This event represents a significant moment that is repeated over and over again with different participants across the United States. It is an event which inaugurates many important, localized discussions about the meanings of Down

syndrome, especially when a prenatal diagnosis is made. Through an analysis of different generic types of discourse including academic arguments, professional training textbooks, and personal online forum discussions—which also represent different stakeholders in the situation including scholars, healthcare professionals, and patients respectively—I aim to determine how Down syndrome is constructed as an object of discourse in this situation.

For this particular study, both social discourse theory and genre theory offer important critical tools and concepts that I will use to analyze the social meanings of Down syndrome. Together these theories provide the backbone for a methodology that can account for the variety of discourse about a particular object across multiple disciplines, contexts, and individual rhetors. However, this project does not simply aim to put Fairclough or Devitt's layered discourse analysis into practice. Although I study one particular, generic situation—the situation inaugurated by prenatal testing for Down syndrome—I am not studying the discursive events of this situation themselves. In other words, this is not an ethnographic study that follows pregnant women through their prenatal care, observing how prenatal testing options are presented and decisions about testing and diagnoses are made and then drawing larger conclusions about Down syndrome's social meanings in this context. For various reasons, an ethnographic study design was not an option in this research.

Instead, this is a study of a typified, recurring situation from its commentaries. Although the discourse from prenatal testing situations is not available to me, I am able to study the discourse talking about that particular situation. In the following chapters, I analyze academic discourse that critiques prenatal testing practices, professional genetic counseling discourse that teaches novices how to discursively structure prenatal testing

information, and personal discourse that reflects on prenatal testing experiences. If the goal of Fairclough's social discourse methodology is to determine how small scale textual features relate to large scale cultural ideologies, my methods offer some advantage when the rhetorical situation under study is a complex one with multiple stakeholders. First, studying commentary may be the best way to attempt a reconstruction of a situation that is not observable. Similar to interviewing the eyewitnesses of a crime, the commentary will never provide an entirely accurate picture of what happened but should help the detective or researcher approximate the plot. Second, when the situation being studied involves multiple participants with incompatible backgrounds and differing participatory purposes, it may be difficult to trace rhetorical motives from their interactions. In the commentaries I study, the rhetors are speaking to their peers, to a like-minded audience. Thus, it may be easier to discern the connections between discursive features and community values in commentary rather than during the actual discursive event. In some cases during the commentary, rhetors explicitly reflect on their values and rhetorical motives, something that probably doesn't happen during prenatal genetic counseling sessions.

Working backwards, an analysis of these commentaries might help us see how particular meanings of Down syndrome gain traction within particular communities of stakeholders. For example, we might be able to see if different participants perceive different elements of the same situation as important or recognizable to them in order to create their responses. Working forwards, it might also help us to understand which elements of the prenatal testing situation are important to reinforcing or reimagining these meanings.

CHAPTER FOUR

THE PRENATAL SCREENING AND TESTING SITUATION: DISABILITY

RIGHTS CRITIQUES AND REBUTTALS

Prenatal screening and testing for Down syndrome and other genetic conditions is one situation in which individuals must navigate multiple cultural and professional discourses about disability in order to make important healthcare decisions. With very few exceptions, after a prenatal diagnosis of disability there are only two options—to terminate the pregnancy, thereby aborting the affected fetus, or to continue the pregnancy and bring the affected fetus to term. It is difficult to overestimate the gravity of the situation that prenatal diagnosis inaugurates since pregnancies being screened are most often wanted pregnancies and pregnant women (and their partners) are tasked with the responsibility of choosing whether the affected fetus will live or die.

Yet the acceptance of amniocentesis, along with other types of prenatal screening and testing, has occurred with very little debate in the American public. It is now a routine procedure for many American women receiving prenatal care. Its role, from a relatively specialized form of care to one that is increasingly routinized, changed with very little input from healthcare providers or pregnant women (Condit 181). However, as supporters point out, it is not very likely that prenatal testing would continue to be used if many people did not find it valuable.

Not all prenatal tests serve the same purposes. However, with specific reference to the array of prenatal screening and diagnostic tests for Down syndrome, the advantages seem to be the following:

1. It provides reassurance to worried parents that the wanted baby is healthy.

2. It provides physicians and parents critical information about the health of the baby so that they may either stage prenatal interventions or prepare for a birth that will require medical interventions beyond those typically needed.
3. It provides parents with time to educate themselves and prepare for a child with a disability.
4. It provides prospective parents with the option to terminate the pregnancy, thus avoiding the birth of a child with a disability. (“Amniocentesis”; Saxton)

As we will see, all of these reasons have been critiqued by those who oppose prenatal screening and testing, but arguably they are compelling to the vast majority of healthcare providers and the large percentage of pregnant women who avail themselves of these services.

In the rest of this chapter, I first describe the typical prenatal testing and screening situation for Down syndrome. Then, I argue that while there is an actual, observable prenatal testing situation, prenatal testing also inaugurates a rhetorical situation, which I explain. Next, I present a layered discussion of the prenatal testing situation as a rhetorical situation by reviewing disability, feminist, and social critiques of prenatal testing. I conclude by suggesting that different readers of the rhetorical situation of prenatal testing represent it differently.

The Prenatal Testing for Down Syndrome Situation

Since Down syndrome is a condition that is typically characterized by an extra 21st chromosome, it is relatively easy to diagnose prenatally. There are two types of prenatal tests for Down syndrome—screening tests and diagnostic tests. Screening tests, which are relatively new, are noninvasive tests such as maternal blood tests or

ultrasounds that cannot give a definitive diagnosis of Down syndrome. However, they can provide a risk assessment about the likelihood that the fetus is affected. On the other hand, the most common diagnostic tests, amniocentesis and chorionic villus sampling (CVS), are invasive and carry a slight risk of miscarriage. However, these tests are so accurate that they are considered definitive with respect to a prenatal Down syndrome diagnosis. A new test, the MaterniT21 test, is a maternal blood test that can definitively diagnosis Down syndrome without risk to the fetus. However, at the time of this writing, the MaterniT21 test is still very new and thus is not being routinely offered as an option for all pregnant women. I will return to a discussion of the potential for this test to impact the rhetorical situation of prenatal testing at the conclusion of this dissertation; however, it will not be discussed further in the following three chapters since the scholarship I refer to and data I analyze was written and collected prior to the introduction of MaterniT21.

Prior to 2007, medical guidelines suggested that only women over the age of 35 or younger women with specific concerns or indicators be offered amniocentesis to test for Down syndrome. Thus, in a typical sequence of events, a pregnant woman over 35 receiving prenatal care would have been informed of her additional risk (Down syndrome incidences increase with maternal age) and offered further testing. If she agreed to testing, she would either have had the amniocentesis or CVS done at her regular ob/gyn's office or have been sent to a more specialized clinic. She may have been offered genetic counseling by a counselor specifically trained to discuss the risks and benefits of invasive testing and to provide information about Down syndrome and other conditions amniocentesis and CVS test for. If the results indicated Down syndrome, the woman

would have again met with her ob/gyn or genetic counselor in order to discuss her option to continue or terminate the pregnancy

In 2007, the American Congress of Obstetricians and Gynecologists changed their prenatal testing recommendations to reflect the value of prenatal screening tests. The new guidelines state that all women, regardless of age, be offered noninvasive screening tests for Down syndrome and other conditions (“Screening for Fetal Chromosomal Abnormalities”). Thus, in the new model, a typical prenatal testing scenario is as follows. All pregnant women, regardless of age, are offered noninvasive screening tests as part of routine prenatal care at their regular ob/gyn’s office. Such screening tests may include ultrasounds where specific physiological markers are sought or maternal blood tests that detect particular proteins and hormones in the mother’s bloodstream. Regardless of age, if the screening tests indicate that there is an increased chance of Down syndrome or other chromosomal condition in the fetus, the woman will be offered more definitive testing. Since the genetic counseling profession is growing, it is now more likely than ever but by no means assured that women will be referred to a genetic counselor to discuss testing options and risks. Test results will be reported by a physician or genetic counselor and the options they present will be the same—to continue or terminate the pregnancy.

In addition to the changes recommended by ACOG, there is a second factor that may have affected changes to the prenatal testing situation in recent years. The Prenatally and Postnatally Diagnosed Conditions Awareness Act was passed in 2008. This bill responds to research demonstrating that parents of children who continued pregnancies after receiving a Down syndrome diagnosis were not satisfied with the information

provided by their healthcare teams. This bill requires physicians to provide patients with up to date information about conditions like Down syndrome, including information about the “range of outcomes for individuals living with the diagnosed condition” (“Prenatally and Postnatally Diagnosed Conditions Awareness Act: Official Summary”). Although the effects of the bill have not been monitored, it is possible that parents are receiving different types of information about Down syndrome within the context of prenatal testing than they were prior to the bill’s passing. In addition, the bill also requires that a national registry of families who are willing to adopt children with disabilities be established. This has led to greater professional attention to distinguishing between the options of continuing the pregnancy in order to raise the child and continuing the pregnancy with the intent to pursue adoption (Perry and Henry).

The above discussion is an attempt to describe the material happenings of prenatal testing for Down syndrome. However, aside from being a real, material, observable situation, prenatal testing also inaugurates a rhetorical situation. From the discussion above, we can see that the initial choice to get prenatal screening may lead to a series of decision-making points all situated in a medical context and mediated by medical professionals and their discourse. Since the situation of receiving prenatal care gives rise to a need for medical discourse to explain and offer prenatal testing, and since that discourse in turn gives way to patient and provider deliberative discourse, justification, and ultimately verbal commitment to a decision, the prenatal testing situation can be said to be rhetorical. I now explain the concept of a rhetorical situation in more detail.

The Concept of Rhetorical Situation

According to Bitzer's definition, a "rhetorical situation may be defined as a complex of persons, events, objects, and relations presenting an actual or potential exigence which can be completely or partially removed if discourse, introduced into the situation, can so constrain human decision or action as to bring about significant modification of the exigence" (6). The term exigence refers to the reason or motivation for speaking.

For example, suppose an angry mob was congregating outside the ice cream parlor on a hot day, demanding free ice cream. Such a situation might call forth a response from the ice cream parlor owner. He could respond by taking action—having the mob members arrested or choosing to hand out free ice cream. He may decide, however, that neither of these actions would be in his best interests. Having his patrons arrested would not reflect kindly on his shop, and distributing free ice cream would cause him to lose money. Instead, he might decide to address the crowd with a speech. Using reason and good humor, he may be able to defuse the situation and talk down the angry mob. He may offer an alternative to their demands, such as discounted ice cream prices. In this way, he would be producing rhetoric, using discourse (or discourse in combination with action) to alleviate a problem (or exigence). The discourse helps both the ice cream parlor and the owner to negotiate possible endings to this scenario. Discourse, according to Bitzer, is rhetorical if it accomplishes some action.

Bitzer argues that there are at least three elements of any rhetorical situation: the exigence or call to speak, the audience, and the constraints that affect what can be said and how it can be said (6). In the above example, the exigence is the demanding mob

outside the ice cream parlor, and the audience is the mob members. It is more difficult to determine the situational constraints since this is the broadest category in Bitzer's list of rhetorical situation elements. The situational constraints affect what can be said and how it can be said. In the ice cream parlor situation, for example, the owner would do well not to incite the angry mob further. He may also want to ensure that he does not lose customers. Both of these elements of the situation could constrain his word choice.

Rhetorical scholars have criticized Bitzer's definition of rhetorical situation for not accounting for the complexities of a real context. Edbauer (2005) for example, argues, "Though rhetorical situation models are undeniably helpful for thinking of rhetoric's contextual character, they fall somewhat short when accounting for the amalgamations and transformations—the spread—of a given rhetoric within its wider ecology" (20). In particular, she traces three critiques of Bitzer. The first, articulated by Vatz, questions the element of exigence as a real event. Rather, he argues that exigence has to be created by the rhetor. In other words, the rhetor has to make her reason for speaking clear to the audience. A second critique suggests that significant rhetorical discourse is called forth by multiple exigencies rather than a single event and that both the rhetor and the audience co-create these exigencies together. Similarly, a third critique Edbauer details suggests that "there can be no pure exigence that does not involve various mixes of felt interests" (8). In other words, the third critique changes the terms yet again by arguing that exigencies are neither real nor explicitly crafted but rather are perceived.

Using these criticisms, Edbaur suggests that rather than examining rhetorical situations and attending to their "conglomerated elements," we instead consider rhetorical ecologies that "recontextualize rhetorics in their temporal, historical, and lived fluxes"

(9). In her own words, Edbauer uses this new framework “to more fully theorize rhetoric as a public(s) creation” (9). Her concern is mostly with the relationship between rhetorical situations and publics. She conceives of a rhetorical situation with messy, undefinable borders and publics that serve as both rhetors and audiences.

Edbauer’s concept of rhetorical situation as a rhetorical ecology fits well with the theoretical models of discourse and genre analysis presented in the last chapter since she, too, is concerned with the effects of a wider cultural milieu on immediate situations. In her article, Edbauer uses the concept of a rhetorical ecology in order to demonstrate how one rhetoric symbolized by the phrase “keep Austin weird” was integrated into a larger fabric of the city’s life. Within a large, public context, the phrase was taken up and transformed by new rhetors for new purposes and audiences. These uptakes (to borrow a term from sociocultural genre theory) drew on the integrity of the original phrase and its rhetorical situation. Even the counter-rhetorics that emerged, such as the “Make Austin normal” sentiment, in some way depended on the existence of the first rhetoric.

Edbauer’s piece is about the relationship between rhetoric and rhetorical situation and about how rhetorics circulate between and among rhetorical situations. Part of her argument, as I take it, is that whether or not a particular rhetoric gets taken up into new situations is dependent on how similar the new situation is to the original situation. Are there similar exigencies, constraints, or audiences? For a rhetoric to transfer into a new context, it must be a good fit—part of the same or a similar ecology, as it were.

The major benefit of Edbauer’s concept of rhetorical ecologies is that it is particularly applicable to studying the uptake of rhetoric into new situations or, conversely, the application of new rhetorics to existing situations. In a similar way to a

biologist who studies how a particular species adapts to a new environment, Edbauer studied how a particular rhetoric was adapted to a new situation. Biologists also study, however, the ways in which different species interact within a given ecological environment. Thus, Edbauer's concept of a rhetorical ecology might also be expanded to consider the tensions, conflicts, and confluences between different rhetorics when they are introduced into the same rhetorical situation. Furthermore, whereas Edbauer traces the flow of one rhetoric—the keep Austin weird rhetoric—into increasingly diverse rhetorical situations, I am interested in the opposite approach. Within the ecology of the prenatal testing situation, parents, who are the ultimate decision-makers, are potentially exposed to multiple medical rhetorics—including those about genetics, prenatal care, and genetic counseling; cultural rhetorics about disability; disability advocacy rhetorics; and others. I focus on one rhetorical situation and examine the rhetorics that flow into it and, simultaneously, back out of it again. I hypothesize that there is a reciprocal relationship between certain rhetorical situations where the same rhetoric is used in each.

In sum, an analysis of the situation inaugurated by prenatal testing for Down syndrome as a rhetorical situation or ecology would do the following things:

- First, it would examine the exigence for testing, keeping in mind that an exigence can be related to cultural ideologies or institutional values.

Furthermore an exigence can be explicitly, discursively constructed by the participants in the situation or the exigence can be tacitly perceived by the participants. Such perceptions may be evidenced by the responses to the situation.

- Second, it would examine the known values and goals of the participants, including pregnant women, physicians, and genetic counselors. Whereas genetic counselors are specifically trained to discuss prenatal testing and thus have a readily available professional rhetoric, pregnant women are essentially novices to prenatal testing and may bring non-medical and cultural discourses to bear on the situation. For example, Press describes how pregnant women are likely to talk about prenatal testing as if it were routine prenatal care despite the fact that, in Press's estimation, prenatal care and prenatal testing have different aims (219). This may be an example of Edbauer's concept of rhetorical uptake into new situations.
- Third, it would examine situational constraints. Such constraints might include audience expectations, genre conventions, technological affordances and limitations, time constraints, or the relationship between the practitioner and the patient. Beyond the immediate situation, Edbauer's piece suggests that the wider ecology that the immediate situation is a part will also constrain the situation in predictable ways.

Ultimately, a situation is rhetorical if the participants are using discourse to accomplish some purpose. An analysis of the rhetorical situation will examine how the various elements of the situation help to shape that discourse.

The Rhetorical Situation of Prenatal Testing for Down Syndrome

In this section, I focus on the elements of the prenatal situation itself that can be read as rhetorical. Rhetorical discourse is discourse that helps us to act in the midst of uncertainty—where there is no certain evidence to lead us to a certain answer. Following

Bitzer's model, I examine how the particular situation of prenatal testing for Down syndrome calls for certain responses.

Essentially, there are three stages of prenatal testing for Down syndrome: screening, testing, and deciding. While they could all be considered as separate rhetorical situations, they are, in reality, very closely linked. Rarely will a woman proceed to stage three without going through stage two. As they are all linked, they may better fit Edbauer's concept of a rhetorical ecology where rhetorics from the first stage trickle down and affect the second stage and so on. The next chapter will provide a more specific analysis of some of the discourses or rhetorics operating at each stage. For now, let me say that this analysis demonstrates how messy the relationship is between rhetoric and rhetorical situation. It raises questions about the extent to which rhetoric is discursive, textual, or symbolic and whether events, technologies, or processes can be rhetorical—not in the sense that they call forth a rhetorical response, but that they are themselves persuasive or influential in some way.

Exigences

Prior to 2007, prenatal screening for Down syndrome was not a routinely offered option. Thus, the main exigence for being offered prenatal diagnostic testing was the condition of being over the age of thirty-five when pregnant. Patients at this age were routinely offered amniocentesis by their physicians for two reasons. First, it was established that incidences of Down syndrome increased with maternal age. That is to say, older women have a higher chance of having an affected pregnancy than younger women. An additional reason—and the specific reason for choosing age 35 as the cut-off point for women to routinely be offered amniocentesis—was not because 35 is the age

when the risk for Down syndrome starts to increase. Actually, even women who are aged 25 are at greater risk for having a fetus with Down syndrome than women who are 20-24. Instead, 35 was chosen as the age when the chance of having an affected pregnancy was roughly the same as the risk of miscarriage from the procedure itself. Both risks were about 1 in 200. In other words, the chances of having a fetus with Down syndrome as a 35 year-old woman are 1 in 200, and the chance that the invasive amniocentesis procedure would cause a miscarriage was also 1 in 200 at that time.

However, when the developers and physicians working with amniocentesis decided that amniocentesis should only be offered to pregnant women 35 and older, this was not because that was the only possible option. As already stated, women under the age of 35 can also give birth to babies with Down syndrome. Rather, they made a decision with regards to at least three factors:

1. perception of the significance of Down syndrome for the parents and physician;
2. statistical evidence demonstrating the rates of Down syndrome in fetuses respective to the age of the mother and the rates of miscarriage caused by amniocentesis;
3. interpretation of the statistical evidence by assigning a rate of acceptable risk to both the chance of miscarriage and the chance of having a fetus with Down syndrome.

While we can by no means refer to this decision as arbitrary, we can refer to it as rhetorical because at least two of the three factors are not facts but are socially determined interpretations. In other words, without professional (and discursive)

negotiation, it is not likely that all prenatal care providers would have provided the same recommendations to their patients, even with access to the statistical data concerning miscarriage and rates of Down syndrome.

This guideline, which was in effect until 2007, is evidence of the rhetorical nature of genetics testing guidelines. Although the recommendations weren't arbitrary, neither were they objective or value-free. To make this recommendation, healthcare professionals had to determine that the two potential outcomes—having a child with Down syndrome or having a miscarriage—meant roughly the same thing. If, for example, there was consensus that a miscarriage was a more serious and negative outcome than giving birth to a child with Down syndrome, they might have recommended that amniocentesis be offered only when the likelihood of Down syndrome was significantly higher than the risk of miscarriage. Instead, by recommending amniocentesis only when the chances of an affected pregnancy were roughly equivalent to a miscarriage, professionals sent the message to prospective parents that the impact of a child with a disability would be as serious as that of a miscarriage. Still, we might ask if the new 2007 guidelines changed the rhetorical nature of the prenatal testing situation. Now, no decisions are made to offer a pregnant woman amniocentesis on the basis of age.

This change was precipitated by two findings. First, screening procedures were developed that could predict the likelihood of Down syndrome without using invasive measures. Screening practices are different from testing practices in that they cannot provide a definitive diagnosis of Down syndrome. They can only indicate whether the pregnancy is more likely to be affected. I will talk about screening practices in more detail at a later point. Second, epidemiological studies were showing that the majority of

babies born with Down syndrome were born to women under the age of 35. Thus, although older women are more likely to have a pregnancy affected with Down syndrome, women under the age of 35 make up a greater proportion of pregnant women. Thus, the majority of women who had affected pregnancies were not being offered prenatal screening or testing for Down syndrome.

Instead, it seems that the new exigence for prenatal testing is the condition of being pregnant. As many feminist scholars have noted, pregnancy has increasingly become a medicalized state such that the condition of being pregnant is itself regarded as reason enough for medical intervention (Barker). Now that the events of prenatal testing for Down syndrome begin with noninvasive screening, however, there are many decision-making points each with their own exigence. Being pregnant calls forth a need for prenatal screening, a positive screen calls forth a need to discuss and consider diagnostic testing, and a diagnosis of Down syndrome calls forth a need to discuss and consider abortion.

Technological Constraints

Again, there are any number of possible constraints on the rhetors involved in a prenatal testing situation—some consistent between any prenatal screen and test for Down syndrome and some specific to the particular patient or healthcare provider involved. One particular constraint involves the limitations of the testing technology. Healthcare providers are constrained in what information they are able to give and when they are able to give it by the technology available. For example, healthcare providers can only offer amniocentesis and chorionic villus sampling during the second trimester due to the safety and mechanisms of the tests. The conditions of these tests are not ideal because

the woman and often the rest of the family are more likely to have established deep bonds with the baby at this stage in the pregnancy. As we will see in Chapter Six, many women choosing to terminate at this stage refer to the fetus as a baby, even when they are in the midst of planning an abortion. Even if the woman is confident in her decision to abort upon learning of a diagnosis of Down syndrome, doing so can be made more painful (some argue, although notably there are some feminist scholars who disagree with this claim, like Rothman) simply because of the timing. Genetic counselors and other healthcare professionals must work around this constraint by factoring it into their information-giving. As we will see in the next chapter, genetic counselors are trained to ask pregnant women to imagine various outcomes of genetic tests. Thus, when explaining amniocentesis to a client, genetic counselors may ask whether she would be willing to consider terminating the pregnancy at this point should the test come back positive. If the woman cannot imagine doing so, she may not be a good candidate for amniocentesis.

Additionally, the limits of screening tests can affect how pregnant women perceive the risk associated with their pregnancies. Screening results may be available in the first or second trimester depending on the screen and its accuracy; the more accurate the screen, the later the results will be available. Women receive their results as a ratio. For example, they might hear, “Your triple screen indicates that your pregnancy has a 1 in 262 chance of having Down syndrome.” However, the results are also interpreted as being positive or negative. A positive screen means that given the woman’s age, the pregnancy has an increased chance of being affected with Down syndrome. When screening results are presented accurately, they are also confusing to the novice who is not trained in medical statistics. For example, most “positive” screens are actually false,

meaning that the baby does not have Down syndrome. To pregnant women, this false positive could be interpreted as a mistake but its actuality a large number of false positives is to be expected given the limited sensitivity of the test. We would expect, for example that most women receiving a positive screen with the ratio of 1 in 262 would actually have a pregnancy unaffected by Down syndrome. Nevertheless, receiving a positive screen does indicate that statistically the woman has a greater chance of having a pregnancy affected with Down syndrome. The question is whether her risk is substantially greater to the point that it correlates with the large increase in anxiety caused by a positive screen.

Rhetors and Audience Members

Within the prenatal testing context, there are many moments of discursive exchange, particularly between doctor (or genetic counselor) and the prospective parents. In a more directive exchange, as in a typical doctor and patient interaction wherein the doctor is viewed as the expert, the pregnant woman and her supporters are likely to be the audience. However, prenatal genetic counseling, as we will see in the next chapter, is a more reciprocal relationship where the patient may sometimes serve as rhetor and sometimes as audience.

The new ACOG guidelines suggest a typical process by which women will be offered prenatal screening and testing options for Down syndrome. All pregnant women receiving prenatal care are likely to be offered prenatal screening for Down syndrome by their primary prenatal care provider. At this point, it is unclear how much counseling women are likely to get on the subject. Since prenatal screening is noninvasive and very safe, it is more likely to be perceived as mandatory rather than as an option. This may be

especially true in a regular physician's office where the provider is not trained to communicate genetic information. Simply put, there is no medical downside to getting prenatal screening. Since there are no *medical* risks to either the fetus or the pregnant woman, the physician is under no obligation to present prenatal screening as potentially risky for the mother. For physicians, having more information about the physical pregnancy and the fetus is always a good thing.

Unfortunately, however, although there are no *medical* risks to prenatal screening, there may be other risks. Most notably, prenatal screening begins a cascading series of events that once begun may be difficult to stop. If the woman receives a positive screen, she is likely to be offered more definitive diagnostic testing. This offer comes with a choice: to continue with the pregnancy knowing that there is a higher than typical likelihood that the fetus has Down syndrome or to pursue diagnostic testing. When the woman pursues prenatal screening as if it were just another product of prenatal care, the decision to choose not to get further testing is a difficult one to make since seeking prenatal care involves taking action and choosing to refuse further testing does not. Thus, even women who are feel certain that they would want to raise a child even if diagnosed with a disability may have a hard time refusing diagnostic testing since the rhetoric required to justify not getting testing conflicts with the rhetoric of responsible motherhood.

If the woman chooses to undergo diagnostic testing, she will again be faced with a choice: this time to continue or terminate the pregnancy. There are no statistics indicating what percentage of women getting positive screens go on to get definitive testing, but research indicates that most women do go on to terminate pregnancies after getting a

definitive diagnosis (Rapp). After all, in the face of risk, it may be more difficult to do nothing, to watch and wait, than to pursue the limited information further. In addition, Skotko found that many women choosing to continue their pregnancies after a prenatal diagnosis of Down syndrome felt active disapproval from their healthcare providers with respect to their decision. Thus, while there is no incentive for healthcare providers to view prenatal screening as risky since there are no medical risks, pregnant women may experience anxiety as a result of conflicting rhetorics about good motherhood. Depending on the woman's inclination towards raising a child with a disability, she may experience tension between wanting to continue to seek good prenatal care and wanting to give birth to any child regardless of ablebodiedness.

Critiques of Prenatal Testing

According to Condit, the character of the debate about the ethics of prenatal testing was irrevocably changed by the Supreme Court's decision to legalize abortion. The perceived position of reproductive rights in the time since has often pitted feminist scholars and disability rights activists against one another. Those fully invested in a woman's right to choose see disability critiques of prenatal testing as infringing upon women's' autonomy, whereas those who critique prenatal testing argue that there is an ideological difference between choosing to abort any fetus and choosing to abort a particular fetus based on one characteristic—disability. Prenatal genetic counselors are situated at the heart of this debate since, as Peterson argues, “advocacy for those with disabilities” and “facilitation of a full range of reproductive choices” make up the “dual roles in genetic counseling” (13).

Not only do these critiques and their rebuttals represent some of the most nuanced thinking about the conditions of the prenatal testing situation, but they also demonstrate the potential to consider a situation to be rhetorical in the sense that it encourages specific actions without needing discourse to mediate them. In other words, part of the conclusions to these arguments against prenatal testing is that the very situation initiated by the existence of a prenatal screen for Down syndrome, its placement as a routine part of prenatal care, and its administration by authority figures in many ways compels women to begin the process of screening and testing and eventually terminating an affected pregnancy without the need for engaging in discursive deliberation. At least this is how I read these critiques.

There are at least three general areas of criticism about prenatal testing in general, all of which also apply to the specific situation of testing for Down syndrome. These areas include feminist critiques, disability rights critiques, and cultural critiques. I will review all three areas here.

Feminist Critiques of Prenatal Testing

Feminist scholars have long called attention to the medical profession's intrusion into the experience of pregnancy for women. They call this process "medicalization." Barker describes medicalization as the process by which society has accepted "biomedical interpretations and treatments for human behaviors once seen as moral failures, legal violations, or organic experiences" (1067). In other words, the medicalization of pregnancy has led society to treat pregnancy as a disease that needs to be attended to by medical professionals rather than as a natural or female driven experience. Lay and other scholars trace the origins of medicalization of pregnancy to

the gradual replacement of midwives by male physicians. She describes how midwives were systematically discredited beginning with the insistence of the medical profession that male physicians be present at difficult births. However, Barker argues that the medicalization of pregnancy was a slow process. She claims that up until the 1940s, most American women did not receive medical prenatal care. In comparison, as of 1996, over 95% of pregnant American women received prenatal care (Barker 1068).

Although prenatal care did not necessarily contribute to better outcomes for mothers or their babies, technological developments did provide new information to pregnant women (Lay, Barker). For example, ultrasounds provided women with a powerful visual image of their babies. They could view the fetus in real time moving about the womb, could see the baby's heart beating, and could even, with help, determine the sex. Medical professionals served as the guides who introduced pregnant women to these new ways of knowing their progeny.

The point for most scholars is not to condemn the medical profession or its practices, but to point out that medicine has changed the experience of pregnancy for women and that some ways of experiencing pregnancy are in danger of being lost. Furthermore, attention to the processes of medicalization can also demonstrate the ideological force of medical discourse and can suggest where medical claims—such as the claim that good prenatal care dictates good outcomes—are overstated. Such research could contribute on a practical level by indicating where monetary resources should and should not be committed.

Prenatal testing and its attendant technologies can be read as one more form of medicalization related to pregnancy. However, prenatal testing's relationship to selective

abortion complicates how it is viewed by feminist scholars. Some feminists argue that prenatal testing helps provide women with greater reproductive choice. These scholars suggest that women ought to have access to more information about fetuses in order to consider the responsibilities and burdens that would be called for (Baily; Kittay).

Selective abortion, for these scholars, is an important and positive option for pregnant women that helps women make important decisions about their own lives. However, not all feminist scholars studying the prenatal testing situation feel this way. Some feminists argue that prenatal testing changes the pregnancy experience in multiple negative ways by producing unnecessary anxiety, creating greater decision-making burdens on women, and conditioning society to blame women for poor prenatal outcomes.

Barbara Katz Rothman's book, *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood*, argues that prenatal testing (and she is specifically talking about amniocentesis) changes the experience of pregnancy by requiring women to suspend their acknowledgement of motherhood. She refers to this state as a "tentative pregnancy" in which women must be prepared to abort a wanted baby should they receive an unfavorable diagnosis. Rothman argues that as a result of prenatal testing, women are no longer viewed as the experts of their own pregnancies. In fact, they cannot trust their own bodies for reassurance of a healthy baby. Rather, they must suspend belief until receiving confirmation from a prenatal test. Moreover, should that test indicate disability, women must be prepared to terminate. Essentially, prenatal testing asks women to postpone developing feelings of motherhood until they receive confirmation from physicians.

Rothman does not question a women's right to choose to terminate a pregnancy under any circumstances; however, she does draw attention to the personal and social conditions which may make abortion a more difficult and painful decision after prenatal testing. First, she draws attention to the fact that women choosing to terminate pregnancies after prenatal diagnosis are women who wanted to be pregnant. A woman who intended to terminate a pregnancy from the beginning would not be receiving prenatal care and would not have been offered prenatal testing. This latter population of women do not see themselves as carrying a baby. In contrast, women who choose to terminate after prenatal testing were intending to proceed with the pregnancy and prepared to give birth. The emotional investment in the pregnancy and in the fetus as a future child is much greater, making it all the more difficult to end the pregnancy.

Moreover, the experience of ending a wanted pregnancy after prenatal diagnosis may be all the more difficult because of social views of abortion. Although reproductive rights are still a contentious issue in American society, some types of abortions are viewed as more acceptable than others. For example, many prolife supporters find terminations for medical reasons to be acceptable. Rothman argues, "Because these abortions are socially more acceptable, many people have assumed that they are psychologically more acceptable than are abortions for what is called 'less reason,' abortions because a woman does not want to be pregnant. That is not true" (5). Rothman finds that women who choose to terminate after a medical diagnosis of disability are more attached to the pregnancy and, in some cases, are morally opposed to abortion in other situations. Thus, the fact that society accepts these abortions may paradoxically make it more difficult for women psychologically. Society, in effect, assumes these

women do not need the same amount of support in order to go through with a pregnancy termination when, in fact, these women may need more support than women choosing to terminate in different circumstances because they are more attached to the pregnancy, the baby, and their role as mothers. Instead of having ample social support, women and their partners must make termination decisions and deal with the consequences in private.

Women's attachments to their pregnancies are further complicated by the current screening and diagnostic practices. Amniocentesis is most commonly performed between the 14th and 20th weeks of pregnancy. This is comparatively late to be considering abortion. At this point in the pregnancy, women have not only made it through the difficult first trimester but are also likely to be outwardly showing their pregnancies and sharing the news with others. Since most providers will not perform late-term abortions, women receiving a prenatal diagnosis are often forced to make a decision about termination quickly or risk not having the choice at all. However, the timeline for prenatal diagnosis and termination decisions will certainly be changing within the next few years. A new, noninvasive maternal blood test has just entered the market that can effectively diagnosis Down syndrome in the first trimester. However, as Rothman points out, earlier tests may also be problematic in that they will result in more women having to choose to make decisions about terminating the pregnancy. Many, many pregnancies affected with chromosomal conditions or other disabilities spontaneously abort early into the pregnancy. Thus, current practices mean that many women do not have to make difficult decisions about whether to continue an affected pregnancy because the pregnancy does not progress to that point. With earlier diagnosis many more women will be forced to wrestle with these complex decisions.

Indeed, even for those women who receive “good news”—that is to say they do not receive a prenatal diagnosis of disability, there is a lot of stress and anxiety involved in the testing process. The very existence of the tests creates the fear that the pregnancy is not typical or healthy. This is part of the medicalization of pregnancy; it creates the assumption that pregnancies need to be monitored. This argument contrasts with the claim made by supporters of prenatal testing that the tests actually provide reassurance to most women. Instead, Rothman, Rapp, and this study all demonstrate that the anxiety caused to women can be very severe. Rothman finds that even when prenatal tests come back showing typical results, that parents can still be worried. In at least one instance, one woman continued to worry that the doctors had missed something and that her child was indeed disabled even after birth. A similar story shows up in the data set for this project. In other words, there is a lot of evidence to suggest that for many women, prenatal screening and testing is not a routine part of medical care. Rather it causes added stress and anxiety even though women may be convinced they are doing the right thing by getting testing. Again, as we will see later, some women who get positive screens for Down syndrome and then end up having typical babies decide that they will not undergo screening again. For them, the testing process was so psychologically stressful that they do not want to have to go through it again.

A final feminist critique of prenatal testing concerns the perceived imperative to undergo testing and the subsequential blame that may be placed on mothers when there is a perceived bad outcome. Legally, women have the choice to opt out of any prenatal screening test or diagnostic test. However, depending on the context in which the testing is introduced, this choice may be made more or less explicit. Genetic counselors, for

example, are trained to be nondirective and to refrain from providing advice about whether or not to test and whether or not to terminate the pregnancy. However, numerous studies show that women often feel pressured to pursue testing or negatively judged if they choose to continue pregnancies affected with disabilities (Helm, Miranda, and Chedd, 1998; Rothman, 1993; Skotko). Thus, there is likely a large disconnect between what is advocated in professional literature and what actually happens in practice.

Furthermore, Landsman's recent research on mothers of children with disabilities argues that the existence of prenatal testing and, to some extent, prenatal care, creates a situation in which mothers can be blamed for perceived bad outcomes—that is to say, for giving birth to children with disabilities. Landsman argues that increased social attention to pregnant women's behaviors that can contribute to birth defects has caused increased guilt and anxiety for women who give birth to disabled children. For example, Landsman points to the barrage of ads portraying "bad" mothers who are drinking or smoking while pregnant and warnings that such behaviors lead to birth defects. She argues that such claims are exaggerated in many ways since the vast majority of birth defects have no known cause. Yet many of the mothers she interviewed had spent many anxious hours searching their memories for a time when they may have had a glass of alcohol while pregnant or blaming themselves for the cigarette they smoked before they knew they were pregnant. This guilt exists even when there is no rational reason for it to be there since for most, if not all, of these mothers, the child's birth defect has an unknowable cause. Landsman's argument is that a culture obsessed with pregnant women's behavior links good behavior to good outcomes and thus provides opportunity to blame women for causing or contributing to a child's disabilities.

Landsman's argument extends to maternal behavior concerning prenatal testing. If women have the opportunity to test for a specific disability and they choose not to or they choose to continue the pregnancy even after a disability is diagnosed, those women are open to societal blame. Landsman cites research demonstrating that both health professionals and lay people blame women who give birth to children with Down syndrome when screening was offered to them and they did not take it (41). Landsman argues, "Access to informed 'choices' through prenatal testing, far from liberating women, can paradoxically aid in perpetuating the notion of mother-blame, imprisoning some women within an atmosphere of guilt and shame" (45).

In summary, feminist scholars critique prenatal testing on four grounds: first, that it further contributes to the medicalization of pregnancy, irrevocably changing the experience for women and potentially causing others ways of experiencing pregnancy to be lost; second, that it causes anxiety in many pregnant women, even for those whose results indicate that the baby is typical; third, that although socially aborting for medical reasons may be more acceptable, there is very little recognition that psychologically aborting for these reasons could be more difficult for women; and fourth, that the routinization of prenatal testing makes it possible to blame mothers for making the wrong choices. Review of this research indicates that there are several gaps that need to be addressed. First, Rothman's work is now over twenty years old. In the time since her book was published, prenatal testing practices have changed dramatically. For example, when she conducted her study, prenatal screening was not available. Only women over 35 were offered amniocentesis. Now women of any age are offered screening and are usually only offered amniocentesis if the screen indicates that there is a greater risk.

Screening, as opposed to amniocentesis, creates an entirely new context for anxiety, especially because screening cannot provide a definitive diagnosis. Furthermore, the emphasis in both Rothman and Landsman's studies is on women who received a positive diagnosis. Less is known about the way that women who receive negative test results respond to the situation. Second, claims that the medical profession is coercive or trivializes women's abortion experiences are relatively unsupported. Much of the research comes from women reporting on their experiences with prenatal testing. Their perceptions may be misguided or exaggerated. More work needs to be done analyzing medical discourse itself, either via studying medical texts, interviewing medical professionals, or observing medical practice.

Disability Rights Critiques of Prenatal Testing

Disability scholars have had varied responses to prenatal testing. In this section, I will report on some of the strongest claims and some of the rebuttals from within disability studies itself. While some disability scholars do take a hard line against prenatal testing and selective abortion for disabilities, I have not come across any scholar who does not support women's reproductive rights including the right to abortion more generally. The difference comes with respect to the circumstances under which abortion is deemed acceptable. For some scholars such as Adrienne Asch, terminating a wanted pregnancy simply because the fetus is disabled is amoral. Other disability scholars—and many feminist scholars—believe that it would be wrong to curtail women's reproductive rights under these circumstances. Thus, prior to beginning this overview, it is important to understand that there are some tensions between disability scholars and feminist scholars, as well as within disability studies itself.

One area of relative consensus among disability scholars concerns the idea that prenatal testing obscures the need for greater social attention to people already living with disabilities. For example, Parens and Asch suggest, “Prenatal diagnosis reinforces the medical model that disability itself, not social discrimination against people with disabilities, is the problem to be solved” (13). In other words, whereas at one time prenatal testing and selective abortion were said to be stop-gaps for a time when medical technology would develop and we could fix “problems” in the womb, they have not become the solution in and of themselves (*Meanings* 128). If fewer people with disabilities are born, then fewer social resources have to be devoted to social services. Despite protests from scholars such as Shakespeare that this interpretation is too polemical, that there is no overtly eugenic program with regard to the introduction and use of prenatal tests, the effect of prenatal testing is that it prevents many disabled people from being born (*Disability Rights and Wrongs* 87). Press argues that the motivations and effects of prenatal testing are made most clear in studies that determine the cost-benefit analyses of prenatal screening measures. Press writes, “This literature contains up-front calculations of the minimum number of pregnancy terminations that can be done before screening ceases to be cost effective” (221). In order to consider prenatal screening to be successful, the cost to society of disabled people in terms of the social and medical services provided to them must be quantified. Whereas disability scholars may disagree about the meanings of disability (to what extent is disability real in a material fashion or is it purely socially constructed?), most would argue that the value of a disabled person cannot be summed up by quantifying the monetary amount of social services needed. Nor would most suggest that prenatal testing ought to substitute for better social programs.

Rather, they would argue that prospective parents can only make informed decisions about prenatal testing when they are sure that there will be adequate social services and support for raising children with disabilities. Thus, disability scholars critique prenatal testing when it is treated as a money-saving mechanism.

A second critique of prenatal testing from disability scholars is more contentious. It is referred to as the expressivist debate. Those who espouse it suggest that seeking prenatal testing and selective abortion for disability constitutes active discrimination towards people with disabilities. Asch is perhaps the most vocal proponent of this message. Asch differentiates between the decision to terminate a pregnancy under any circumstances no matter the characteristics of the fetus and the decision to terminate a particular pregnancy as a direct result of particular knowledge about the fetus. The distinction rests in the woman's attitude towards the pregnancy in both circumstances. Press summarizes this distinction clearly: "For Asch there is, virtually from its inception, a perceived difference between a wanted pregnancy and one that is not wanted at that time. In the first case there is an immediate, imaginative sense of carrying a baby; in the latter, the pregnancy remains a fetus" (215). Asch argues that when the prospective parents in the first scenario choose to get prenatal testing and decide to abort on the basis of the information provided, "now they are picking and choosing among possible recipients of their parental care, on the basis of what those fetuses would be like were they to come into the world" (Nelson 201). Asch, Press, Saxton and others who distinguish between abortion under any circumstances and abortion under the particular circumstances of prenatal testing argue that the second case expresses discriminatory attitudes towards people with disabilities. Parens and Asch explain, "Many people with

disabilities, who daily experience being seen as past because of some single trait they bear, worry that prenatal testing repeats and reinforces that same tendency toward letting the part stand in for the whole. Prenatal testing seems to be more of the discriminatory same: a single trait stands in for the whole (potential) person. Knowledge of the single trait is enough to warrant the abortion of an otherwise wanted fetus” (14). People with disabilities may take offense at the perceived message being sent by prenatal testing and selective abortion that indicates society would prefer disabled persons not to be born.

In a series of Hastings Center workshops, a group of invested researchers and scholars grappled with the questions raised by the expressivist critique. Although all of the participants were invested in disability rights, many of them objected to the strict guidelines suggested by the any/particular argument. Those who objected argued that the meanings of abortion under prenatal testing circumstances are numerous and muddled. In particular, Nelson argues that the any/particular distinction Asch makes is not so clear. He suggests that women may choose to terminate pregnancies diagnosed with a disability both because of circumstantial reasons and because of the intrinsic characteristics of the fetus. For Nelson, there is no clear distinction between fetal characteristics and a woman’s life circumstances. In another work, Shakespeare makes a similar argument. Furthermore, Nelson argues that we cannot know the intentions of individual actors who choose to terminate pregnancies and so we should not assume that they intend to express negative attitudes to those living with disabilities. Likewise, Baily argues that there is a distinct difference between wanting to avoid disability and active discrimination towards disabled people (64-71). Her argument rests on the idea that it is reasonable to want to avoid both becoming disabled and giving birth to a child with a disability. Kittay also

argues that it is reasonable for women to choose to abort disabled fetuses, especially if they are well-informed about the particular future needs of the child. Kittay writes, “Having a child, any child, is a great burden and a great responsibility, our obligation as a society and as prospective parents is to go into that great adventure with our eyes open and with as much forethought as we can muster about whether we can assume that burden in a responsible way” (177). In other words, Kittay acknowledges that all children create burdens for their parents, that it is difficult to quantify what that burden will be, but that nevertheless, women and their partners should be free to assess that burden for themselves.

There seem to be several unacknowledged tensions within this debate. First, there is the definition of disability. For some scholars such as Asch and Kent who argue that disability ought to be a non-factor in termination decisions, the implication seems to be that disability is neutral. In other words, disabilities may have positive or negative effects on people’s lives. Some of Asch’s critics, however, explicitly take up this discussion and argue that disabilities are not neutral but have negative consequences that far outweigh any positive consequences. Steinbock, for example, argues that disabilities are not neutral forms of variation. She suggests, “Parents are told what is ‘normal’ for a two-month-old, a six-month-old, or a nine-month-old baby. There can be wide variations of ability and temperament within normal variation. But if your six-month-old never smiles or your nine-month-old cannot sit up, this indicates not merely difference but a problem, a reason to check with pediatricians” (112). Kittay makes a similar argument that it is reasonable for parents to assess potential disabilities and abort fetuses if the parents determine that the life consequences will be too negative. However, it is possible that these authors are

simplifying Asch's argument. Since Asch's argument is only that parents should not decide to end pregnancies based on the results of prenatal testing, it could be read less as an argument about the neutrality of disability and more as an argument about the inadequacy of the tests. Asch could be arguing that prenatal tests provide only limited information about whether disability is present, but can often not provide detailed information about what form that disability will take. Amniocentesis is a good example here since it can diagnosis Down syndrome but cannot tell the degree of mental retardation or the types of physical impairments that will be present. Her argument might be read as a need to consider whether prenatal tests actually provide enough information for parents to make such life-altering (and life-ending) decisions.

A second and related tension involves the scope of prenatal testing. Whereas some critics may be opposed to some forms of prenatal testing, others are opposed to all forms of prenatal testing. Once again, Asch takes perhaps the strongest line arguing, "I am convinced that professional limit setting based on a committee's list of 'acceptable' and 'unacceptable' disabilities or variations will erode what cooperation exists among people across disabilities. It will weaken those alliances being built between disability organizations and other political groups pressing for changes in how society handles new technologies, thinks about families, or deals with human difference" (252). In other words, not only would it be difficult to make decisions about which disabilities were most severe and warranted prenatal testing, but it could also be potential harmful to a disability rights minority agenda as well. But for others, there are real, material differences between disabilities that should impact prenatal decisions. Shakespeare, for example, argues that we can and do make distinctions between more and less severe

disabilities. He lists Tay-Sachs as one example of a very severe disability since the person born with it is likely to die in infancy and suffer a great deal during life. Shakespeare argues that Tay-Sachs is significantly different from a condition like Down syndrome and, therefore, warrants different treatment. Following Shakespeare, I would suggest that whether we explicitly make distinctions between disabilities or not, we will always make distinctions tacitly. Therefore, it is perhaps necessary to acknowledge this debate more fully and consider whether there are ways to acknowledge the differences between disabilities without affecting the political gains of the disability rights movement or expressing negative attitudes towards people with disabilities deemed to be more severe.

A final unresolved tension among disability scholars involves the emphasis on individual actor's intentions or societal effects. Within the context of prenatal testing and selective abortion, critics suggest that a negative message is sent to people living with disabilities that they are not wanted or needed. However, those who believe that this statement is too strong focus their rebuttals on intentions of the individual women choosing to selectively abort disabled fetuses. Steinbock argues, "From the fact that a couple wants to avoid the birth of a child with a disability, it just does not follow that they value less the lives of existing people with disabilities [...] The wish to avoid having a child with disabilities does not imply that if that outcome should occur, the child will be unwanted, rejected, or loved less" (121). Nelson also focuses on the intentionality of the actor by arguing that it is impossible to trace the intentions of the actor through a single act. He suggests that actions, as opposed to language, may have multiple and ambiguous meanings and since there is no agreed upon significance of selective abortion,

we cannot assume what women mean by it (210). In contrast, it seems that intentions mean less to those who oppose prenatal testing and selective abortion under all or many circumstances. Asch, Kent, and Saxton are more concerned with the effects of prenatal testing. Saxton argues, “In our discussions during The Hastings Center project about the disability community’s views of PND [prenatal diagnosis] and selective abortion, I felt that some members of the group did not grasp the impact of stigmatization on disabled people’s sense of self, and how that might affect our views of PND” (151). For these scholars, whether or not women or healthcare professionals intended for prenatal testing options to offend people with disabilities is not the point. The point is that these practices have offended the disabled population and made them feel oppressed. Thus, there seems to be a tension between what is more important, the intent of certain actions or the felt consequences of such actions.

Cultural Critiques of Prenatal Testing

Cultural critiques of prenatal testing tend to focus on the ideological power structures inherent in the context of prenatal testing. There are major cultural critiques of almost every element of the prenatal situation including the way decision-making is structured, the role and allegiances of healthcare providers, the supposed objectivity of prenatal testing technologies, and the dominance of medical values at the expense of other ways of knowing.

First, there is a fairly substantial tradition of critiquing the emphasis on autonomous decision-making in medicine. Mol’s work, *The Logic of Care*, perhaps best delineates some of the issues with this emphasis. Her central argument is that a paradigm of choice in healthcare does a disservice to patients in many instances. Patients’ rights,

including the right to choose among treatment options or to forego treatment at all, can be read as a necessary response to an older model of paternalistic medicine in which patients were not included in decision-making and sometimes were not even given all of the information relevant to their condition. In this former model, the physician was clearly acknowledged as the expert and bore all of the responsibility for decisions made. Mol suggests that a logic of choice has replaced this model. In a logic of choice, patients are not just included in decision-making, they are given the sole responsibility. This does not mean that patients don't take advice from physicians, nor does it absolve physicians of the responsibility to provide patients with the information necessary to make informed decisions. However, in practice, Mol suggests that the logic of choice often places patients in an impossible position where they are free to make their own choices but also susceptible to being blamed for the decisions they make. The logic of choice undermines a respect for the extremely complex and difficult decisions that patients must make—decisions for which there is no clear cut right answer

The prenatal testing situation is a clear example of a context in which decisions are complicated and must be made without adequate information. In fact, although most of Mol's work focuses on diabetes care, she begins her book by sharing a personal example of her experiences with prenatal testing. She tells a story about choosing to get amniocentesis even though she was worried about the potential for the procedure to harm the fetus. Mol was clearly an informed patient; she was interested in the information that amniocentesis could provide but was also aware that the procedure carries a small risk of miscarriage. Weighing the risks, she chose to get amniocentesis done. But making this decision did not resolve her fear or worry! As she was being prepped for the procedure,

she commented to the nurse that she hoped everything would be all right. The nurse responded, in Mol's memory, rather bluntly by reiterating that it was Mol's own choice and that she didn't have to go through with the procedure. For Mol, this experience demonstrates some of the problems with a logic of choice. A logic of choice precludes patients from worrying about the choices they make. Although Mol does not include extensive discussion of this incident, it seems that the prenatal testing situation calls for women to make rational decisions when it might not be possible to do so. Mol talks about a logic of choice, but we might also talk about a logic of risk which assumes that women will be able to make choices easily once they weigh medical and circumstantial risk factors. However, the situation obscures the fact that making the most logical or rational choice may still produce an undesired outcome. A woman who is at low risk for a Down syndrome pregnancy after screening may choose to forego diagnostic testing and still give birth to a baby with Down syndrome. A woman may feel it is important to know whether the fetus has Down syndrome, decide to get amniocentesis, only to miscarry a healthy baby. Thus, the prenatal testing situation may encourage women to view risk assessment as a reliable assessment of the pregnancy itself even though prenatal testing may have unpredictable outcomes.

Several other scholars note that the prenatal testing situation creates the illusion of objectivity. Jennings argues that current cultural knowledge about prenatal testing assumes that the technologies associated with testing are value-neutral. He disagrees with this claim suggesting, "Technology demands a response; it does not necessarily force any particular choice, but it does force choice in general" (134). Jennings argument is that prenatal testing technologies actually structure the prenatal testing situation because the

information that they give sets up particular situations requiring particular responses. The information they give is not neutral either since “all knowledge systems focus and exclude, and genetics is no exception” (136). While Jennings does not wish to limit prenatal testing or to suggest that genetic knowledge cannot be beneficial, he does argue that the information given by genetic tests is incomplete. He suggests that parents may find it difficult to imagine other aspects of the future person that the fetus will become when they are faced with test results that give them such a small, but specific picture. Thus, while prenatal testing might present itself as just another way to get more information about the fetus that cannot yet be seen, it actually provides information that orients parents in specific ways.

In addition, Rothman argues that medical professionals have underestimated the role that fear plays in decision-making after prenatal testing (7). All women, Rothman suggests, have fears about their capabilities as mothers, but prenatal testing asks women to make rational decisions in the midst of that anxious state. Not only that but prenatal testing itself causes some of those fears. As I mentioned at the beginning of this chapter, proponents of prenatal testing suggest that testing provides reassurance for pregnant women that their pregnancies are going well. However, as Rothman says, “Thus, amniocentesis is only able to allay those fears it first raises” (110). In other words, the testing situation creates anxieties before it (usually) allays them. Ironically, prenatal testing can only provide reassurance about a limited number of conditions. In that way, it may be providing false reassurances to some women.

A third cultural critique of prenatal testing suggests that the situation obscures public health motivations. For example, Press and Saxton each point that prenatal

screening has been routinized in order to achieve public health goals. In a discussion of these goals, Press writes, “A truly open approach to the centrality of abortion to prenatal screening is found almost exclusively in the cost-benefit analyses done on MSAFP [maternal serum test] and other prenatal screening. This literature contains up-front calculations of the minimum number of pregnancy terminations that can be done before screening ceases to be effective” (221). Of course neither individual practitioners or patients are expected to consider these numbers when they make their decisions; however, Press and others find it problematic that these motivations are obscured. Moreover, Press finds that the ultimate ends of these testing practices—the choice to terminate the pregnancy—is obscured as well. Press and Browner found that prenatal testing procedures were viewed as a standard part of prenatal care. Press argues, “For some women, the identity of meaning between standard prenatal care and prenatal testing was so complete that MSAFP was described in terms of helping to protect the fetus. The actual purpose of MSAFP screening—to find cases of untreatable birth defects in order to allow women and couples the opportunity to terminate a pregnancy—appeared to be obscured from view” (219). They also found that healthcare providers “were often quite open about the fact that the link between abortion and prenatal screening was intentionally avoided” (221). Rothman found a similar unwillingness to bring up potentially frightening subjects in her study of genetic counselors (37-39).

Thus, ultimately, these cultural critiques suggest that prenatal testing suggest that prenatal testing for Down syndrome can become a series of cascading events in which parents are constantly being pressured to make autonomous choices but in situations which they have not been adequately prepared for. Sometimes they are expected to make

rational decisions with incomplete information. Other times they are asked to make decisions when there are no good outcomes guaranteed. Pregnant women may begin this process without fully understanding where it will lead, and thus, feel ill-equipped when it ends up leading to a difficult decision. The experience of prenatal testing and decision-making responsibilities may be especially challenging when contrasted to other forms of prenatal care. Typical prenatal care involves regularized check-ups, blood tests, and ultrasounds. The healthcare provider is essentially treating the fetus as much or more than the mother. During informal preliminary research, I overheard one perinatologist telling a pregnant woman that as much as they (the healthcare team) were concerned about her, their real patient was the baby. Thus, the pregnant woman may have little to no autonomy within a traditional prenatal care setting and may be perceived as merely the vessel holding the real patient. In contrast, the prenatal testing situation requires the woman and her partner to take full control. This may be something that they are unprepared or, perhaps more accurately, not conditioned for. Rothman observed that many of the women she observed did not seem to understand why they were receiving genetic counseling (39). I have observed the same phenomenon in prenatal counseling sessions. It may be that going from traditional physician-patient encounters to one in which patients are asked to make all the choices is an unrealistic expectation.

Finally, it seems likely that healthcare providers working in prenatal testing situations are likely to be oriented in particular ways towards their patients. While genetic counselors and physicians no doubt have many insights about how difficult the prenatal diagnosis decision-making process can be for women and their partners, they most certainly lack information about how parents cope with disabled children. Thus, while

these healthcare providers may fully understand the range of parents' immediate reactions to diagnostic information, such information is not the full picture. Research shows that parents of children with disabilities often adapt quite well to parenting and in ways that they would not have expected prior to giving birth to the child (Landsman; Ferguson, Gartner, and Lipsky). Without intimate knowledge of the range of family coping mechanisms after birth, healthcare providers might consider the parents' immediate reactions to be the most important in the decision-making process.

Implications of Prenatal Testing Critiques

The above overview of prenatal testing critiques suggests some areas for future research. First, there are several ongoing debates about what changes should be made to prenatal testing practices and policy. First, there is a debate about whether policy changes are necessary or whether what is most needed is a greater public attention to these issues. Second, if interventions are to be made, critics debate when and where they should be made. Some suggest that mandating changes in prenatal testing practices will result in a change in public attitudes towards disability; others argue the opposite, that addressing public attitudes of disability will affect changes in prenatal testing practices. The major recommendation of the Hastings Center Project devoted to addressing issues of prenatal testing and disability rights was that parents need more information in order to make informed decisions and that healthcare providers need more information about disability. However, this recommendation is carefully phrased. The authors do not just suggest that audiences—both parents and providers—be given *more* information; they say, they want to “reform *how* prenatal genetic information is communicated” (Parens and Asch 38, my emphasis). This suggests that what is necessary is to better understand current practices

of how prenatal genetic information is communicated in actual practice and how parents understand and make decisions based on that information in order to suggest how such practices might change.

Studies that pay attention to specific language use are urgently necessary in order to fulfill this goal. To return to a discussion of the rhetorical situation of prenatal testing, there are numerous places where language choice becomes important. I will give three major examples from the prenatal testing situation where language choice is likely to play an important role and where discourse analysis is needed. First, unlike current diagnostic practices, screening for Down syndrome can take place during the first trimester of pregnancy. Between the eleventh and the thirteenth week, women may be offered an ultrasound and a maternal blood test. Both are considered to be noninvasive because they require no physical entry to the womb. During an ultrasound at this stage, one area the technician looks closely at is the back of the fetus' neck. This area is called the nuchal fold, and having a larger nuchal fold can indicate Down syndrome. However, it is possible to have a larger than average nuchal fold and still have typical chromosomes. Other markers, such as shorter than normal femur bones or echogenic bowels can also be indicative of Down syndrome, but with even less reliability. These other markers are called soft markers, terminology which indicates their unstable meaning. But what is the effect of calling these signs "soft markers"? Are parent audiences able to make distinctions between reliable and nonreliable indicators?

Second, although each test, in and of itself, is fairly unreliable, when the measurements are combined, labs can predict Down syndrome with up to 80-95% detection. This means that out of all pregnancies that are screened for Down syndrome,

between 80-95% of pregnancies actually carrying a fetus with Down syndrome will show an increased risk for Down syndrome. This means screening tests will not show increased risk for 5-20% of pregnancies carrying fetuses with Down syndrome. In addition, screening tests can give a false positive, meaning that they can indicate Down syndrome when, in fact, the fetus has typical chromosomes. Medical guidelines suggest that screening results be provided as a numerical risk figure so that women can determine for themselves what that figure means. For example, whereas results used to be given in terms of high or low risk, now a woman is likely to be told something like, “The fetus has a 1 in 275 chance of having Down syndrome.” This ratio can be compared to the mother’s age-related risk to determine whether the screens show she is at higher or lower risk than is typical for her age. For example, if the woman is 40, her age related risk is 1 in 100. Thus, after screening, she is at a lower risk. In contrast, if the woman is 20, her age related risk is 1 in 1400. Thus, after screening she is at a higher risk. Providing the screening ratio in the context of other information such as the woman’s age-related risk or the rates of miscarriage following amniocentesis may help a woman decide whether the risk is acceptable for her or not. A 1 in 275 risk may sound low to one woman but high to another depending on her circumstances. We do not know much about what causes women to have different reactions to risk ratios, but it certainly has something to do with how she interprets the risk and what it means to her. Furthermore, studies suggest that women often report feeling judged for the prenatal decisions they make, even though medical guidelines suggest that healthcare providers try to remain neutral (Skotko). It is unknown to what extent providers may provide additional advice or recommendations concerning the meaning of that information. Patients may ask for an interpretation

directly, or they may ask what the provider would do in a similar situation. Perhaps providers believe the language they are using is neutral while patients feel it is no.

Finally, much consumer information about prenatal care and prenatal testing refers to the fetus as a baby. In fact, this choice of terminology is consistent with the women on the pregnancy online forums that I will discuss in a later chapter. This word choice indicates an assumption that an audience concerned with prenatal care will also be planning to continue the pregnancy and give birth to a baby. Nevertheless, using the word baby draws attention to one problematic aspect of prenatal testing. Using the term “baby” conveys the idea that prenatal testing is consistent with prenatal care. In particular, screening is talked about as being noninvasive giving the impression that it is not harmful to the fetus, perhaps even careful of the fetus or good for the fetus, when, in reality, prenatal testing is not at all like other kinds of prenatal care. It is not meant to keep the baby healthy or to prevent bad things from happening. Quite the opposite. If the beneficiary of prenatal care is the baby, the beneficiary of prenatal testing is the mother or the parents. The information does no good to the baby—its effect is for the parents. Thus, referring to the fetus as a baby at this stage or using the euphemism “termination the pregnancy” rather than abortion, may in fact make the woman’s decision more difficult. If the woman is experiencing a wanted pregnancy that she decides to terminate or abort, she is losing her child. Unlike women who would choose to abort any pregnancy, the woman choosing to abort after a prenatal diagnosis probably already bonded with the child. It is possible that calling it a termination rather than an abortion is actually minimizing the trauma of their decision.

Those are just three examples which come to mind where language choice may have important effects for women making decisions in a prenatal testing context. I am interested in investigating how much of the critiques of prenatal testing have made it into public and medical professional view.

As I am concerned with the public representations of prenatal testing for Down syndrome and the impact of those representations on individuals, like Edbauer, ultimately, I am interested in the relationship between individuals and the publics they respond to and are also a part of. Individual choices about Down syndrome pregnancies have an impact on public perceptions and meanings of Down syndrome. By applying the concept of rhetorical ecology, we can consider the multiple spheres of influence outside the immediate situation occurring in the clinic. In the following chapters, I will rhetorically analyze several significant elements of the rhetorical ecology of prenatal testing including genetic counseling discourse and parent discourse.

CHAPTER FIVE

THE RHETORICAL POTENTIAL OF GENETIC COUNSELING AS A SITE OF RESISTANCE TO BIOMEDICALIZATION: A CASE STUDY OF GENETIC COUNSELING TEXTBOOKS

Medical historians, sociologists, and cultural theorists are increasingly concerned with medicine's seeming encroachment on daily life. They use the term "medicalization" to describe "the processes through which aspects of life previously outside the jurisdiction of medicine come to be construed as medical problems" (Clarke et al. 161). Since the 1970s, scholars have documented the ways in which social deviancies such as alcoholism and homosexuality and normal bodily experiences such as pregnancy and menopause were placed under expanding medical purview (Barker; Bell; Conrad and Schneider).

I conducted a small pilot study at the beginning of this research project and it serves as a good example of the extent to which society accepts medicalized definitions of disability. In spring 2011 with the help of colleagues, I surveyed 106 undergraduate students concerning attitudes toward and knowledge about two different kinds of genetic testing. Approximately 38% of those who responded to the question "How would you describe Down syndrome to a friend who is unfamiliar with it?" used the language of medical genetics, despite the fact that they were not specifically asked to do so. Respondents used terminology such as "DNA," "chromosome," "mutation," "gene," and "trisomy 21." Of these responses, several included technical information that was inaccurate. For example, one respondent described a person with Down syndrome as "someone who has a mutated gene." Not only does this description use technical medical

language (“mutated gene”), but that language is not correct with respect to Down syndrome, since Down syndrome is characterized by an extra 21st chromosome not a single, abnormal gene. In addition, nearly all of the respondents mentioned aspects of Down syndrome which could be considered “symptoms” of the disorder in more general, medical terms. For example, respondents used language such as “birth defect,” “shorter in stature,” “underdeveloped brain,” “mental retardation,” and “facial disfigurement.”

The survey was administered to students in a personal health class; thus, one interpretation of this result is that the respondents assumed the question called for a medical definition. However, the question specifically did not ask for a medical definition, although it did not preclude one either. The question was carefully worded to elicit social rather than medical descriptions of Down syndrome. For this reason, a second interpretation of the results might be that respondents felt more comfortable explaining a disability like Down syndrome in medical terms—even if such terms were incorrect. Such an interpretation would be in line with theories of medicalization, suggesting that it is culturally more acceptable to speak of disability in medicalized language that can be viewed as objective or even neutral rather than to discuss the social conditions surrounding, and defining, disability.

In the rest of this chapter, I introduce a theory of biomedicalization and argue that an analysis of genetic counseling discourse with respect to prenatal genetic testing for Down syndrome can further the development of this theory. Then, I present genetic counseling textbooks as a data set that presents an idealized version of professional discourse and thus best represents the potential of genetic counseling to disrupt biomedicalization. Finally, I analyze the textbooks and present conclusions about the

rhetorical function of genetic counseling technique and its potential to help clients make informed decisions about Down syndrome.

From Medicalization to Biomedicalization

Recent work by Clarke et al. argues that Western societies are seeing a shift from medicalization to biomedicalization. While medicalization processes emphasize control—control of disease and control of bodily experience—biomedicalization processes emphasize transformation. Moreover, Clarke et al. see this shift occurring in the midst of medicine’s increasing expansion into “technoscientific” and institutional realms. Biomedicalization is not just medicalization to a higher degree but is a more insidious form of influence, one that is “multisited” and “multidirectional” (162). Beyond recasting more and more conditions under the medical umbrella, biomedicalization goes so far as to regulate the state of being healthy, insisting that health must be constantly monitored and regulated. This process requires far more regulation than medicine can provide, and, therefore, individuals are obligated to monitor themselves.

Biomedicalization also implies a greater association with technology, either as a means of health surveillance, bodily transformation, or knowledge distribution.

Although I know of no disability studies scholarship that specifically engages with the concept of biomedicalization, there is potential to do so. Clarke et al.’s work invites at least two different arguments about the effects of biomedicalization on perceptions of disability. For example, they argue, “In the biomedicalization era, the focus is no longer on illness, disability, and disease as matters of fate, but on health as a matter ongoing moral self-transformation” (172). In other words, biomedicalization encourages us to view disability as negotiable and transformable rather than as fixed and

stable. Moreover, there is a suggestion that we ought not to accept disability, but instead to avail ourselves of transformative technologies that allow us to eliminate disability either through transformation or prevention as a moral self-imperative. In a later article comparing recent scholarship on medicalization and biomedicalization, Clarke and Shim borrow from Rose to characterize biomedicalization in terms of optimization—a process which they define as “the increasing legitimacy of securing ‘the best possible futures’” (178). They further argue that the increased attention to reproductive technologies is an indication of biomedicalization’s capabilities to transform rather than control life. With respect to reproductive technologies such as in vitro fertilization or prenatal genetic testing, biomedicalization increasingly obligates us to choose the best possible progeny or, more accurately, to select against defective progeny.

Resistance to Biomedicalization

Clarke’s arguments echo the critiques of prenatal testing and screening from disability studies scholarship and advocacy groups presented in the last chapter. Like those discourses, a theory of biomedicalization offers a way of perceiving prenatal genetic testing as a technoscientific imperative to regulate pregnancy and progeny. And like those discourses, biomedicalization theories have been criticized for suggesting that medicine is all-encompassing and downplaying discourses and practices that resist medical purview (Clarke et al. 184). Despite this criticism, in later work, Clarke insists that the theory does allow for contradictions, transgressions, disruptions and alternative discourses even within medicine itself (184). Clarke et al. point to new “instabilities” that create “new forms of agency” and “new sites of negotiation” (185), pointing to several practices that may signal resistance, including patients sharing information with one

another on online message boards, patient-led advocacy groups demanding representation on professional committees, and the dissemination of lay or alternative health publications.

Genetic Counseling as Resistance to Biomedicalization

In 2007, the American Congress of Obstetricians and Gynecologists (ACOG) issued new recommendations for prenatal screening and testing procedures. The new recommendations stated that “all pregnant women, regardless of their age, should be offered screening for Down syndrome.” The new recommendations account for the relatively new availability of non-invasive screening procedures, such as maternal blood tests and more accurate ultrasound technology, which allow physicians to calculate whether the fetus is at an increased risk for Down syndrome.

It is important to note that screening practices cannot diagnosis Down syndrome; they can only provide an assessment of whether the pregnancy is at greater or lesser risk of the condition. Prior to 2007, only women over the age of thirty-five were routinely offered genetic counseling and invasive diagnostic testing in the form of amniocentesis or chorionic villus sampling (CVS). Age thirty-five represented the age when the risk of miscarriage caused by invasive testing was equal to the age-related risk of having a child with Down syndrome.

The new ACOG guidelines can be read as a process of biomedicalization since they encourage the use of technology to increase knowledge about health. By offering screening practices to a larger population of women, more women will be implicated in a cascading series of medical exigencies that call for decisions concerning “the best possible futures” (Clarke and Shim 178). In other words, more women will be faced with

the decision to terminate or continue a pregnancy based on a diagnosis of Down syndrome, a situation that we have already established is problematic even for women who appreciate being given the choice.

Reading the new guidelines carefully, it is evident that medical professionals are careful to define their role in the prenatal screening and testing context. Screening is to be “offered” not “required” of patients. This wording reflects an awareness that “at the base of any application of genetic technologies is a hierarchical judgment: some genetic configurations are better than others” (*Meanings* 128). For example, the existence of prenatal diagnosis for Down syndrome suggests that trisomy 21 is an abnormal or deviant genetic configuration; otherwise, why screen for it at all? As numerous scholars including Condit, Resta, and Snyder and Mitchell have shown, genetic science and the eugenics movement share a common historical origin. Condit, in particular, has demonstrated that medical genetics professionals are acutely aware of this history and have explicitly resisted association with eugenic thinking since at least the 1940s and the aftermath of World War II (*Meanings* 63). Condit’s work also demonstrates that medical genetics has made several rhetorical moves to distance itself from eugenics. First, she argues that genetics professionals present genetic selection (that is the process of prenatal diagnosis and the option of abortion) as a temporary measure. She notes, “Genetics professionals often argue that the emphasis on prenatal selection is undesirable and that it is only a short term measure. They suggest that in the long term, gene therapies (or treatments derived from genetic knowledge) will replace genetic selection” (*Women’s* 132). Such arguments reflect an awareness on the part of genetics professionals of the burden placed on women by requiring them to make such choices. If the routinization of prenatal

screening and testing is any indication, this rhetorical move has been very effective despite the fact that very few gene therapies have been introduced and “it is not at all clear that gene therapy will ever be economically feasible, given the relatively low financial costs of genetic selection (by abortion)” (*Women's* 132-33).

A second move that Condit documents was the establishment of the genetic counseling profession and its rhetorical presentation. Genetic counselors are experts in medical genetics and counseling. In a prenatal setting, they report prenatal screening and testing results, explain diagnostic testing options such as amniocentesis, and help the patients interpret risks and make decisions about reproduction. Considering the history of genetics, the establishment of genetic counseling in the 1970s required “careful negotiation of several ideological tensions” (*Meanings* 124). Condit suggests that genetic counseling was presented as a profession that could translate complex, technical information on genetics thereby helping parents produce healthy children and eliminate the suffering caused from severe genetic diseases (*Women's* 127-133). She notes that the focus on creating healthy children helped establish a positive image of genetic counselors as merely helping parents “[complete] nature’s work” (*Women's* 127). In addition, when genetic selection was presented, it was often with regard to the most severe genetic diseases, such as Tay-Sachs, rather than more uncertain and, therefore, ethically complicated conditions such as Down syndrome. Such portrayals probably forestalled some of the objections to genetic counseling practices.

Of course the most appealing element of the new genetic counseling profession was that, in theory, genetic counselors were to inform the parents but also to allow the parents to make final, autonomous decisions. Indeed, as we will see, current genetic

counseling literature still asserts that the genetic counselor's primary role is to help the patient assert her agency and make informed decisions for herself. Thus, if any element of the prenatal testing situation represents a disruption of biomedicalization, it would be the practice of genetic counseling. However, because part of the definition of biomedicalization is that it tends to absorb alternative discourses, co-opting them to its own purposes, we cannot presume genetic counseling achieves these goals. A robust discursive analysis of genetic counseling discourse and practices is required to determine whether genetic counseling is an actual site of disruption within medicine or whether it is, in fact, serving the purposes of biomedicalization.

Situating Genetic Counseling

The American College of Medical Genetics suggests that “diagnostic testing [for chromosomal disorders such as Down syndrome] should be made available, if requested, after appropriate counseling including risks and benefits” (Driscoll and Gross 819). The field of genetic counseling is arguably best equipped to conduct this counseling even though not all pregnant women have access to genetic counselors. However, as genetic counselor training programs proliferate, increasing numbers of women who decide to get prenatal testing will be referred to a genetic counselor. If the parents learn of a diagnosis of Down syndrome at birth, they are also likely to be referred to a genetic counselor who can help explain the medical diagnosis and help the parents articulate their reactions. Genetic counseling is a medical service that is offered unevenly, both in the sense that it is not available to everyone and in the sense that it is practiced differently at different sites of service. In this way, it fulfills at least one feature of biomedicalization described by Clarke et al. They argue, “Even as technoscientific interventions extend their reach

into ever more spaces, many people are completely bypassed, others impacted unevenly, and while some protest excessive biomedical intervention into their lives, others lack basic care” (170).

There are twenty-nine genetic counseling graduate (master’s level) programs in the United States, and they are highly competitive (National Society of Genetic Counselors). The first program at Sarah Lawrence College was started in 1969, making the profession just over 40 years old (McCarthy Veach, LeRoy and Bartels 25). The profession has a symbiotic relationship with genetic technologies since the more genetic tests become available, the greater the need for genetic counselors. Thus, the first generation of genetic counselors practiced mostly in reproductive settings since some counseling about hereditary disease could take place without genetic testing. When amniocentesis was discovered to be useful for diagnosing Down syndrome and other chromosomal anomalies in the prenatal period, the role of genetic counseling expanded. Now, forty years into the development of the profession, genetic counselors have extended their territory. Some counselors now specialize in cancer genetics, and as new conditions such as obesity and cardiovascular problems are found to have a genetic basis, genetic counselors will continue to develop new roles corresponding to these areas of expertise.

Despite the growth of genetic knowledge and testing, there are several factors which place genetic counselors in a precarious position as a profession. First, there are a growing number of genetics labs such as 23andMe and Map My Gene that are marketing direct-to-consumer testing. Consumers can order testing kits and make decisions about their use with or without speaking to a genetic counselor. Results are sent directly to the

consumer and thus the entire profession can be bypassed. The practice of direct-to-consumer testing is again reflective of biomedicalization which is said to emphasize “*corporatized and privatized*” care (Clarke et al. 167). In addition, genetic counselors work in a very hierarchical environment. Guidelines suggest that genetic counselors can work autonomously and do not need to be supervised by a physician. However, in many cases they do work on healthcare teams where physicians are traditionally placed in the leadership position. During informal, preliminary research, one genetic counselor reported to me that physicians can be reluctant to trust the expertise of genetic counselors, treating genetic counselors as “glorified secretaries for the MD geneticists.” It seems that since genetic counselors have a role that moves between medical genetics and communication and counseling, they are in a position to be to be conferred less respect than other health professionals. Nevertheless, since genetic counselors are specifically trained to communicate and counsel about genetic information, they are arguably better trained than physicians to talk to new parents about Down syndrome. In other words, genetic counseling discourse, more than obstetrics or perhaps even pediatric discourse, may represent the most progressive medical discourse concerning genetic disability.

Genetic Counseling Textbooks

This chapter seeks to understand genetic counseling’s potential for disrupting a pervasive process of biomedicalization, a process that disability scholars and advocates find harmful. Textbooks present an idealized version of genetic counseling rhetoric. Actual counseling practice is sure to be a messy and complicated endeavor, but in textbooks, the essential values of genetic counseling are made clear. Thus, an analysis of textbooks will help determine, from a rhetorical perspective, what the affordances and

constraints of a genetic counseling rhetoric are.

In order to look more closely at the rhetoric of genetic counseling, this chapter analyzes four of the most widely used genetic counseling textbooks: *A Guide to Genetic Counseling*, *Facilitating the Genetic Counseling Process*, *Psychosocial Genetic Counseling*, and *Genetic Counseling Practice: Advanced Concepts and Skills*. I compiled this list by sending a questionnaire to the director of every genetic counseling graduate program in the United States. Fourteen programs responded—a response rate of 48%. The requests I sent asked for a list of textbooks and additional resources that were required for genetic counseling students. Most schools assign multiple types of reading, including textbooks, online resources such as GeneTests.com, primary scholarship from medical genetics and genetic counseling journals, and more popular literature such as films, memoirs, and television shows that portray genetic conditions. Nevertheless, most directors were only able to send a list of textbooks, as this type of list is readily available to program coordinators while other materials would require soliciting information from individual instructors.

Many respondents expressed concern that a list of textbooks would not be an adequate measure of all the information that genetic counselors are exposed to. This is certainly a limitation of this chapter's analysis. It is beyond the scope of my study to conduct a thorough analysis of how genetic counseling students are trained and all of the discourse they are exposed to. That research question would probably have to be answered through an ethnographic study that observed graduate classes, mentoring relationships, and peer interactions in addition to analyzing course materials. Considering the goals of this chapter, however, textbooks provide a reasonable sample of discourse.

Towards this end, I limited my analysis to the four most popular genetic counseling textbooks as indicated by the responses to my email solicitation. I focus on the aspects of genetic counseling that deal with communication between practitioners and patients (or clients as they are referred to in some of the literature). Thus, I eliminated textbooks that were focused on medical genetics as opposed to genetic counseling. Although genetic counselors spend a great deal of time learning about the mechanical processes of genetics and although this knowledge is essential to their counseling practice, it is not my focus here. In addition, I eliminated a popular book that was devoted to counseling for cancer genetics since it not pertain to the prenatal testing situation I am interested in.

The four books I analyzed are each focused on general topics in genetic counseling. The first, *Facilitating the Genetic Counseling Process: A Practice Manual*, was published in 2003 and written by McCarthy Veach, LeRoy, and Bartels. One of the authors directs a graduate program in genetic counseling, another is in a psychology department, and the third is in a Center for Bioethics. *Facilitating the Genetic Counseling Process* introduces students to the skills they will need to develop as counselors. It begins with a history of genetic counseling, then moves on to devote six chapters to basic genetic counseling skills including attending, providing primary empathy, asking questions, structuring a session, collaborating with clients, and providing advanced empathy. These chapters appear in order of importance with attending being, in the authors' view, the most important and most basic skill. The remaining five chapters address common challenges in genetic counseling practice: understanding and dealing with client resistance, knowing when and how to give advice or self-disclose, behaving

ethically, recognizing counselor burnout, and navigating internet resources. Two additional appendices list the National Society of Genetic Counselors (NSGC) code of ethics and the American Board of Genetic Counselors (ABGC) practice-based competencies. This text is very clearly oriented towards use in the classroom since at the end of every chapter the authors provide several structured activities including class discussion, group work, written exercises, and role-playing scenarios. Each chapter also includes an annotated bibliography of primary sources. These bibliographies serve to model for the students that best practices are based on empirical research that is up-to-date.

The second text analyzed is *A Guide to Genetic Counseling*, edited by Uhlmann, Schuette, and Yashar. I analyzed the second edition which was published in 2009. In contrast to the first, this text attempts to situate the practice of genetic counseling within a larger field of genetics in general. Since the topics for chapters vary so widely, each author depends on a vast array of sources from multiple fields. This text demonstrates how interdisciplinary the field of genetic counseling is and how much it benefits from research conducted in other fields. The first seven chapters are the most specific to the practice of genetic counseling. The topics include a history and overview of genetic counseling practice, instruction on eliciting a family genetic history, interview techniques, case preparation and management, psychosocial counseling, providing genetic information, and understanding risk communication and decision-making. The next three chapters provide information that is relevant to an entire genetics team and covers medical genetics physical examinations, the properties of genetic tests, and medical documentation. The final chapters in the book provide information on

professional issues such as multicultural counseling, ethics, student supervision, research, and nontraditional roles for genetic counselors. The book ends with three detailed case studies for students to work through.

The final two textbooks I studied were more specific and are likely to be used in advanced courses. The first, *Psychosocial Genetic Counseling*, by Jon Weil, was published in 2000. As the title suggests it focuses specifically on counseling the client rather than providing genetic information to the client. In addition, the text emphasizes that clients do not necessarily respond rationally to genetic information, but that they have individual psychological needs and exist in a social framework. The first two chapters introduce these two aspects and are titled, “The Counselee as Individual” and “The Counselee in a Social Context” respectively. The next four chapters focus on specific skills of genetic counseling: using psychosocial counseling techniques, structuring the session, using nondirective counseling to promote autonomous decision-making, and providing advice for the two major genetic counseling settings (prenatal and cancer) as well as to two specific populations, children and adolescents. The last two chapters give an overview of cultural and disability critiques of genetic services and suggest some remedies to these critiques.

Finally, the last textbook analyzed was *Genetic Counseling Practice: Advanced Concepts and Skills*. This text was compiled and edited by the same three authors as the first text and was published in 2010. This book is the only one to be aimed not just at students but at practitioners as well. As the book title indicates, this text is meant to cover advanced topics, topics for which there has been debate but not necessarily a resolution. The editors state that this “book grew out of our ongoing discussions of various

challenges in practice. We found ourselves repeatedly coming to the conclusion that there is a need for more literature that speaks ‘in depth’ about these issues from the perspectives of genetic counselor practitioners and/or researchers who study genetic counseling” (LeRoy, McCarthy Veach, and Bartels 2). This book discusses some of the challenges which practitioners and researchers have documented in the brief time genetic counseling has been an established profession. In some senses, the original program directors were taking a stab in the dark at the types of skills their students would need to learn. In the introduction, the editors define genetic counseling and provide a description of the model of counseling they hope to promote. The next seven chapters discuss complicated issues in genetic counseling practice: autonomy, decision-making, risk communication, grieving, patient anger, patient resistance, and countertransference. The next four chapters discuss specific counseling populations: clients from non-Western cultures, families, children and adolescents, and women with intellectual disabilities. The final three chapters are devoted to professional concerns such as maintaining a healthy psyche, practicing reflectively, and developing leadership skills.

Defining the Practice of Genetic Counseling

All of the textbooks present a picture of genetic counselors as people who are both experts in medical genetic information related to the mechanical modes of inheritance, disease prevention, and testing options and procedures, and expert counselors who help patients make choices about testing and come to terms with testing results. In 2006, the NSGC released a revised definition of genetic counseling based on 20 previous definitions they found in the literature (Uhlmann , Schuette, and Yashar 7). The definition states:

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following:

1. Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
2. Education about inheritance, testing, management, prevention, resources and research.
3. Counseling to promote informed choices and adaptation to the risk or condition. (7)

The two textbooks with initial publication dates after 2006 cite this definition, while a third textbook provides an earlier NSGC definition from 2001. The fourth textbook focuses on the psychological aspects of counseling and provides only a brief definition of the genetic counselor's role: “Genetic counselors serve as gatekeepers between the information and technology of science, on the one hand, and the lives of those individuals for whom the science is applied, on the other” (Weil vii).

This picture of genetic counselors as facilitators of informed choice—providing technical information but encouraging patient autonomy—is complicated, nevertheless, by genetic counseling’s historical emergence as a profession. The genetic counseling profession emerged in response to a variety of social and medical situations. Its relationship, in particular, to the eugenics movement has been an uneasy one and one that has shaped the profession's values and methods. Resta argues that while genetic counselors would like to claim that the goals of genetic counseling (to emphasize patient autonomy and provide unbiased information) are a reaction against the eugenic

movement, in actuality, history does not bear this interpretation out. Rather, “eugenics and nondirectiveness have long coexisted without ethical contradiction in the minds of the physicians who shaped the philosophy and goals of clinical genetics” (257). While two of the textbooks acknowledge the profession’s association with the eugenics movement, they tend to gloss over Resta’s warnings by presenting a smooth and complete transition between “traditional, paternalistic approach[es]” and approaches that encourage “patient autonomy in decision-making” (Uhlmann, Schuette, and Yashar 4).

Although the historical development of genetic counseling from an unethical practice to a progressive discipline is not questioned, the textbooks do reflect an uneasiness with genetic counseling’s place in medicine. For example, Djurdjinovic states:

In my earliest days as a genetic counselor I struggled to understand what genetic counseling was all about. What did I have to offer that other professionals could not? The cognitive challenge of appreciating the medical and genetic variables in a case was very exciting, but these technical elements took a different shape when I sat with a patient. It was when I recognized that my empathetic attunement with patients and families brought the science to life that I really understood my genetic counseling experience. (133)

In addition to this narrative about the questioning of genetic counseling's purpose, there is a sort of defensiveness present, as indicated by this statement:

Years ago I recall a discussion about genetic counseling. We were planning the Ph.D. degree for genetic counselors at the University of Pittsburgh and one of our advisory members commented that it was a shame that genetic counselors did not have an area of expertise. After I recovered my composure (read: refrained from

attacking the person), I began to think about our skills as counselors and came to the conclusion that the profession makes us bereavement specialists. (Gettig 96)

These excerpts emphasize that between genetic counseling's two primary functions—information giving and counseling—the latter is the one that distinguishes the profession. However, precisely because genetic counselors are unique to the rest of the genetics team, they are also vulnerable in a setting that is traditionally hierarchical. This discourse reflects a felt-sense that genetic counselors are both inside and outside of traditional medicine.

The tension between insider and outsider status is reflected in the terminology genetic counselors use to refer to genetic counseling clients. The four textbooks use different terms to refer to the genetic counseling clientele; two of the books even vary within the text. In *Facilitating the Genetic Counseling Process*, the authors consistently use the term “client,” a term that they indicate comes from Carl Rogers' client-centered counseling model. In this model the client is viewed as a capable individual who can be trusted to make decisions that are in her best interests. The word client implies someone who is seeking services purposefully but will remain in charge of the process. In *Psychosocial Genetic Counseling*, Weil consistently uses the term “counselee,” a more specific term than client which is used in many settings outside of healthcare. Weil's text also emphasizes that genetic counselors are there to facilitate the counselee's decision-making, not direct it or control it. In *Advanced Concepts and Skills*, still another term is used consistently—“patient.” In this book, also the most recently published, the terminology used is more consistent with a traditional medical setting. It is possible, since this is the most recently published text, that this change represents a shift in the field

towards a more medical orientation. There are also many clinics where genetic counselors work as part of a medical team, and “patient” might be the preferred term for the sake of consistency.

These textbooks indicate that genetic counselors are still struggling to define their profession, especially with respect to its relationships with other medical professions. In part, this is probably due to the profession’s rapid and ongoing expansion—hence the attention to professional development, leadership, and research. As the practices of genetic counseling continue to develop, genetic counselors may seek to align themselves further with traditional medicine by emphasizing their expertise with genetic information; conversely, they may emphasize their differences by focusing on practices that encourage facilitation and counseling.

Analysis: Values in Genetic Counseling

Genetic counseling values and professional goals are very similar to and, in some cases, modeled after psychotherapeutic goals and values. Three of the textbooks explicitly outline some of these professional goals within the first chapters. In particular, *A Guide to Genetic Counseling* lists seven major values including: (1) voluntary utilization of services, (2) equal access to services, (3) client education, (4) complete disclosure of information, (5) nondirective counseling, (6) attention to psychosocial dimensions in counseling, and (7) confidentiality (Walker 8-11). Several of these values are self-explanatory and consistent with other medical professional values. For example, most healthcare professionals respect the rights of patients to refuse treatment. Truth-telling and confidentiality are also valued in other areas of healthcare, although confidentiality may be particularly important in a genetics setting due to fears regarding

genetic discrimination. However, three of the values listed—client education, nondirective counseling, and attention to psychosocial aspects of counseling—are, if not completely unique to the genetic counseling profession, particularly meaningful in this context. These values will be discussed in greater detail below.

Client Education and the Inherent Value of Information

Advanced Concepts and Skills begins its discussion of the five tenets of genetic counseling by stating that “genetic information is key” (LeRoy, McCarthy Veach, and Bartels 3). The authors go on to suggest that “engaging in discussion with patients about this information is a particularly unique aspect of genetic counseling” (3). Similarly, in *Facilitating the Genetic Counseling Process*, the authors write, “The information that you present is an integral part of collaborating with clients, helping them understand and sort through factors relevant to their decision” (McCarthy Veach , LeRoy, and Bartels 122). Genetic counseling relies on a foundation of genetic knowledge and, more importantly, presumes that full comprehension of this information is necessary for patients to make good health decisions. In other words, in this context of genetic medicine, counselors believe technical information regarding genetic susceptibility, mechanisms of genetic inheritance, options for genetic testing, and prevention and treatment options is fundamental to decision-making. While other types of knowledge are not excluded, they are also not essential. McCarthy Veach, LeRoy, and Bartel’s statement that not all factors of the situation are necessarily relevant to a particular patient’s decision hints at the challenge of genetic information-giving. Genetic counselors must make decisions about how much information to give based on what information they determine is relevant.

Psychosocial Genetic Counseling addresses this tension by explaining that both

the client and the counselor have agendas for the genetic counseling session. Rather than assume that the counselor's agenda is more important, it is in fact the counselor's job to "identify, insofar as possible, the counselee's agenda with respect to the nature and intensity of factual and psychosocial issues that he or she wishes to have addressed. [...]

This inferred agenda must then be integrated, insofar as possible, with the genetic counselor's agenda" (Weil 102). In other words, genetic counseling places the client's concerns at the same level as the healthcare professional's.

One popular narrative that exists in these textbooks is the danger of the genetic counselor dominating the session with too much technical information that is simply not relevant to the client at the time. For example, *Facilitating the Genetic Counseling Process* states, "Beginning counselors tend to emphasize content and overlook affect. In addition, Western cultures tend to stress intellect, often at the expense of feelings" (61). These frequent warnings correspond with research in the field of genetic counseling that suggests that information-giving often dominates counseling sessions (Barlow-Stewart; Butow and Lobb; and Meiser, Irle, and Lobb). Rhetorically, there may be mixed messages concerning the value of genetic information. For example, later in the same textbook, the authors write, "You need to respect the client's wishes to end early. However, remember that there is some information that you must present, such as risk. One option is to send a follow-up letter detailing the information that you feel requires more explanation" (106). In other words, if the client resists being given information, the counselor must still find a way to give it. Likewise, in *A Guide to Genetic Counseling*, the authors conclude a section on the dangers of overwhelming the client with too much information by stating, "Despite these pressures, however, it will always be critical for

the counselor to disclose any information *relevant to decision-making* in ways that the client can interpret and act on” (Uhlmann , Schuette, and Yashar 10). On the one hand, genetic knowledge is presented as being foundational to the practice of genetic counseling and essential to the client. Genetic information is the key that unlocks a good decision-making process for patients. On the other hand, the textbooks clearly state that information-giving is not meant to be the major component of genetic counseling practice. A counselor that is managing her time well during a session should spend less time giving information and more time counseling the patient. It is no wonder that genetic counselors have difficulty achieving this goal in practice since it must be hard to reconcile understanding genetic information to be foundational while also limiting the time spent espousing it.

Although the textbooks acknowledge that genetic counselors must select and present relevant information, they simultaneously imply that information-giving is a neutral enterprise. For example, in *Facilitating the Genetic Counseling Process*, the authors state, “Information giving differs from advice, in that advice is an attempt to suggest what your client should do. Information giving, when done effectively, provides clients with knowledge that can help them choose their own course of action” (McCarthy Veach , LeRoy, and Bartels 123). A few sentences later they write, “A second way to provide information is to determine what additional facts or details may be pertinent to a given client's situation and to present them” (123). The purpose of advice-giving is to intentionally influence action; however, information-giving can be influential as well—otherwise why provide it? In addition, the selection of information is a rhetorical act. At no point in the text is there acknowledgement that choosing certain information over

other information can structure the conversation and guide the client in certain directions. There is also no discussion of how the counselor should go about judging what information is relevant to the patient's specific situation

Furthermore, information is often presented as being inherently beneficial. *A Guide to Genetic Counseling* unequivocally states, "It is often said that knowledge is power. For individuals affected by or at risk for a genetic condition, having adequate knowledge about a specific diagnosis, including its etiology and management implications, gives one the power to respond to one's own life situation" (Smith and Pollin 177). This statement presents an uncomplicated view that knowledge is good and avoids the competing view that knowledge may actually cause paralysis in decision-making or make people unhappy.

Although genetic information is usually presented as being possessed by the genetic counselors and bestowed upon the clients, the textbooks also refer to the scientific literacy of patients and the availability of information on the Internet. For example, *A Guide to Genetic Counseling* states, "Information availability is an opportunity in that it has the potential to create informed consumers, but also a challenge in that it has the potential to spread misinformation" (Smith and Pollin 181). It continues by suggesting, "Counselors need to expand their role from empowerment via the *provision* of information to empowerment via the *navigation* of information" (182). On the one hand, this statement can be read as suggesting a more progressive, democratic view of information-getting. On the other hand, the statement still ensures the expertise of the genetic counselor as the only one who can successfully navigate the information available. The words *provision* and *navigation* are interesting here since in other excerpts

the counselors are providing the information and the patients are interpreting (with the help of the counselors) and making decisions with the information. The phrasing of this statement seems to give more interpretive power to the counselor who will provide guidance as the client moves through the information.

Nondirective Counseling and Psychosocial Counseling

Perhaps no other genetic counseling goal has been debated in the genetic counseling scholarship as much as nondirective counseling. *A Guide to Genetic Counseling* defines nondirective counseling as “involving procedures promoting the autonomy and self-directedness of the client. Nondirectiveness is a way of interacting and working with clients that aims to raise their self-esteem and leaves them with greater control over their lives and decisions. Nondirectiveness is an *active* strategy requiring quality counseling skills” (Uhlmann, Schuette, and Yasher 236). Put simply, nondirective counseling is a method of counseling meant to prevent undue coercion on patient decision-making.

Nondirective counseling has been a central tenet of genetic counseling since the profession’s origins (*Meanings* 135). In the early 1900s, the eugenics movement which included many prominent scientists argued that undesirable traits such as low intelligence and criminal tendencies were hereditary. Eugenic arguments led to discrimination against immigrants, poor people, and those with intellectual disabilities. At the extreme, many in these populations were sterilized and forced to live in government run institutions (Trent). Not until WWII and the awareness of the Nazi concentration camps did the ramifications of eugenic practice become clear Western societies. After such atrocities, it was clear that any new medical services in genetics that involved implications for reproduction would

have to give individuals the right to control their own care. In this way, genetic counseling tried to explicitly distance itself from eugenic attitudes, banking on the fact that people would be reluctant to use genetic testing or counseling if it retained overtly eugenic practices. Training in nondirective counseling skills was meant to ensure that new professionals in genetic counseling would value patient autonomy and resist the coercive practices that the eugenics movement embodied.

The textbooks are generally insistent on the differences between eugenic practice and modern genetic counseling. For example, *Facilitating the Genetic Counseling Process* argues, “This era of genetics [the era after WWII and the beginning of the genetic counseling profession] marks a significant turn in that the scientific community took over the ownership of the practice of genetic counseling and adopted the belief that individuals should make decisions for themselves about their genetic risk” (McCarthy Veach, LeRoy, and Bartels 24). This statement makes a strong rhetorical move when it insists that this new era represented the first time that the scientific community became involved with genetic counseling. The statement implies that the eugenics movement was not a part of science, when it was actually entrenched in mainstream science in the U.S., as well as in Europe. For the authors of this text, the flaws of the eugenics movement render it a non-science. Of course, this can only be done in hindsight, simplifying the profession’s relationship and connection to eugenics by denying its history and setting up an untenable binary: eugenics was not science; genetics is science.

Further, nondirective counseling is presented as the safeguard to slipping back into coercive genetics practice. Although eugenics and genetics are both concerned with heredity, eugenics, this text claims, was not a legitimate way of approaching the subject

while genetics—and by extension, genetic counseling—is. Nondirective counseling techniques ensure that “patient autonomy is valued over any other factor” (McCarthy Veach, LeRoy, and Bartels 24). The text goes on to refer to some of the founding fathers of genetic counseling, Dr. Sheldon Reed and Dr. Seymour Kessler, who argue that the rise of genetic counseling as a facet of scientific genetic study represented a paradigm shift from a “preventative medicine model” to a “psychosocial medicine approach that emphasized patient self-determination” (25). Nondirective counseling, then, is the means by which patient autonomy is to be achieved.

The extent to which patient autonomy is a distinguishing factor of genetic counseling is questionable, however. The section above has already shown how information-giving can dominate counseling sessions and how the selection of information is not a neutral enterprise—both of which affect patient autonomy. The same is true for nondirective counseling techniques. Although the textbooks set up this practice as the gold standard or ideal for genetic counselors, their treatment of the subject gets more complicated, reflecting the tensions within genetic counseling scholarship, once past the introductory chapters.

The textbooks present nondirective counseling in practice as subject to some of the same pitfalls as information-giving techniques. For example, *Psychosocial Genetic Counseling* states the following:

Consider a couple whose fetus has been diagnosed with trisomy 21 and who are torn between not wanting to raise a child with Down syndrome and ethical reservations about abortion. Nondirective counseling would include information about the “positive” and “negative” aspects of Down syndrome, an exploration of

the meaning for the counselees of both courses of action, and implicit or explicit support for either decision. By contrast, consider a couple for whom abortion is firmly precluded for religious and cultural reasons. Nondirective counseling for them would primarily involve a discussion of practical and emotional preparation for the birth of their child, with implicit or explicit support for their unequivocal decision to continue the pregnancy” (Qtd. in Weil 123)

In this example, nondirective counseling becomes quite complicated because it presumably involves some directive statements. In this scenario, for example, the counselor may need to offer explicit support of the counselee’s decision. The counselor may also need to be directive when giving information about the positive and negative aspects of Down syndrome, perhaps by correcting the inaccurate knowledge of the parents. This example also demonstrates that counselors will need to evaluate and select counseling content on the basis of the perceived needs of clients. Attentiveness to the specific context of the client is referred to as psychosocial counseling. Thus, the counselor will need to solicit information about the client’s social situation—her support system, financial situation, and moral values—in order to determine the direction the counseling session should take.

Biomedicalization and Genetic Counseling Goals

Reading the themes of client education and nondirective counseling against the theory of biomedicalization leads to certain additional considerations. In the practice of genetic counseling, the information being given to the client is usually about risk. In the prenatal setting, the genetic counselor presents information concerning the risk of hereditary disease or the risk of invasive testing to a fetus. If patients agree to diagnostic

testing or parents are referred after the birth of a child with a genetic condition, the genetic counselor can also give diagnostic information. The creation and assessment of risk is an important aspect of biomedicalization. In biomedicalization, “health becomes an individual goal, a social and moral responsibility, and a site for routine biomedical intervention” (Clarke et al. 171). A sick person has no need for information about risk; he is already experiencing illness. However, a healthy person who is interested in staying healthy can use information about risk to modify behavior and prevent illness. Prenatal genetic counseling is a profession that distributes risk information to generally healthy, pregnant women.

However, the goal of technoscience and the end result of biomedicalization is meant to be transformation of the self. For example, a woman who discovers she is at an increased risk for breast cancer can choose to get a prophylactic mastectomy, thus minimizing her risk and ensuring her continued health. After the mastectomy, she can choose to get breast implants via plastic surgery, transforming her body once again. However, prenatal genetic counseling, especially concerning Down syndrome, complicates the idea of transformation. A woman who learns that her fetus is at risk for Down syndrome does not have any way of transforming that risk. The fetus either has Down syndrome or does not have it; the risk information indicates whether it is more or less likely. In contrast, the woman with a risk of breast cancer is healthy but could develop cancer. She wants to maintain her health. There is no maintenance for the fetus; the pregnant woman can only decide whether or not to undergo more testing.

Still, prenatal risk information does offer a type of transformation for the mother, if not for the fetus. Pregnant women can choose to undergo diagnostic testing, and, if

diagnostic tests indicate Down syndrome, they can choose to terminate the pregnancy or continue. In either case, the women are transformed by the information. A woman choosing to end the pregnancy is transformed because she no longer designates herself as a mother. In contrast, a woman choosing to continue her pregnancy is also transformed; she is not just a mother, she is the mother of a disabled child (Landsman; Rothman). Genetic counselors are heavily invested in giving women this choice because they value autonomy, but they are also heavily invested in the value of genetic information. Their expertise is in genetic information and in communicating genetic information, and as they become enculturated into their discipline they learn to value genetic information as a vital form of knowledge about the self.

Analysis: Down Syndrome in Genetic Counseling Textbooks

The genetic counseling profession presents itself as a profession that is capable of advocating for people with disabilities. The National Society of Genetic Counselors, the professional organization of the field, has published a position statement on disability on its website. In its entirety, it states:

The National Society of Genetic Counselors appreciates diversity and values all individuals. It is the goal of the genetic counseling profession to advocate for all individuals and families according to their unique physical, medical, cultural, educational, and psychosocial needs. The NSGC believes that no person should be discriminated against because he or she has a disability. (“Position Statements”)

The website notes that “position statements reflect concrete application of the society’s Code of Ethics.” This particular position statement was adopted in 2011.

In some ways, this statement can be read as an aggressive statement about the rights of people with disabilities. Such phrases as “values all individuals” and “no person should be discriminated against” seem unequivocal enough. The sentence encouraging genetic counselors to “advocate for all individuals and families according to their unique physical, medical, cultural, educational, and psychosocial needs” could suggest a broad view of disability’s effects. To live a quality life, disabled people must not only have access to proper medical and physical care, but also to appropriate education and social accommodation. This sentence could be read as an endorsement from the profession for attention to the systemic social conditions which contribute to disability. However, read another way, this sentence is meaningless and not at all a strong statement about the profession’s support of individuals with disabilities. It is noteworthy that this particular sentence does not mention disability at all. What it does recommend is that genetic counselors should advocate for everyone—“all individuals and families.” It is difficult to imagine that advocacy could accomplish anything in a context where the needs of everyone are being advocated for—especially in a stratified society where minority populations experience greater discrimination.

Thus, this position statement can be read in two ways. Does it demonstrate the profession’s commitment and active support for people with disabilities? Or, is it hedging in order to prevent critique of a profession that enables large numbers of women to abort undesirable fetuses on the basis on disability? Rather than a statement of the profession’s commitment to disability rights, I argue that this statement represents the profession’s commitment to client choice, autonomy, and belief about disability in the context of a disability rights movement.

Not surprisingly, the textbooks also present a confused discourse on the subject of disability. With the exception of Weil's *Psychosocial Genetic Counseling*, which I will discuss later, none of the textbooks contain an extended discussion of disability's place and meaning in society. However, disability becomes a topic indirectly in the many narratives and illustrations that accompany discussion of counseling techniques. Thus, while there may be no explicit discussion of Trisomy 18, Trisomy 18 may show up in an example of dialogue illustrating the counseling technique for delivering bad news. One reason for the lack of information on disability is probably because the textbooks in this study are not medical genetics textbooks. These are not the texts where genetic counseling students will learn about the biological errors in cell division that cause trisomies or their physical symptoms. However, I would also suggest that the lack of explicit discussion about the social meanings of disability is a symptom of the same tension seen in the NSGC position statement: rhetorically, it is difficult to both promote client autonomy and a disability rights position.

In the rest of this chapter, I return to Down syndrome as an example of one disability that genetic counselors must frequently discuss with their clients. I record how Down syndrome is referenced in these texts and analyze the implications of these references. This analysis demonstrates a tension between the rhetorical patterns of counseling techniques and the claim that genetic counselors can be advocates for people with disabilities, at least within the context of prenatal genetic counseling. In order to provide some structure for the types of discourse about Down syndrome used, I have divided the examples into three sections—progressive discourse about Down syndrome and skepticism of prenatal technology, medicalized discourse about Down syndrome, and

typical narratives contextualizing patient and counselor responses to a Down syndrome diagnosis. These categories are artificial in that many examples could fall into more than one category. However, this classification allows me to highlight the most prominent types of discourse about Down syndrome.

Progressive Discourse about Down Syndrome and Skepticism of Prenatal

Technology

Discourse in this category tends to reflect many of the tropes prevalent in disability studies and advocacy discourse, including critical reflection on the uses of prenatal technology. In addition, examples of discourse in this category are the most consistent with the profession's goal to promote the welfare of people with disabilities.

The textbooks recommend avoiding judgmental language with respect to Down syndrome. Down syndrome and trisomy 21 are presented as appropriate terminology for the condition, and other, derogatory terms are presented as inappropriate. *A Guide to Genetic Counseling* explicitly directs counselors to “model language for the family” (81). The text provides an example of how to correct clients who use the term “Mongolism” to refer to Down syndrome:

After asking a few questions about this cousin, the counselor might say, “It does sound as though this cousin had what some people call Mongolism. Most people now call this Down syndrome or trisomy 21.” During the rest of the counseling session, the counselor would use the term “Down syndrome” as an example for the client. (Uhlmann , Schuette, and Yashar 87)

This statement demonstrates for genetic counseling students how to gently correct clients who may be using insensitive language. In doing so, the counselor models appropriate behavior and attitudes about disability.

Likewise, at certain points, the textbooks encourage genetic counselors to provide clients with information about the social, as opposed to strictly medical, effects of Down syndrome. *A Guide to Genetic Counseling* suggests that counselors should provide “syndrome-specific information” including “local support group information” and “pictures of children and adults with common conditions such as Down syndrome” (Uhlmann, Schuette, and Yashar 194). *Advanced Concepts and Skills* recommends a well-known essay, “Welcome to Holland,” written by a parent of a child with Down syndrome (LeRoy, McCarthy Veach, and Bartels 116). Such recommendations reflect an awareness on the part of the authors that medical information is not the only relevant information about Down syndrome. Moreover, these examples of discourse show that genetic counselors are willing to refer patients to outside sources—support groups and parent-authored texts that may provide experiential knowledge about Down syndrome that genetic counselors do not have access to.

The most progressive statement about educating clients with respect to the social meanings of Down syndrome occurs in *A Guide to Genetic Counseling*. The authors review a recent sociological study on perceptions of Down syndrome and suggest that the implications of this study have profound ramifications for genetic counselors:

The authors argue that information available to parents within the prenatal testing context should not perpetuate stereotypes that reinforce a perception of people with a disability as “other,” and that materials must be developed with those who

have practical experience of living with the relevant condition. This suggests that it is not enough to counsel nondirectively, but that counselors have an obligation to educate people about these viewpoints in order to enable counselees to make truly informed decisions. (Uhlmann, Schuette, and Yashar 218)

This is the most progressive statement about providing non-medical information about Down syndrome found in any of the textbooks. It reflects an advanced awareness of the differences between empirical and experiential knowledge about disability. It also implies that genetic counselors have an active role in advocacy and an ethical imperative to challenge initial, negative reactions to a prenatal diagnosis of Down syndrome that are based on stereotypes. This is the only statement about Down syndrome in any of the four textbooks that acknowledges that negative reactions to a prenatal diagnosis are likely to be influenced by cultural ideologies including ableism.

There are also several statements in one textbook, *Advanced Concepts and Skills*, that criticize the indiscriminate application of prenatal technology regardless of the pregnant woman's specific context. This text suggests that in certain situations "the genetic counseling session [...] could start by acknowledging the limited value of amniocentesis for the patient," and, in other situations, "the counselor might take a more directive approach and discuss with such patients that perhaps they may not want to undergoing [sic] serum or sonographic screening in the first place because screening could lead to a path (amniocentesis, abortion) that is not a realistic option for economic, cultural, or social reasons" (LeRoy, McCarthy Veach, and Bartels 16). These examples encourage genetic counselors to consider the client's individual values and concerns. For patients who cannot afford amniocentesis or are morally opposed to abortion, this text

recommends that the counselor openly acknowledge that certain prenatal technologies will not be appropriate for them. Such explicit discussion is likely to relieve any pressure the client may feel to utilize such technologies simply because they are there. Moreover, this is the only example in the textbooks that reflects a major concern raised by disability advocates and critics of prenatal testing—that even the most routine, non-invasive prenatal technologies, such as a sonogram, can start a cascade of events that the patient did not intend. In the face of increased risk for Down syndrome, only an invasive diagnostic test can provide more information; in the face of a prenatal diagnosis of Down syndrome, the only action that can be taken is abortion. This text reflects an awareness that it may be more difficult not to act than to act by terminating the pregnancy, even if the client was initially opposed to abortion.

Medicalized Language and Significant Information

Despite including some statements that encourage progressive views of Down syndrome, these textbooks have many more examples of medicalized discourse about Down syndrome. For example, when referring to the probability that a pregnancy will be diagnosed with Down syndrome, the textbooks consistently use the phrase “risk for Down syndrome.” Although “risk” is used indiscriminately in medical genetics, it has negative connotations to the lay public. We do not talk about the risk of winning the lottery. Only twice in the textbooks do the authors use a different word—chance—to describe the likelihood of a prenatal diagnosis of Down syndrome. For example, a statement in *Advanced Concepts and Skills* reads, “Based on the results of your first-trimester screening test, your chance of having a pregnancy with Down syndrome has decreased to 1 in 1080” (LeRoy, McCarthy Veach, and Bartels 70-71). Not coincidentally,

this is the only text that distinguishes between risk and chance, stating that “although chance, likelihood, and risk are synonyms, risk has a more negative connotation than do chance and likelihood” (66). Despite this acknowledgement, the rest of the chapters in this textbook (which were written by different authors) consistently use the word *risk*. Thus, on the whole, these textbooks advocate counseling techniques that retain medicalized language even to the detriment of patient understanding. By using the word *risk*, counselors do not discriminate between the possibility of developing a disease, such as cancer, and the possibility of having a child with Down syndrome despite the fact that these two situations are very different, socially and medically.

There are other instances where the language used may promote prejudice. In several statements, the birth of a child with Down syndrome is referred to as “bad news” and a “burden” (Uhlmann , Schuette, and Yashar 168 and 186; Weil 34). Whereas the term “bad news” is given by the authors of the texts, in both cases the word “burden” is used to describe the perception the client may have that a baby with Down syndrome will be a burden. Thus, the textbook authors avoid suggesting that the genetic counseling profession views Down syndrome as a burden; instead, they present clients as likely to have this perception. For example, *Psychosocial Genetic Counseling*, in a chapter of the client’s social context and family belief system, suggests, “Whether the birth of a child with Down syndrome is perceived as personally and socially acceptable or as an unacceptable burden that may include social disapproval for the failure to use prenatal diagnosis and elective termination” is “particularly relevant to genetic counseling” (Weil 34). In contrast to the statements discussed in the above section in which counselors were asked to challenge prejudicial client views, the author here recommends more muted

actions, arguing that while “thoughtful questions concerning beliefs” can lead counselors to correct misinformation, beliefs may also affect the client’s potential to cope or adapt to a new genetic situation (Weil 36). The overall message in this chapter is that client values and prejudices are deeply embedded in “lived reality,” and that it may be harmful to the client to challenge such values (Weil 34).

While such a method might seem contradictory to a professional goal to advocate for persons with disabilities by contradicting stereotypes, it is quite consistent with other genetic counseling goals. In particular, it takes seriously the goal of considering the client’s own agenda. A client who will not receive familial support for choosing to continue a pregnancy after a prenatal diagnosis of Down syndrome may not be prepared to consider alternative knowledge about Down syndrome. By consistently deferring to the parents’ perceptions of the burden of raising a child with Down syndrome, however, the textbooks are also able to avoid taking a stance on whether Down syndrome is or is not an acceptable condition to be born with.

Although the textbooks do not explicitly state that the genetic counseling profession condones the use of prenatal testing to select against fetuses with Down syndrome, a popular narrative within the texts is that of the counselor who would personally abort for Down syndrome and is disturbed by a patient who will not. In one instance, a text warns against this type of thinking, suggesting, “You should be careful about assuming that your clients will feel exactly what you would feel, since this may not be the case. For example, you might feel devastated if your baby had Down syndrome. However, a couple who desperately wants to have a child may feel very disappointed, but also happy that they will be parents” (McCarthy Veach, LeRoy, and Bartels 59). In every

scenario like this presented in these textbooks, the counselor considers Down syndrome to be more serious than the client does. Moreover, there is usually some qualification of the client's reasoning. In this instance, notice that the parents "desperately want children." We might complete that sentence with the phrase "no matter the cost." There is an implication that it is only acceptable to have a child with Down syndrome when there is a rational reason for doing so. In this case, we understand that the parents think it better to have a child with Down syndrome than no child at all. In another example, a "Catholic Hispanic couple wants a child under any condition. They do not perceive a high risk of Down syndrome as negatively as you might" (McCarthy Veach , LeRoy, and Bartels 59). Here again, the counselor perceives Down syndrome negatively, and the parents have a reason for wanting to continue the pregnancy. They are Catholic and, thus, likely to be morally opposed to abortion.

Another popular narrative is that of the counselor who is able to better able to determine relevant medical information than the patient. In other words, the genetic counselor is presented as considering the right information for a decision about Down syndrome, while clients are presented as being preoccupied with the wrong information. Three examples of this narrative come from *Facilitating the Genetic Counseling Process*:

- For example, your client says, "My child is just a little developmentally delayed, but the doctors told me he'll catch up if we just work with him." You might respond, "You say that he's going to catch up, but your medical records indicate that he has Down syndrome." (163)
- Confused reasoners may spend a great deal of time on a small point, while missing the larger issue, for example, the client who wonders if her unborn child

who has Down syndrome will look like her, while missing the point that the child will be cognitively impaired. (189)

- A 33-year old client was referred because her triple screen showed that her risk for Down syndrome was 1 in 44. The risk for Down syndrome in her last pregnancy was 1 in 180, but she reported that everything “turned out perfect.” Although she had never met with a genetic counselor before, she assumed that the genetic counselor was a “spoiler” of her experience. She hardly listened during the session and kept saying, “Those blood tests are always wrong anyway.” She even refused to have an ultrasound because she didn’t want to be told any more “fake bad news.” (214)

While these examples could be read as client resistance to a medicalized diagnosis, within the text they are interpreted as wrongheaded on the part of the client.

For example, the second instance is presented as a case where the client is merely confused. The text suggests, “Confused reasoners are not less intelligent than other clients, but they have never learned to process information. They may experience intellectual confusion because they cannot differentiate between important and trivial information” (McCarthy Veach, LeRoy, and Bartels 189). This statement represents a judgment of the patient’s concerns. Just because the counselor may believe that the child’s potential intelligence is an important factor does not mean it should be a relevant factor for the client. Perhaps the client values intellectual variability more than the counselor does. The client’s concern, that the child with Down syndrome may not resemble her, may be important for many reasons—not least of which because people with disabilities are stigmatized for their appearance. Moreover, in any of these three

examples, the client could be actively resisting the medicalization of her pregnancy. In particular, the client in the last example is trying to communicate to the counselor that she does not experience prenatal screening and testing in terms of probabilities. For her, a positive screen (a 1 in 44 risk) does not provide enough information to be worthwhile. Rather than respecting the client's differences of opinion, these examples assume that the genetic counselor is in the right and provide techniques to help counselors intervene.

Available Narratives Concerning Down Syndrome

There are particular narratives about Down syndrome that show up in multiple instances, across textbooks. The first type of narrative concerns the acceptability of prenatal testing or the acceptability of continuing a pregnancy for specific populations. The second type of narrative concerns the role of genetic counselors in providing information and helping with decision-making after prenatal diagnosis.

Population-Based Narratives

As indicated earlier, narratives in which the clients intend to continue the pregnancy after a diagnosis of Down syndrome are more likely to include qualifiers or reasons why the clients made this choice. Certain populations appear more frequently in these narratives including older women for whom the pregnancy might be a last chance at having a child or religious couples who are morally opposed to abortion. One example in *Advanced Concepts and Skills* states,

The couple spoke with their counselor and postponed a decision about pregnancy termination until they spoke to the religious authority in their community, who would "make the decision about termination." The counselor felt very ambivalent about her role in the face of a decision that felt so far away from the core value of

autonomy that is a part of the genetic counseling code. (LeRoy, McCarthy Veach, and Bartels 213)

This example illustrates a tension between the counselor's desire to promote patient autonomy and her desire to respect cultural and religious beliefs. This example is presented in the context of a discussion about cultural competencies, and the discussion immediately afterward suggests that the counselor should feel satisfied that the clients are making choices consistent with their belief system. If it is routine for them to consult religious authorities for every important decision, than a consultation regarding pregnancy termination is probably the best course of action for these particular clients. This view is consistent with other examples referencing religion. Generally, religious reasons for continuing a pregnancy after prenatal diagnosis of Down syndrome are not commented on and tacitly accepted as valid. The same is true for clients of advanced maternal age. The narratives in these texts tend to present older mothers as women who believe their current pregnancy might be their last opportunity to have a child. This belief is supported by medical statistics showing that it is more difficult to get pregnant as a woman ages. Thus, by qualifying clients who choose to continue their pregnancies after a prenatal diagnosis as belonging to certain populations, the sum of these narratives implicitly argues that there are rational reasons to knowingly give birth to a child with Down syndrome but only in certain circumstances.

Interestingly, there is one textbook that assigns blame to women of advanced maternal age for contributing to an increased incidence of Down syndrome births. This example does not refute the argument that women should continue Down syndrome pregnancies when there may be no other opportunity for them to have additional children,

but it does argue that Down syndrome births have reached “epidemic” proportions due to the prevalence of older mothers:

The increased risks of Down syndrome and other chromosomal abnormalities in such pregnancies have been known since the 1930s. The increased number of pregnancies to women 35 and older since 1980 has resulted in an 80% increase in the number of Down syndrome pregnancies predicted. Since 1990, the live birthrate predicted for babies with Down syndrome has increased from 1 in 876 births to 1 in 614 births (assuming no prenatal diagnosis, to illustrate a point). Women 35 and older now account for slightly more than half of all pregnancies with Down syndrome. This is perhaps closer to an epidemic attributable primarily to specific behavior than to the purported epidemic of “crack babies.” (LeRoy, McCarthy Veach, and Bartels 17-18)

This critique of older women who knowingly decide to get pregnant despite the increased risk of chromosomal abnormalities is given in the context of an argument against placing blame on women who drink alcohol or take drugs during their pregnancies. Thus, we may read this argument as tongue in cheek; we do not blame women of advanced maternal age, nor should we blame women who do not take proper care of themselves. Or we may read this as a serious criticism. One of the most interesting aspects of this statement is the inclusion of the live birthrate statistic which the author notes “has increased from 1 in 876 to 1 in 614.” In parentheses, the author qualifies this statement by stating that this statistic assumes no prenatal diagnosis. Of course, in reality, this cannot be assumed. In fact, as we have seen, the impact of prenatal diagnosis is quite great since 80-95% of clients choose to terminate a pregnancy with Down syndrome after a prenatal diagnosis

(Rapp 223). Moreover, there is an unfair comparison between “crack babies” and babies with Down syndrome. These are two separate conditions. A child born with fetal alcohol syndrome, for example, did not have this condition from the moment of conception, whereas a child with Down syndrome has always had Down syndrome. Fetal alcohol syndrome may be decried as a universally lamentable condition that is preventable through regulation of maternal behavior. Down syndrome, however, is the result of a random chromosomal variation. Although older mothers are more likely to have children with Down syndrome, even at an advanced maternal age the odds are great that they will not. Furthermore, younger women are not immune to having children with Down syndrome. Thus, if we are to take this textbook’s criticism of older pregnant women seriously, we see that rhetorically the example serves to illustrate both a narrow view of disability and establish the relevance of population-based statistics.

In contrast to the examples above, in narratives where the client decides or seems likely to decide to terminate a Down syndrome pregnancy, no population qualifiers are necessary. The following example from *Facilitating the Genetic Counseling Process* illustrates this:

Cl[ient]: I don’t want to have a baby with Down syndrome.

Co[unselor]: Tell me more about that.

Cl: I just don’t think I could handle it.

Co: So you are afraid you couldn’t manage?

Cl: Right.... I have to work full-time and I’d have no one to watch the baby. And I’m not sure I could give it all of the special care it would need. (80)

The client in this situation seems to be leaning towards abortion. We know relatively little about her from this excerpt, except that she works full-time and does not have someone to take care of the baby during the day. We don't know whether this was a wanted pregnancy or not; although if it was a wanted pregnancy, she might already have plans for a caregiver. This example does not tell us whether the woman is married, what her age is, or anything about her cultural beliefs.

The Role of the Genetic Counselor

A second type of narrative that is common concerns the role of the genetic counselor. Many textbook examples involve clients who need support making their decision to terminate or continue a Down syndrome pregnancy; in nearly every example, the genetic counselor is able to provide this support by supplying medical genetic information.

One common narrative involves the client who feels guilt for having a pregnancy affected by Down syndrome. *Facilitating the Genetic Counseling Process* states, “Parents whose child has Down syndrome were struggling with guilt and shame because they came into the session believing that they had caused this to happen. The genetic counselor explained the simple mechanics of meiosis and emphasized that it was no one's fault—no one can make it happen or prevent it from happening” (McCarthy Veach, LeRoy, and Bartels 188). Likewise, *Psychosocial Genetic Counseling* argues that counselors must be firm in their correction of client misinterpretation:

Although scientists have known about the maternal age effect for a long time, they are still searching for an explanation of why older mothers are more likely to have a child with Down syndrome.

Contrast this with the more authoritative statement

There is still no explanation for why older mothers are more likely to have a child with Down syndrome. (Weil 65)

The text asserts that the second statement “establishes a context of humankind’s ongoing efforts to understand and eventually prevent such events” (Weil 65). In addition to assuming that events such as the birth of a child with Down syndrome should be prevented, these examples also suggest that clients are likely to blame themselves for causing their child to have Down syndrome. More significantly, however, the examples assume that providing rational, scientific information that contradicts the parent’s feelings will make the parent feel better. There is no discussion of the fact that feelings of guilt and shame are likely to be irrational and that they may not be changed with a genetics lesson. Instead these examples are idealistic representations of what might happen when the counselor corrects patient assumptions.

A second common narrative presents Down syndrome as a complicated prenatal diagnosis because the condition has such a high level of variability. People with Down syndrome may be born with any number of serious physical limitations including low muscle tone or heart defects. On the other hand, they may be born perfectly healthy. In addition, the degree of mental retardation can vary from mild to more severe. Prenatal genetic testing cannot predict what the effects of Down syndrome will be; it can only state whether there is or is not an extra chromosome present. One textbook suggests, “Results of testing may be clear or wrought with uncertain findings. Even a ‘clear’ diagnosis (e.g. trisomy 21), cannot predict the future achievements or medical complications of a child with Down syndrome” (LeRoy , McCarthy Veach, and Bartels

31-32). This makes it difficult for genetic counselors to select information or to help patients determine what the best decision is in any given context. For example, *Psychosocial Genetic Counseling* states, “Some counselees would abort for trisomy 21, whereas others would not. For some counselees, mental retardation represents the most serious type of abnormality, for others, physical abnormalities are the most serious, and for some, specific experiences or beliefs determine particular disorders for which the pregnancy would be terminated” (Weil 157-158).

Despite the complications of this diagnosis, the usefulness of prenatal diagnostic testing for Down syndrome is never questioned. Rather, the way out of this uncertainty is to provide more information. *Facilitating the Genetic Counseling Process*, for example, the authors write, “In many situations you will have to provide complicated and ambiguous information such as risk rates, sensitivity and specificity of tests, and severity of conditions diagnosed prenatally such as Down syndrome. It is your responsibility to present this information in a comprehensible way” (McCarthy Veach , LeRoy, and Bartels 122-123). In other words, the textbooks assume, for the most part, that it is both possible and helpful to provide complicated and ambiguous information to patients.

If the client is confused or conflicted about the information provided, the textbooks recommend that genetic counselors help their patients envision the possible consequences of each available choice. For a Down syndrome pregnancy, these scenarios might include imagining terminating the pregnancy, imagining raising a child with Down syndrome, or imagining continuing the pregnancy but giving the child up for adoption. *Psychosocial Genetic Counseling* warns that these scenarios will be different depending on the client:

One individual might envisage the birth of a child with Down syndrome in terms of the effects of mental retardation on education, social relationships, and achievement, visualizing the child's and family's life at various ages. For another, the scenario might focus on the possibility of severe medical problems involving hospitalization, surgery, pain to the child, and possible death. (Weil 140)

This text encourages counselors to lead patients in “assessing the worst case outcome, to determine whether the consequences were ones with which the counselee could cope” (141). However, the text also notes that imagining such scenarios is of limited value because the clients are unlikely to have experiential knowledge about raising a child with Down syndrome and are likely to underestimate their ability to cope. However, for the most part, the dominant narrative about the role of the genetic counselor is that by providing good explanations of complicated information, counselors will provide adequate support for patients making decisions about Down syndrome.

Conclusions: Genetic Counseling's Rhetorical Potential

For Clarke et al., the shift from medicalization to biomedicalization primarily involved a shift to broader and more expansive regulations of health created by diversification of health services, the creation of risk groups, increasing technological capabilities, and self-governance (165). A cursory examination of genetic counseling as a profession seems to place it well within the purview of biomedicalization. Genetic counselors are a relatively new and specialized type of healthcare provider. They serve populations who are labeled “at risk” by new screening technologies of medical genetics. However, it is Clarke et al.'s last criteria that is complicated by an analysis of genetic counseling discourse—the criteria of self-regulation and transformation.

Self-regulation is reminiscent of Foucault's concept of governmentality. Both terms refer to the more insidious ideological processes which compel individuals to regulate themselves rather than being subject to the direct control of the government or, in this case, the healthcare system. Under biomedicalization, individuals do not only seek out health services to treat disease, but they also depend on it to regulate their health. Health becomes a "moral obligation" to which all individuals should aspire (171). The context of prenatal testing enables this obligation by allowing potential parents the opportunity to select against or abort pregnancies that do not conform to cultural standards of health. The availability of prenatal testing also suggests that disease and disability are not inevitable experiences of life but rather can be controlled and prevented.

Genetic counseling, however, is meant to prevent coercion or undue pressure on parental decisions about genetic selection. It is intended to provide a space for parents to reflect on their reasons for using or refusing to use medical technology. In this sense, genetic counseling has the potential to offer a different kind of self-regulation and transformation—it may allow patients to regulate their use of technology or their appropriation of risk identity. However, based on my analysis of professional genetic counseling discourse, I see three problems with the rhetorical implications of genetic counseling techniques that ultimately are likely to prevent genetic counseling sessions from serving as a site of resistance to biomedicalization in most cases.

First, genetic counseling techniques are unable to resolve tensions between valuing patient autonomy and valuing cultural belief systems. While the most important goal in genetic counseling is to promote autonomous, informed decision-making, the counseling techniques of client education, nondirectiveness, and psychosocial counseling

are often at odds with each other. A counselor may feel that a client is uninformed about medical genetics but also sense that medical information is not relevant to the client because her family believes she should continue the pregnancy under any conditions. Thus, the goal of client education may be at odds with the goal of psychosocial counseling. Given the genetic counselor's training and identification with the medical genetics, it seems likely that the counselor would consider client education to be the more important goal. In some scenarios with some clients, this may be appropriate. Perhaps the client remains firm in her decision to continue the pregnancy because she is confident in the support of her family, but she also learns a little bit more about the medical effects of the condition. On the other hand, perhaps an extensive discussion of medical information and a corresponding lack of attention to potential support and adjustment strategies overwhelms the client, at worst forcing her into a decision that she will regret, at best leaving her ill-equipped to adjust to new emotional demands.

The tension between social concerns and medical concerns is symptomatic of a larger problem. Genetic counseling techniques cannot distinguish between a patient's autonomous choice and a patient's ideological interpellation. In other words, it is difficult to both support a client through nondirective counseling and neutral information-giving while at the same time challenging a client's subjectivity. Does the client wish to abort a fetus with Down syndrome because she doesn't have the resources to care for a child with special needs, or is she denying the responsibilities and uncertainties that come with parenting any child? The techniques of genetic counseling are indebted to psychological counseling techniques which emphasize the internal motivations of the individual. Such techniques are ill-equipped for confronting systematic, cultural ideologies.

Second, the genetic counselor's primary concern is with the needs and well-being of the client not with the disabled fetus. I wish I could avoid creating a binary between the mother and the fetus, as doing so calls to mind an obvious connection to abortion debates. However, it is impossible to escape the fact that genetic counselors can only offer one service to parents with a prenatal diagnosis of Down syndrome—abortion. As such, the mother and her supporters are the counselor's patients and the fetus is not. As a consequence, it would be impossible for genetic counselors to advocate against prenatal genetic selection on the basis of disability as many disability advocates do.

Finally, and perhaps most importantly, counseling techniques present an unbalanced view of one type of knowledge about disability at the expense of other types of knowledge. Genetic counselors claim to be experts at facilitating decision-making in a prenatal context. However, they can only offer expert medical knowledge of disability. They are trained extensively in medical genetic knowledge, and, as the textbooks themselves warn, are likely to over represent the importance of this information. However, most genetic counselors lack experiential knowledge of disability. As we have seen in the prior chapters, disability advocates claim that experiential knowledge is a vital part of understanding disability. We now turn to an analysis of the online discourse of pregnant and recently pregnant women who are making decisions after a prenatal diagnosis of Down syndrome. This discourse indicates that women rely on experiential knowledge about disability to a much greater extent than genetic counseling discourse predicts.

CHAPTER SIX

WOMEN'S ACCOUNTS OF PRENATAL DIAGNOSIS

From analyzing genetic counseling discourse as an example of medical discourse commenting on the prenatal testing situation, I now turn to an analysis of a second commentary on this situation—accounts of women using prenatal testing and receiving prenatal diagnoses of Down syndrome. User accounts represent an important strand of discourse about the experience of prenatal testing and one that is quite different from medical discourse about this situation. Unlike genetic counselors and other medical professionals, pregnant women and their supporters are relative novices to this specific situation. They are not experts in genetic discourse about heritable conditions or risk. In addition, while women receiving prenatal care may be familiar with a typical doctor-patient relationship, the goals are different for a genetic counseling session. Women and their supporters may attend the session expecting to be given advice and informed of a specific course of action, only to be surprised that the genetic counselor is not going to make decisions for them. In fact, there may be conflicting ideas about what should happen in the session and discursive confusion if patients insist on treating the session as a typical doctor's appointment.

While the users of prenatal testing may not be experts in genetic knowledge, they will bring different discourses about prenatal testing, disability, and Down syndrome to the situation. Women using these tests will bring whatever discourses about these topics they have been exposed to to bear on their decision-making. Such discourses may include stereotypical discourses about disability or personal feelings about abortion. As I have shown, genetic counseling discourse attempts to predict the types of concerns pregnant

women and their supporters will have and uses these narratives to train new counselors. However, systematic study of users' own narratives about their experiences has not been done. In this chapter, I attempt to fill that gap by analyzing the accounts of prenatal testing and diagnosis of Down syndrome on one popular online parenting forum. Through rhetorical analysis of the narratives women produce about their experiences, we can see the different strands of discourse that women bring to bear on their decision-making processes.

This chapter describes actual narrative practices occurring on one particular online parenting forum. I will characterize one narrative genre in one sub-forum discussing Down syndrome pregnancies and then discuss how members of a second sub-forum for women who choose to terminate pregnancies after prenatal diagnosis respond to the first narratives. The narrative genre I analyze is a popular one the Down Syndrome Pregnancy sub-forum. One thread entitled "Prenatal Diagnosis- Our Stories," was active for four years and contains thirty-two posts makes up the bulk of this data. However, in my analysis of one month's worth of posting on this sub-forum, I noticed that the narrative of the prenatal diagnosis story was one of the most common genres. Thus, in addition to the above thread, which was the designated space for these narratives, new members would also often share their prenatal diagnosis stories as a way of introducing themselves in other threads. Those narratives were also included in my analysis. In addition, I have deliberately avoided providing identifying information, such as screen names, as a way of protecting the authors quoted here.

In addition to describing the typical features of these digital narratives, this chapter also considers how these narratives function rhetorically. Phelan describes a

rhetorical approach as that which “defines narrative as somebody telling somebody else on some occasion and for some purpose that something happened” (88). This definition takes into account rhetorical theory’s attention to a speaker (or rhetor), an audience, and a particular situation. Moreover, Phelan’s definition conveys the idea that rhetorical speech is used to accomplish some purpose within the given context. By examining the larger context of these narratives, this chapter also argues that the rhetorical purpose of these narratives about prenatal diagnosis is to provide a counter-narrative about Down syndrome and mothering a child with Down syndrome and, ultimately, to support specific types of decision-making within the context of prenatal testing itself.

Analysis of disability narratives is becoming increasingly recognized as a necessary methodology in disability studies. Disability rights scholarship and advocacy is sometimes seen to exist in opposition to medical and public health models of disability where disability is viewed as inherently negative. Over the years, disability studies scholars have challenged medical models of disability and public health narratives suggesting that people with disabilities suffer and have a lower quality of life than non-disabled people. The struggle for disability rights and against disability discrimination has necessitated the construction of counter-narratives of disability. Counter-narratives suggest that disability is socially rather than biologically constructed and that people with disabilities are more alike nondisabled people than they are different. These counter-narratives have themselves become the object of study in several instances. Recently, for example, Dinerstein traced the evolution of Supreme Court opinions on landmark cases involving disability from those that concur with dominant narratives about disability to those that are more progressive. Similarly, Lalvani, who is also working with mothers of

children with Down syndrome, argues that such mothers use counter-narratives to reposition themselves as typical rather than special mothers, thus countering a stereotype that children with disabilities are only born to special, saint-like, or exceptional parents. Finally, Barton describes the narratives told in IDEA (Individuals with Disabilities Education Act) training classes and argues that counter-narratives are carefully structured to negate fundamental aspects of dominant narratives about disability. Barton finds that this rhetorical function is so important that counter-narratives that do not fit the approved model are silenced within the particular context she studies. In sum, counter-narratives are important to disabled groups and their advocates because they represent a viable way to resist dominant narratives of disability. Yet, as these studies suggest, the authenticity of these counter-narratives can sometimes be subsumed by rhetorical purpose.

The thread “Prenatal Diagnosis- Our Stories” contains narratives that are written by women who received a prenatal diagnosis of Down syndrome during their pregnancies. Most commonly, the posts are written after the birth of the child. Common features of these narratives include an opening that describes relevant background information, a discussion of prenatal testing options and decision-making, a description of the woman’s reaction to the diagnosis, a discussion of the birth, and some sort of afterword that describes the woman’s current life with the child. I will discuss each of these features in turn.

Openings in Prenatal Diagnosis Stories

Out of the five narrative elements listed above, the openings show the greatest amount of variation. The most common types of openings begin by providing the reader with background information on the woman’s family including her marriage and prior

children or by providing information on the pregnancy prediagnosis. For example, one post begins, “I found out in March of 2008 that we would be expecting a very unexpected addition to our family of two. Only having been dating for a year and a half, I thought, here we go! At first we were stunned, and then we were excited and giddy with joy.”

Another post starts,

Our story begins typically enough. Boy meets Girl. Boy and Girl begin to date. Girl moves to California. Girl and Boy miss each other. Girl moves back to DC. Boy proposes to Girl, Boy and Girl get married. Boy and Girl move to townhouse in perfect neighborhood. Boy and Girl learn they are expecting a baby. And that's where our story stops sounding like a fairy tale.

Like these examples, many posts begin by emphasizing what the authors perceive as typical life circumstances. Most of the women posting describe a happy and stable relationship and family life. Many remember feeling happy and excited to learn about the pregnancy. Others emphasize the normalness of the pregnancy; for example, one woman begins, “My pregnancy was very normal. I was 23 years old and went through all the normal testing with no abnormal results.”

The purpose of these openings seems to be to set up the prenatal diagnosis of Down syndrome as something that was completely unexpected. In fact, of the six women who titled their stories, two include the word “unexpected” in the title. In describing their typical lives and pregnancies, the women on the Down Syndrome Pregnancy board also establish themselves as both good mothers and typical mothers. There is nothing special about their lives or pregnancies that mark them as capable of mothering children with disabilities. This finding echoes both Lalvani and Landsman’s findings that mothers of

children with disabilities resist dominant cultural narratives suggesting that they are special or atypical mothers, confirming instead their typicality as mothers. In addition, by emphasizing the normalness of their pregnancies, they maintain their claims to being good mothers because it shows that there were no signs suggesting that something was wrong or atypical with their children.

Several openings were more unique in both style and content. One woman writes of a friend's premonition that she would have a special baby girl. The author writes, "[My friend] went on to explain that God had given her a dream, and in the dream we were blessed with a beautiful girl. She said that there were people everywhere surrounding this baby with joy after she had been born (that part she couldn't quite figure out), and that she even saw the flowers that were sent to me!" This particular author claims she kept this news to herself since it was so strange but remembered it and took strength from it after her baby was born. Several other openings begin *in media res*—either in the midst of learning the diagnosis or in the middle of life after the birth. These stories then backtrack to discuss the events leading up to the prenatal diagnosis.

Testing Experiences in Prenatal Diagnosis Stories

A second feature of the narratives in the "Prenatal Diagnosis- Our Stories" thread is a discussion of the actual testing experience or a discussion of the decision to get testing. There seem to be several common reactions to prenatal testing. First, many of the authors report viewing the tests—and especially the ultrasound—as routine. They view the ultrasound not as a test for birth defects but as a chance to "see" the baby. For example, one woman writes, "We had honestly completely forgotten about the true purpose of the ultrasound, to check our baby's heart, as we really just wanted to know if

our baby was going to be a girl or boy.” This perception of ultrasounds is common among many pregnant women. Press found that until prenatal tests detect medical issues, women are likely to view them as opportunities to receive reassurance about their pregnancies.

A second common element in discussions of prenatal testing is to mention the circumstances under which testing was conducted. For example, many women make it clear that they are uncomfortable with prenatal testing due to their religious beliefs. Three women mention that they are Catholic and were therefore wary of prenatal testing. One woman says, “As a Catholic and a mother, prenatal testing for birth defects always seemed unnecessary to me. I would never abort my child after all, so what was the point?” Nevertheless, these women describe getting the tests for reasons that were beyond their control. For example, a second woman writes, “I was 7 months pregnant when I had my Amnio done and as a Catholic I really fought it! The only reason I finally decided to have it done was my baby's health.” Another woman describes getting the amniocentesis done after learning of the pregnancy’s increased risk for Down syndrome. She describes being surprised by her own reaction to the news and feeling compelled to learn the diagnosis rather than live with uncertainty for the rest of the pregnancy. It is worth noting that women who refuse or resist prenatal testing for religious reasons is also a commonly expressed narrative in training materials for healthcare professionals counseling about and administering these tests. Given the prevalence of these narratives in the training materials, it is not surprising to find these narratives echoed by the women on these boards; however, it is important to note that many women did not mention religion as a reason for resisting prenatal testing. Thus, perhaps health professionals need

to be aware of the additional reasons women choose to use or refrain from using prenatal testing.

Along those lines, in these narratives a more common element of discussions of prenatal testing was to view it as a series of escalating tests that women felt compelled to continue. In other words, rather than viewing each separate test—the ultrasound, the triple screen, the amniocentesis—as a choice, women’s narratives present each test as logically following from the other. If these women did make conscious decisions to pursue each additional test, those decision-making processes are not presented in these narratives. For example, one woman writes, “I decided to do the NT test because my CMN recommended (I was 34). She said that one of their ultrasound technicians was trying to get certified and needed additional films to help her get the cert. She said that they would not charge my insurance so I agreed.” At this point, the author continues, “Then, after the results [sic] were inconclusive, they said that I needed to go to have another ultrasound done. I agreed because I just wasn't even thinking - it's another chance to see my baby.”

The language here suggests that the author either did not understand the relation between the procedures or is misrepresenting them for unknown reasons. Ultrasound tests are never conclusive; they can never give a diagnosis. Thus, it does not make sense that she would be told she needed another ultrasound based on the results of the first one. It is more likely that the first ultrasound showed an indicator for Down syndrome and that a second, more sensitive ultrasound was suggested in order to get a clearer picture of the potential defect. Second, the author states that she was told she “needed” another ultrasound. However, guidelines for health professionals state that all prenatal tests

should be presented as options. From this point, the author moves from a second ultrasound to amniocentesis, a test that she initially did not want.

A second woman also reports not wanting amniocentesis. However, when she was confronted with a positive screen for Down syndrome indicating that the pregnancy was at higher risk, she says,

I immediately asked for an amniocentesis [sic]. To say that this was a surprise to both myself and my husband is an understatement. An invasive test like amniocentesis [sic] can put a baby at risk, something I never wanted to do. But I had to know. I couldn't live with those odds for the next five months -- I just knew I would torture myself trying to settle my feelings.

Despite her concerns about invasive testing, the situation of knowing the pregnancy was higher risk made the option of definitive answers impossible to resist. Unfortunately, waiting for and receiving the results of the amniocentesis put her in an unexpected situation. She continues, "Someone told me after the test -- during the ten day wait before we got the definitive results -- that sometimes beliefs will change when confronted by circumstances. It was like that." This author goes on to describe an extremely painful period in which she received the Down syndrome diagnosis and considered terminating the pregnancy, something that prior getting prenatal testing she would have never considered. Her feelings, she writes, were "a departure from how I had always believed I would feel."

I point out these two examples not to argue that these women made poor or inconsistent decisions to get prenatal testing, but to suggest that for many women the prenatal testing situation inaugurates a series of events and decisions that are unexpected.

Prior to getting prenatal testing many women report feeling excited about ultrasounds and other aspects of prenatal care. They are excited to view the baby on the ultrasound monitor and learn the sex. The women telling stories in this thread do not anticipate having to make difficult decisions or hearing bad news; prenatal tests are seen as routine and as opportunities to receive further reassurance that the pregnancy is going well. Arguments in favor of routinized prenatal testing also suggest that they provide reassurance. However, the narratives presented in this online forum suggest that such a belief may be inaccurate at best and harmful at worst. The women represented here are unprepared for the news they receive and, in many instances, appear to be unable to frame the prenatal testing situation as a series of choices. The absence of sustained discussion about decision-making processes suggests that within the context of prenatal care, it may be more difficult than healthcare providers realize to view these tests as options.

Reactions to Down Syndrome in Prenatal Diagnosis Stories

A third feature of the narratives about prenatal diagnosis on this forum is a thorough discussion of the woman's reaction to the diagnosis and the reactions of her family and friends. Without exception, every woman described the diagnosis as difficult to hear and as a cause for sadness. Most of the women described a serious and severe time of grieving as a result of the diagnostic information. They describe sobbing and crying for days at a time. One woman describes the Down syndrome diagnosis as a turning point in her pregnancy when the experience of being pregnant became much worse. She writes, "I "endured" the pregnancy, though. The joy went out of it for me. I detached from the pregnancy and my body, and I stopped taking care of myself. I didn't

exercise or eat right. And I suffered for it.” For this author, learning the diagnosis eventually caused her physical pain. Other women describe a range of difficult emotions; for example, “We felt shocked, scared, overwhelmed, fearful, ill equipped and sad that our dreams for this baby were not going to unfold as we had planned.”

In addition to the grief, many women describe a process of losing all of the expectations they had previously had for the new baby. One woman says, “And I was sad, angry and devastated. I was sure *he* would not play soccer and *he* would not go to college. I was so sure of a lot of things that *he* would never do. I asked Daddy was it wrong I wanted to change his name because Kai wasn’t a boy with Down syndrome.” For this woman and at least one other in this thread, the diagnostic information that the baby had Down syndrome was so significant that it caused them to imagine their future children as completely different people even requiring different names. (In both cases, the parents decided to give the child the originally planned name.)

In describing their grief and loss of expectations, the authors also emphasize the length of this dark period of their lives. For many of the women, it takes them months to adjust to the diagnosis. Stylistically, they will come to the end of describing one period of grief only to begin the next paragraph with a similar story. For example, one woman describes the difficulty she had telling the news to her husband and her parents only to begin the next paragraph, “In the meantime, my shock was wearing off and I was descending into my own private hell. I would wake up crying. I would go to sleep crying. I cried in the shower. I cried while driving. I cried at work. I cried when talking to friends.” For this woman, things do get better, but only “eventually.” Another woman emphasizes, “Eight weeks of my life were mostly lost to sadness and mourning.” It seems

important to the women telling these stories to emphasize the traumatic impact that learning about a Down syndrome diagnosis had on their lives, and representing the extended lengths of time during which they were deeply emotional appears to be one way to achieve this. Since one of the functions of this forum is to provide support for other pregnant women who may receive prenatal Down syndrome diagnoses, it makes sense that the long period of grief and adjustment would be emphasized.

Likewise, many of the stories include some information about how others reacted to the diagnosis—either husbands, family, friends, co-workers, or medical professionals—since new members often have questions about how to share the news. Sometimes the narratives emphasize the support the authors received from other people. For example, one woman describes her husband’s response to her “crying and hysterical” phone call: “‘We’ll be fine. I *know* we can do this.’ How? How did he know?” More often, however, the authors include some information about the people who were not as supportive when they learned about the diagnosis. One woman describes a difficult struggle with her mother, the grandmother of the baby, who was certain that the woman should get an abortion. It was difficult to hear such a close family member sound so certain that she should terminate a wanted pregnancy. Another woman reports that her doctor assumed that she and her husband would want an abortion without discussing the possibility of continuing the pregnancy (which they did choose to do). Others found it easier to avoid talking about the pregnancy at all. One woman writes, “My bump was beginning to show and I found it very difficult when people would smile and ask about the baby. At first I didn't know what to say – I felt very negative about something that was supposed to be positive.” Still others tell about their experiences with other mothers,

often feeling frustrated by unwanted advice or having to listen to the seemingly trivial concerns that go along with having a healthy baby.

The women authors seem most encouraged by meeting other parents of children with Down syndrome. Many of these narratives contain some kind of awakening moment even before the birth of the baby where the authors begin to recognize that people with disabilities are all around them. For example, one woman remembers,

My prior knowledge of individuals with Down syndrome had been memories of children in my grade school, who were mostly kept out of site. From school age into adulthood, I had no recollection of seeing people with Down syndrome in my community. BUT, after receiving the Down syndrome diagnosis, I saw individuals with Down syndrome all over the place. And in sharing our story, people would often say “my sister”, “my uncle”, “the girl across the street”, “my friend’s granddaughter”, etc... has Down syndrome. There were a world of resources and support for us.

Others specifically mention seeking out other parents of children with Down syndrome and, more commonly, finding support on the forums. Although many areas do have Down syndrome support networks, many more rural areas of the United States do not. In addition, some parents posting on the boards have only recently learned the prenatal diagnosis and are not ready to share that information with others yet. The online forums clearly offer the dual advantages of always being available and of having a high number of potential responders. Since it is unlikely that new parents will know several other parents of children with Down syndrome to seek support from and even less likely that they will know other, still pregnant parents with a similar diagnosis, the online forums

serve as a virtual gathering place where a critical mass of new and adjusted parents can find each other.

Depictions of Births in Prenatal Diagnosis Stories

Whereas several women describe significant shifts in their perceptions of Down syndrome prior to giving birth, nearly all of the women authors describe an even more significant shift after the birth. Many describe a moment that sounds like love at first sight. For example, one woman writes, “But then I held her, and that was it. I fell so hard in love with her, and it just keeps getting deeper and deeper. These days I say to her, "If only I'd known it was YOU inside me all that time, I wouldn't have been so sad!" For this woman and others, seeing the baby for the first time is an important moment. Whether it is a biological reaction or confirmation that a baby with Down syndrome is still a baby, the moments after birth are important bonding moments for these mothers.

Others view the birth as a miracle because of the health complications involved in the pregnancy. Fetuses with Down syndrome are much more likely to spontaneously abort than typical fetuses, and babies with Down syndrome can have serious physical defects requiring immediate medical attention. Several mothers note the normality of birthing since their children were born without serious medical complications. Others, however, describe a long period of time in the NICU followed by surgeries. One mother writes, “They took my precious newborn immediately into the NICU. I remember touching her tiny toes and looking at her. Oh, how my heart ached, even though I was supposedly prepared, I was not! I didn't get to hold her, to cuddle her, to let her know that everything was going to be okay.” This particular baby, the mother says, was in the NICU for four and a half months. Given the tentative hold on life that several of these

babies had, it is not surprising that their mothers describe the birth and hospital stay as one continuous journey. Whereas the adjustment to the Down syndrome diagnosis and the bonding process appears to happen very quickly for the mothers of babies without health issues, it seems to be somewhat delayed for the others. Clearly the uncertainty of health problems makes mothers anxious and, while they express love for their children during this time, the birth is not described with the same finality or resolution as it is in the narratives where the babies are healthy.

Whereas some authors expressed thankfulness over prenatal diagnosis and suggested that it helped them adjust to a diagnosis of Down syndrome before the birth thus helping them enjoy the birthing experience more, others were surprised by their initial reactions after birth. Again, nearly all of the authors describe the birth as a moment where they fell more deeply in love with their baby; however, some qualified this feeling. One woman says she thought she was prepared, but in reality she was not. Another woman writes, “In the delivery room I looked at Phoebe's face and saw the tell-tale slanted, wide-set eyes and felt the disappointment again (hey, amnio is only 99.9% accurate! What about the 0.1% chance it's wrong!?),” before going on to describe the rush of love she felt soon after.

Several of the authors also describe the health concerns as a blessing. One woman writes, “In a unique way, though, Abby’s heart condition is a blessing in disguise. It put the developmental delays associated with Down syndrome into better perspective.” In other words, this woman feels as though her child’s physical problems helped her view the intellectual challenges associated with Down syndrome as less important. Since the health problems were so serious, they made the intellectual disability seem minor in

comparison. Other women make similar statements indicating that having immediate concerns about the baby's health, helped them not to focus on the intellectual disabilities, at least until they had gotten to know the child's personality. Whereas there is something to be done about health problems—open heart surgery can fix a leaky valve, for example—there is nothing to be done about intellectual differences. Parents must just learn to accept the child as is.

Happy Endings in Prenatal Diagnosis

Acceptance and love are often the closing sentiments in these narratives. The authors describe their new lives with a child with Down syndrome, and they are often lives that would sound familiar to any mother. In fact, one of the purposes of these narratives seems to be to demonstrate that children with Down syndrome are not so different from typical children; likewise, parenting children with Down syndrome is much like parenting children without Down syndrome. For example, one woman describes all of the activities her son, now a fourth grader, participates in. She writes, "He can read, solve math problems, is a whiz on the computer, plays with his Leapster, loves SpongeBob and his two younger sisters [...]. He attends day camp in the summer, loves to swim, participates in t-ball and bowling and overall is happy with his life." The women writing these narratives also often include frustrating moments of parenting, but they are careful to choose moments that could occur with any child. As one author explains, "There is so much to say about Kiera and our life with her. And of course it's not always easy. She's going to her terrible twos right now and enjoying every minute of it! Driving everybody crazy." They also describe the extra care needed in the form of speech therapy, physical therapy, individualized education plans, and extra doctors'

appointments. However, these extra obligations are not the focus of these endings. Rather the women emphasize two outcomes of having a child with Down syndrome.

First, they emphasize their own transformation as mothers. Coping with a scary diagnosis and raising their differently-abled children have positive effects on these mothers. Here are several examples from these narratives:

- “He has definitely changed who I am for the better! I feel eternally blessed that God chose me to be his mother!”
- “Yes, some days are harder than others, but those are days when I realize that I’m growing into a much stronger person.”
- “Alex has given me a sense of purpose. He has given me a whole new perspective on life.”

Interestingly, these traits are not necessarily traits that have to be viewed positively. We assume that growing into a stronger person and having a sense of purpose means facing adversity. Perhaps some women, even these women, would have preferred not to have needed that extra strength or to go through life with a purpose that was self-determined rather than determined by the necessity to advocate for one’s child. Nevertheless, within the context of these narratives, the transformation of the women is presented uniformly as a positive aspect.

Finally, many of these narratives also point out the unique connections that their children seem to have with others. The authors describe their family lives as being enriched from a strong network of supporters. They feel they are quickly able to determine who their friends and enemies are. Moreover, several women describe their children with Down syndrome as having magnetic personalities that strangers are

attracted to. One woman describes her son's smile as "infectious." Another claims that her daughter "seems to know when someone needs a hug, even before they do." She goes on to say, "I've seen grown men and women cry as Kara hugs them, which is the reason I like to call them healing hugs." While not all of the women authors make such strong claims about their children's perceptiveness, most of them do describe their children as being eminently loveable—just like all children.

In sum, the typical features of prenatal diagnosis narratives in this thread appear to serve three rhetorical purposes related to disability: first, they establish prenatal diagnosis of Down syndrome as an event which can and does happen to typical and good parents; second, they demonstrate that grieving over the diagnosis is a normal response; and finally, they suggest that after birth, if not before, new parents will learn to accept a Down syndrome diagnosis and appreciate their children for who they are apart from a medical diagnosis.

Counter-narratives and Disability

In her work on disability counter-narratives, Barton argues that minority groups such as the disabled establish dominant counter-narratives for rhetorical purpose. Barton studies a group of parents who are being trained by facilitators to negotiate the individualized education program (IEP) in public schools. This program is mandated by the Individuals with Disabilities Education Act (IDEA) which guarantees children with disabilities the right to a free and appropriate public school education. The IEP document is meant to be a written record of the accommodations the school will provide to educate the child. The group of parents Barton studies is being trained to understand the IEP procedures since, by law, parents are required to participate in the planning process.

Within this setting, the group—both the facilitators and the other parents—works hard to promote one, united counter-narrative and silence narratives that diverge from the established narrative. The facilitators and parents promote narratives about successful parent advocacy and silence narratives about unsuccessful advocacy. Barton suggests that the promotion of a specific type of advocacy serves at least two rhetorical purposes. First, it helps to fulfill the group’s purpose as a training group rather than a support group. The facilitators in the study note that they cannot allow one parent to derail the rest of the group by spending too much time on a personal story. The types of personal narratives that the facilitators encourage are those that demonstrate successful use of the advocacy techniques they are trying to teach—specifically the ability to apply a thorough knowledge of the law to the IEP process.

It is also possible to read into Barton’s data a second conclusion. As a minority community, the disability community must also combat dominant, discriminatory narratives about disability. Thus, it is possible that the group objects to alternative narratives not only because they do not achieve the rhetorical purposes of the specific group, but also because they do not achieve the rhetorical purposes of a disability rights agenda more broadly. While it seems likely that every parent of a child with a disability could identify with the parent who expresses frustration both with her child and with the education system, perhaps that is a discussion that is viewed as being more appropriate for a private setting, such as a support group. Disability advocacy groups have consistently portrayed a more positive and upbeat message about disability; thus, it is possible that rhetorically, this group would also like to portray a consistently upbeat

narrative. The stories they sanction are those that portray what it is possible for motivated parents to achieve and demonstrate that disabled children can often exceed expectations.

There is some evidence that the women participating on the Down Syndrome Pregnancy board also sanction some narratives and not others. As the above section demonstrates, there are typical features of prenatal diagnosis narratives. However, there are several narratives that are distinctly different from the typical form. Of these alternative narrative structures, some authors are aware of the differences and make an effort to explain them; three other authors—who are all also new to the forums—do not recognize the differences in their own narrative and thus get atypical responses to their posts.

One of the women authors with the longest narrative diverges from the typical prenatal diagnosis story in many ways. First, this woman spends an inordinate amount of time talking about her grief after the diagnosis including some atypical details such as her incommunicative husband and her wish for a miscarriage. Some of the thoughts that she shares are more personal, more specific, and more depressing than what is typically shared. However, in recognition that such her story might be more disturbing than usual, she includes this statement near the beginning of her narrative:

At this point I want to say that I am about to reveal some of the emotions and thoughts that I had during this time. Some of them may be offensive; they are definitely dark and I don't mean to offend any one with anything I am about to say. I certainly want to stress that these are the feelings I felt at the time and in retrospect, thank God, know that this is not what having a child with Down syndrome is even remotely about.

Thus, because she reveals some darker thoughts, she takes a step that the other women authors don't feel the need to. That is to say, she reveals the conclusion of her story at the beginning. Whereas the other parents present a narrative arc in which their opinion of Down syndrome slowly changes over time, this woman states upfront that her actual experience with Down syndrome has been completely different than what she expected. It seems she feels the need to do so because she recognizes that her narrative does not follow the typical pattern and she does not want to offend readers with different expectations or receive criticism from the group.

A second way that her narrative differs is in its judgment of prenatal testing. Whereas some of the other women criticize the way healthcare professionals handled their testing, most do not criticize the procedures themselves. At least two women authors in this thread state that they are grateful that having a prenatal diagnosis gave them time to prepare for the baby and adjust their expectations before the birth. However, this woman explicitly criticizes prenatal testing and diagnosis. At the end of her narrative she writes, "Throughout the pregnancy I told everyone that I was thankful for the diagnosis because it gave me time to prepare, but in retrospect I don't know if that was true or not. It was a long, painful, difficult journey and I sometimes wonder if it would have been better to find out after I had my precious baby in my arms, knowing already how much I loved him." Once again, this woman seems to recognize that there is a sanctioned narrative about technology. The dominant narrative assumes that women will be grateful for receiving additional information about their pregnancies; however, this woman recognizes that the prenatal diagnosis provided her with incomplete information. She suspects that she might have had an easier time adjusting to the diagnosis after the birth.

In contrast to the above example, three additional women's prenatal diagnosis narratives do not conform to the typical structure nor do they acknowledge the differences. Without exception, these three women are all new to the forums and have not given birth to their children yet. The main difference between these three stories and the typical narratives on this thread are that while these authors seem to have made up their minds to continue with their pregnancies, they have not reached the same acceptance of the diagnosis that the other authors describe. Each of the three seems to be in a different place regarding the diagnosis. For example, one woman writes, "I am 25 weeks along- have known for 2 months. Still keeping this secret. We only told a handful of folks our results. I sometimes wish that I wouldn't [sic] have told anyone." While other women mention the difficulties they have with telling other people, they usually also include a description of helpful support they have received. In contrast, this woman seems to want to remain isolated. As she continues her narrative, she expresses even more sadness: "About every other day - I want to jump off a bridge and I just keep on pretending that everything [sic] is fine. I hate everyone and I am so angry. Why can't my daughter be 'normal?' She will struggle and it will hurt me so much." This passage also emphasizes this woman's desire for isolation and resistance to the idea that she should pretend everything is fine. Her desire to jump off a bridge, even if it is not a serious suicide threat, is a much stronger expression of anger and sadness than the other narratives on this thread. In many ways, this woman's narrative focuses on herself more than on her child. For example, she notes that her child's future suffering will affect her as a mother. Other narratives do not dwell on the emotional suffering of the mother in connection to a child's physical pain.

Although the woman above appears to be in a great deal of emotional pain, she also seems to be reaching out to the other women on the boards for support. She states that she needs someone to talk to (even though she simultaneously wants to isolate herself) and states some factors in her specific situation that worry her. Several women on the boards do respond to her, but their responses are not typical for this particular thread. Most narratives garner responses of praise. Commenters respond that the narratives are beautiful or emotional. One respondent tells the author she enjoyed the story so much that she posted it on Facebook. In contrast, the respondents treat this narrative and the others like it very differently. They are sympathetic and direct about answering questions and offering support. In other words, they read the different narratives as being part of a different genre familiar to these boards—the story of the parent with the new diagnosis.

In response to this particular narrative, one frequent forum user writes several paragraphs in which she accomplishes three things. First, she reassures the author by emphasizing that she felt and thought the same things when her daughter was diagnosed. Second, she describes her own daughter with Down syndrome as an active, vivacious, and very typical sounding 20 month year old. Finally, she directly confronts two specific concerns the author has by reassuring her that it is possible to have a job and raise a child with a disability and by offering to find her a local support group. Thus, in many ways, this responder is redirecting the author's inconsistent narrative. She provides reassurance that it is okay to feel sad about the diagnosis—after all, most of the other authors do; but she corrects what she sees as the woman's misperceptions about life with Down syndrome and suggests that she take action by seeking support. In this forum, being a

good mother means taking active steps to educate oneself and reorient one's expectations, adapting to a Down syndrome diagnosis.

Narrative Impact

The same online forums that house the prenatal diagnosis narrative thread also house a subforum for women who choose to terminate their pregnancies after receiving prenatal diagnoses. Although the forum rules forbid the two groups of women from discussing their different decisions, it is clear that women in both groups read each others' posts since they sometimes mention doing so in their writing. For example, one recent post begins, "I shouldn't have done it, but I went to the board that is against TFMR [termination for medical reasons]. I can't tell you how hurt I am by what I read there." Thus, within the context of these forums, the authors of the prenatal diagnosis narratives have a somewhat hostile audience—that is, they may be aware that women who did not make the same choice to continue a pregnancy after receiving Down syndrome diagnosis are reading their stories.

I also conducted analysis of one month of the active threads in the subforum dedicated to women choosing to terminate their pregnancies after a prenatal diagnosis. Of the 238 threads, 63 of them or 26.5% mentioned Down syndrome. Down syndrome is one of the most common conditions that can be prenatally diagnosed, so it makes sense that a substantial portion of these forums would talk about terminations for this condition. Within the threads that discussed Down syndrome, there were three that were particularly relevant to the prenatal diagnosis narratives discussed above. They were titled "The T21 Disconnect," "Down's syndrome termination," and "Reasons for termination due to T21" respectively. T21 is shorthand for Trisomy 21, another name for Down syndrome. These

threads are relevant to the genre analysis above because they seem to be responding to the prenatal diagnosis narratives, or rather both the narratives and these threads seem to be in conversation with each other. This is significant because the participants of both forums are encouraged not to speak with one another. Arguments are forbidden and, if they start, will be deleted because they are against forum rules. Yet it is clear that part of the appeal of online forums is that as a participant you can both receive support for your decisions from the other users of your forum and read justifications for making different decisions. Either this helps women better understand the choices of the other side or it helps them learn how to anticipate counterarguments and craft narratives that provide rhetorical justification for their own choices. Next I will discuss some of the most common discussion points on the termination for medical reasons sub-forum and consider how they respond to the prenatal diagnosis narratives.

Factors in Decision-Making

Like the prenatal diagnosis narratives, the three threads listed above have a lot of posts dedicated to discussing the reasons the authors made the decisions they did—in this case, choosing to terminate. One of the most common reasons for choosing to terminate the pregnancy involves the uncertainty of the diagnosis. As previously discussed, Down syndrome is a highly variable condition that is associated with physical defects and mental retardation, but, the physical defects can range from serious—such as a heart defect requiring immediate open heart surgery—to minimal, and mental retardation can range from mild to moderate. Furthermore, there is no way to predict prenatally how Down syndrome will be expressed once the child is born. For many women who choose

to terminate their pregnancies, the uncertainty becomes too frightening to want to continue the pregnancy. One example of this rationale reads:

I knew that some cases of Down syndrome are more minor, with milder retardation and less affected body systems. But I also learned that some cases are very severe [...] Ultimately, the uncertainty of our baby's condition, the knowledge that if he survived the pregnancy he would not lead a 'normal' life, and the very real possibility that he could suffer significantly in an abbreviated life all led us to our decision to end our pregnancy.

Another woman writes, "Uncertainty of the outcome was a big factor in our decision - we felt we could not risk the more severe outcome, and even 'moderate' Downs does not always look great." These women know that people with Down syndrome have a range of different outcomes; however, they are not confident that they could adapt to the most severe outcome. Another woman states that she feared the severe outcome and that fear influenced her decision. One woman states her feelings about the uncertainty of the diagnosis in this way:

For me, it just came down to RISK tolerance. Whereas, I hear the doctors telling me the diagnosis, the risks, the outcomes, the future, and I freak and feel like someone set me on fire continuously, and then think through what it all means for every person in the situation, and all the aspects of our lives, and decide absolutely NOT, there are others who can look at that and come to a decision they are comfortable with, even if it's not the same as mine.

This woman phrases her concerns in an interesting way. Whereas other women seem to be suggesting that they made the decision to terminate just in case their baby was born on

the most severe end of the spectrum, this woman seems to be suggesting that it was actually the state of not knowing and the anxiety that not knowing created that caused her to terminate. For this woman, the information provided by the diagnostic test seems to not have been enough to make her feel comfortable with her decision.

Most women on the termination for medical reasons subforum associate the severe end of the spectrum with suffering, even though they are aware that people with Down syndrome can have a high quality of life. Thus, many women worry about giving birth to children who will only live a life of suffering; in fact, this is the most common justification for choosing to terminate. Again, one of the many examples of this belief reads, “But I think the question that drove our decision to [terminate] was, What type of life would our child have and how could we standby [sic] and watch our child suffer physically, mentally and emotionally?” However, while there were a fair number of women stating that they did not want their children to suffer physically, through surgeries or birth defects, many women also acknowledged that the physical disabilities were likely to be minor (what the prenatal diagnosis narratives suggest) or were not a major factor in their decision-making. As one woman puts it, “It is about making the decision that mental disabilities can cause great suffering as well.” The authors on these boards also try to counter the idea that they are trying to avoid any heartaches with their children. For example, one woman says, “I realize that anything can go wrong at any time, however, it just didn't seem fair for my child to start out life at such a disadvantage. It just wasn't something we wanted for our baby and so we said good-bye.” In other words, this woman acknowledges that by terminating this pregnancy, she recognizes that she is not guaranteeing herself a smooth parenting experience. However, she suggests that there is a

difference between coping with hardship when you don't have a choice and choosing to prevent hardship when you do have a choice.

Finally, some women also take a similar stance to quality of life as disability rights advocates but with different ends. One woman suggests, "Even the "high functioning" DS people have challenges. For me it was also about society. I know how society treats people that are different. Also, it would hurt me every day for my child NOT to have the life I wanted for it." And another woman writes, "i sometimes feel like T21 is not so much an incompatible with life dx [diagnosis], but an incompatible-with-society dx." This last woman author is referring to a common suggestion on this forum that it is easier to make the decision to terminate if the diagnosis is one that physicians deem incompatible with life. However, this woman suggests that Down syndrome is made a more difficult diagnosis by society's reaction to it. These women imply that it would be impossible to change society's opinion of people with Down syndrome or to change the way society operates so that people with Down syndrome could live more independently. It is almost as though they remove themselves from the decision-making process and imply that the context makes it impossible for people with Down syndrome to thrive.

A third common justification for choosing to terminate involved familial concerns, how the child with Down syndrome would affect the rest of the family and, in particular, the other children. One mother writes of her nondisabled son, "We just didn't think it was fair to subject him to a life of feeling like he had to take care of his little sister." Another says that her living daughter's "needs absolutely have to come before mine and unfortunately before any unborn child." Some women even suggest that they

would be worse mothers to their other children if they gave birth to a child with Down syndrome. One mother says, “And what kind of mother would I be to them as I cared for a very sick child.” This quote demonstrates that the justification of choosing to terminate to avoid hurting other siblings often relies on the authors establishing that a Down syndrome diagnosis will lead to a sick or unhealthy child requiring much additional parental time and energy. Also in this category are women who suggest that raising a child with Down syndrome would require extra financial resources that they do not have.

The fourth common justification for choosing to terminate is skepticism about parenting abilities. Like the women in the forum who choose to continue their pregnancies, these women also experience fear regarding their abilities as parents. For example, one woman reports feeling comforted by her genetic counselor: “She told me that it was a great thing that I knew and understood my own limits. That's what it was. I just knew that I couldn't have handled it the way other parents do.” These women often express that they felt a gut reaction that they were not capable of raising a child with special needs.

Approaches to Information

The women choosing to terminate their pregnancies talk a lot more about medical information than do the women writing prenatal diagnosis narratives who go on to have their babies do. Perhaps this is because the women writing prenatal narratives also want to focus on their children. However, the approaches to information on the termination for medical reasons boards are distinct. Regarding Down syndrome, the women authors on this forum assume that there is a “disconnect” between the public’s view of Down syndrome and the reality of Down syndrome. They believe that the public view is that Down syndrome is a relatively minor condition that is not cause for a pregnancy

termination. However, they are also aware of the statistic that the vast majority of women receiving a prenatal diagnosis for Down syndrome choose to terminate. This is another way in which there is a disconnect between the public and reality. One woman explains the disconnect in this way: “Why is it that there is this disconnect between the public image of Down Syndrome and the medical one? Why is it that tx for T21 is regarded with such disapproval, yet 90% of diagnosed T21 pregnancies are tx'd? This really adds so much to my feelings of guilt, and it makes me so angry!” This quote demonstrates the exigence for the women to draw attention to what they perceive as inaccurate descriptions of Down syndrome. They feel—sometimes with evidence and sometimes without evidence—as though society judges them for making the decision to abort. Conveniently, they have access to the boards where women choosing to continue their pregnancies often post. Although the women on both boards are discouraged from having textual exchanges with one another, as stated earlier, they do read the other boards. In fact, one of the threads I analyzed was closed by the moderator because it started to contain discussion of the other boards. One of the comments that prompted the closures reads, “I know there are outcomes that are not so sad. But to just assume that having a DS baby will turn out like the ones on the board, the ones that are shown as the representatives to the public is not a fair assessment of the possibilities. Outcome is completely unknown when you are diagnosed with a DS pregnancy. The outcome is often not a ‘no big deal’ like is frequently heard on those boards.” The author here is making several accusations: first, that the participants posting on the Down syndrome pregnancy board are only mothers of high-functioning children with Down syndrome who have few physical complications and mild retardation; second, that the narratives posted on those

boards are representative of all of the narratives in public consumption; and finally, that the purpose of those narratives is to demonstrate that it is easy to raise a child with Down syndrome.

The frequent slippage between the larger public and the women on the Down syndrome pregnancy boards is interesting. It suggests that when participating in an online environment, rhetors may find it easy to feel as though a large portion of the population is represented. Certainly the online forums represent a larger group of women working through issues of decision-making regarding Down syndrome than each individual woman is likely to run across in her daily life. However, since, at times, both groups of women seem to complain about being misunderstood by the larger public, it is likely that there are a far greater number of public opinions in the social milieu than the author above seems to be suggesting.

Nevertheless, the women on the termination for medical reasons board are certainly concerned with the ways their actions are perceived and also with how social judgment might affect their own personal feelings of guilt. Their preoccupation with these topics leads them to focus on medical information in specific ways. First, they are very concerned with the worst-case scenario. As mentioned before, Down syndrome has a great range of variation, but these authors tend to focus on what the worst possible outcomes could be. One woman writes, "Though we would never know if our little one would be a "mild case" or not, we didn't want to take that gamble. We already had been on the outlier end of odds (1:20 risk of T21 and we were the "1"). DH [husband] told me we had to assume the worst." This post demonstrates how the woman and her husband process risk information. She feels that since she already experienced bad luck by getting

a prenatal diagnosis of Down syndrome in the first place, it is more likely that she will experience bad luck again. Other women make similar statements. This fear of the worst-case scenario plays a role in some women's decisions to terminate: "I would probably still be pregnant right now if my geneticist hadn't asked me this: 'what is the worst case scenario that you can think of?' [...] I simply couldn't BEAR the thought of my precious son, who never did anything wrong, ending up in a group home/institution when we were gone wondering where his family was and not having anyone who loved him to take care of him. I broke down in hysterics and said I couldn't continue the pregnancy." For this woman, the question her counselor asked her brought out her deepest fears about a disabled child.

Finally, the women on these forums are also concerned with getting accurate, nonbiased information—which, for them, means medical rather than experiential information. They constantly discredit the narratives of parents of children with disabilities. For example, one woman writes, "I just want unbiased facts. I feel like when I read some of what these women who have DS children say it's like well my baby is near normal so yours will be too. I don't know." This woman does not have to elaborate on the story of the woman who already has a child with Down syndrome because the other women on the boards can fill it in for themselves. They feel that parents are biased because they are trying to secure more resources and respect for their children. Another woman suggests, "I guess bottom line what I'm getting at is that people fighting for those living with DS need to focus on and promote the rare high-functioning cases in order to give the people in their lives with DS an opportunity to be valued and accepted by others. So, the typical reality of life with DS is whispered about for fear that if we tell the truth

then services and treatment for people living with DS get reduced or eliminated.” This woman argues that parents of children with Down syndrome are willing to lie about their experiences in the name of offering their children more opportunities. Both the imagine parent of a child with Down syndrome and the more real parent on the other side of the forums so to speak are depicted as sinister and calculating by some of the authors on this board. There is also a sense that women choosing to terminate made the right intellectual decision—the authors here characterize their decision to terminate as the more difficult one, emotionally, but the right one according to the facts. For example, one woman says, “The intellectual side of me knows I made the right decision.” By extension, she implies that women choosing to continue their pregnancies made a decision that was easier emotionally but not as logically sound.

Implicit Conversations

Returning to the prenatal diagnosis narratives of the women who chose to continue their pregnancies, it is evident that these narratives do speak back to the concerns of the parents choosing to terminate. First, the narratives of the women choosing to continue their pregnancies echo many of the concerns of the women choosing to terminate. When the women in the first group describe their reactions to a prenatal diagnosis of Down syndrome, they bring up all of the issues that the second group raises. They also struggle with the uncertainty of the diagnosis, their own capabilities as parents, and the effects the diagnosis will have on their relationships with other people. However, as we have seen, the narratives of the women continuing their pregnancies often end happily. The parents come to terms with diagnosis and find that it does not affect their lives in the ways they imagined it would. Thus, one way to read the

narratives in the first group is as an argument to take time to consider the decisions made in a prenatal setting. While such narratives sanction the grieving process, they also argue that it does not last forever and that families with children with Down syndrome get on quite happily with their lives. Second, the narratives demonstrate that children with Down syndrome do not suffer but have high qualities of life. Again, while many narratives do take extensive time to describe long hospital stays or health problems, they also emphasize that such problems are usually temporary and do not define their children's lives.

In conclusion, online communities offer the opportunity for groups to develop their own typified narratives and, through these narratives, to form group identities and rhetorical strategies. In this project, analysis demonstrates that the narratives of prenatal diagnosis for women continuing pregnancies have become fairly typified. Within the context of the online forums, a separate subforum for women choosing to terminate their pregnancies becomes a real manifestation of an adversarial cultural narrative. Although explicit discussion of decision-making rationales between the two groups is against forum rules, the typified narratives of the first group serve a rhetorical purpose by including experiential evidence countering the second group's concerns.

CHAPTER SEVEN

CONCLUSIONS

This dissertation provides insight into a number of different discourses that are initiated and circulated by the rhetorical situation of prenatal testing for Down syndrome including disability critiques, genetic counseling discourse, and parent experiential narratives. Together, these analyses demonstrate that the prenatal testing situation is a complex one with many rhetorics affecting the outcome of each individual decision.

Chapter Four reviewed critiques of prenatal testing from cultural, feminist, and disability rights perspectives. One goal of this project was to determine if any of this critique has made it into the prenatal testing situation. In some senses, it is represented in both genetic counseling discourse and patient discourse. In Chapter Five, we saw that genetic counselors are trained to consider representations of disability. Both the textbooks analyzed and the position statements of the governing professional body indicate that genetic counselors are concerned with disability rights. This concern manifests itself in the way they are trained to correct patient misperceptions about disability, to explain the natural, genetic processes through which heritable conditions occur, to refer patients to advocacy groups and materials with experiential information about disability, and to facilitate informed decision-making. Thus, they are concerned with representing disability fairly and accurately. Furthermore, genetic counseling textbooks make an effort to present nondirective counseling as a complex practice whose effects have been questioned. In other words, genetic counseling discourse acknowledges the critique that nondirective counseling is not truly nondirective; in other words, counseling must have some effects or else it would not be necessary.

However, rhetorical analysis of genetic counseling materials suggests that there is no way for genetic counselors to fully embrace the critiques of feminist, cultural, and disability rights scholars. The discursive practice of genetic counseling limits what they are able to rhetorically achieve. For example, despite recognition that nondirective counseling is a naïve concept, analyses of the textbooks indicates that genetic counseling discourse still differentiates between neutral and biased information. Neutral information is scientific, genetic information about the testing procedures and the medical definitions of Down syndrome and other conditions. Counselors do not acknowledge that although this information may be factually accurate, it can still have (and does have) rhetorical effects. Thus, the problem that critiques of prenatal testing raise is not solved by being more careful about representations of disability. Although the situation of prenatal testing is one that provides information, counseling practice does not acknowledge that the situation is rhetorical as well, that by receiving information, however factual, users are affected in ways they cannot un-do.

A second issue raised in Chapter Four is an unresolved dilemma in the disability rights critiques about what the meaning of prenatal testing is. In other words, critics argue over whether prenatal screening, testing, and subsequent termination for disability expresses discriminatory attitudes towards people with disabilities. Women's discourse in Chapter Six helps further nuance this debate. In this chapter we see that women who choose to continue their pregnancies do seem to be more convinced by disability rights arguments that disabled individuals can live fulfilling lives and contribute to society while women who choose to terminate their pregnancies seem less convinced. However, women who choose to terminate their pregnancies explicitly reject the idea that they

devalue people with disabilities once they are born. In other words, they claim that their decision to terminate does not have an effect on the way they treat living people with disabilities. Nevertheless, analyses of their justifications for terminating indicates that this group of women generally views medical discourse about prenatal testing and Down syndrome as more authoritative than other discourses about Down syndrome.

Disability scholarship suggests that medical discourse is very limited in its capacity to represent disabilities like Down syndrome. Furthermore, although the prenatal testing situation does force women to engage with medical discourse about prenatal testing and disability, it does not force them to engage with alternative discourses about disability. This lapse is particularly troublesome in light of estimates that up to 90% of women who receive a prenatal diagnosis of Down syndrome choose to terminate their pregnancies. It should be troubling to everyone that these decisions may be being made by women who have not had the benefit of engaging with discourses about Down syndrome that provide alternatives to medical discourse.

Chapters Five and Six analyze two different commentaries on the situation of prenatal testing—genetic counseling discourse and user discourse. When these different commentaries are compared, different discourses about Down syndrome and prenatal testing are evident. Before discussing their differences though, it is important to mention one way in which they are alike. Analysis of the genetic counseling discourse indicates that there is no one, universal way that good motherhood is portrayed. Counseling narratives suggest there are many ways of being a good mother in the prenatal decision-making context. If anything, the only behavior that is universally represented as good is careful, inquisitive, and reflective decision-making. Likewise, pregnant women's

narratives offer many different ways of being a good mother. In general, good mothering for women choosing to continue their pregnancies after a Down syndrome diagnosis means accepting and loving their children regardless of disability. For the women choosing to terminate, being a good mother also means loving their children. However, these women represent love as being willing to suffer in place of their children whom they decided to abort in order to save them from the challenges of a disability. Thus, both sets of data demonstrate that “good motherhood” can be marshaled as a support for either practice in the wake of a positive diagnosis. Significantly, being a “good mother” appears to be an important element of both discursive moves.

With regard to the differences, analysis shows that there are many. First, genetic counseling discourse demonstrates that despite qualifications and nuanced understandings, medical information is still inherently valued for being factual and close to neutral. As a result, medical information is perceived by clients as neutral, and it is emphasized to the exclusion of experiential information about disability. User discourse shows that women choosing to terminate are very reliant on medical information and that they also value it to the exclusion of alternative ways of knowing about Down syndrome. However, women choosing to continue often exhibit skepticism about medical information. In several instances, users in the latter forum explicitly challenge medical authority. It is much more common, however, for users in the latter category to simply disregard medical information as irrelevant. As I showed through the analysis of prenatal diagnosis narratives, women choosing to continue their pregnancies spend considerable amounts of time representing their children after birth and effectively arguing that the medically relevant elements of Down syndrome become insignificant at this point. For

these women, the changing rhetorical situation from before birth to after birth affects the relevance of medical information, whereas for genetic counselors and women choosing to terminate medical information is always perceived as relevant.

In addition, analysis of the genetic counseling texts shows that genetic counselors perceive the information available from prenatal tests to be useful to decision-making. Both women choosing to continue and choosing to terminate after a Down syndrome diagnosis question this presumption. Many examples of discourse on the forums demonstrate that users of prenatal testing are concerned with both screening and diagnostic results. Screening results are so difficult to understand without expertise in statistical risk analysis that women on the boards resent the anxiety such results provoke in relation to the uncertainty of what the results indicate. In addition, even a diagnostic test gives uncertain information because the diagnosis of Down syndrome is so vague. The diagnostic test cannot give the information that many women want—that is to say the degree of severity of either physical or mental traits of the fetus. Thus, the experience of prenatal testing may result in users feeling as though the information given is not useful enough or worth the anxiety, whereas for genetic counselors, additional information is always perceived positively.

There is also conflict between what different groups represent as neutral information. Genetic counselors and women choosing to terminate often represent medical information as being unbiased and logical and experiential information about disability as being biased and emotional. Women choosing to terminate often point to discourse by women choosing to continue or by advocacy groups and suggest that it is flawed. They suggest that parents of children with Down syndrome are motivated to

represent only their positive experiences with the condition in order to garner more respect and resources for their children. While their critiques are in many cases apt—parent discourse is rhetorical in these ways—women who choose to terminate seem unable to analyze medical discourse in the same way. Since medical discourse is seen as logical, they do not think it can also be rhetorical. Genetic counselors are in no position to correct this assumption. First, they are not trained in rhetorical communication and are subject to the same prejudices about logical, scientific discourse. Beyond that, however, we would not expect them to challenge their own authority or the usefulness of prenatal testing—a technology that effectively creates their jobs. As I demonstrate in the fifth chapter, prenatal testing is part of a process of biomedicalization which suggests that health is a moral imperative. Genetic counselors operate within this process of biomedicalization and therefore are poorly situated to help users resist it. On the other hand, parents who choose to continue their pregnancies can and do go on to offer alternatives models of disability. They present perfect health as an unnecessary component to achieving satisfactory and fulfilling lives.

While genetic counselors may not explicitly value either the choice to continue a pregnancy or the choice to terminate after a prenatal diagnosis of Down syndrome, they certainly do value the deliberative process of decision-making. They value autonomy and try to encourage autonomous, rational decision-making. Women who choose to terminate often express similar desires. They strive to present their choice as rational and logical. Women who choose to continue their pregnancies, however, are more likely to question the ability to make autonomous, rational choices. Rarely, for example, some women in this category mention perceived coercion on the part of a medical professional, relative,

or friend to make one decision or another. More common and significant, however, women in this category are likely to assert that the knowledge one can gather about a disability before the baby is born is incomplete. They talk both about emotions and about rational knowledge when describing the differences between before and after the baby is born. They suggest that their own emotional states after a prenatal diagnosis prevent them from fairly and rationally judging the information about disability. Thus, after the birth, they view the same information from a different perspective. In addition, they suggest that they would have been completely unable to predict their own and their families' coping capabilities before the birth of the baby. Thus, while genetic counselors and many women choosing to terminate attempt to distinguish between rational and emotional factors of decision-making, many women choosing to continue represent these factors as inextricably linked.

Thus, one recommendation this dissertation points to is the need for women making decisions about prenatal testing and Down syndrome to go outside the medical situation and seek alternative representations of these events. Genetic counseling discourse is not prepared to challenge inaccurate views of disability as a burden or medical knowledge as inadequate because it is only prepared to challenge factual, logical, and rational information. Counselors do engage with patient emotions; however, they always seek to fit emotions into the context of decision-making. Women choosing to continue pregnancies after prenatal diagnosis challenge this practice by representing emotional and rational decision-making processes as sometimes being at odds with one another. In other words, counselors seem bent on distinguishing between emotions and rationale, they also encourage women to respond to their emotions in the decision-

making context. In contrast, women choosing to continue their pregnancies seem to recognize that it may be impossible to distinguish between emotions and rationales in this context. Thus, for these women, what they perceive as a truly rational decision-making process might be prohibited in this context.

The study of genetic counseling textbooks indicates that there are certain popular narratives that get repeated as lore regarding women's reasons for seeking or refusing genetic testing. For example, it is viewed as acceptable that older women may wish to continue a pregnancy after a prenatal diagnosis of Down syndrome because they view it as their last chance to have a baby. Likewise, analysis of the online forums suggests that religious reasons for continuing a pregnancy are overemphasized in genetic counseling discourse; far fewer women mentioned religion as a reason to continue the pregnancy than might be expected from the textbooks. Genetic counselors and other healthcare professionals need to be trained to recognize other, more nuanced reasons for refusing prenatal screening or invasive testing. For example, analysis of the parent forums indicates that some women simply feel that prenatal diagnostic testing does not provide them with enough information. Although amniocentesis can diagnosis Down syndrome, it cannot tell how the condition will be manifested. For some women, this uncertainty is difficult and others wish they hadn't gotten testing and been faced with this decision at all. Counselors need to be aware that prenatal testing can provoke this anxiety and be explicit about what information the tests can and can't provide.

The new, noninvasive MaterniT21 diagnostic test will change the rhetorical situation of prenatal testing for Down syndrome drastically. The benefit of this test is that it can provide an early diagnosis of the fetus without any risk of miscarriage. Proponents

of the test argue that early testing means that termination procedures will be less complicated and therefore less burdensome on the mother (Hill). However, if this test becomes routinized, it will likely represent important changes to the rhetorical structure of the prenatal testing situation. Currently, women must receive counseling before choosing to get diagnostic testing. Healthcare providers are required to present diagnostic testing as an option because it puts the fetus at risk of miscarriage. Essentially, this counseling serves as a stopgap for women and their supporters. It provides time for them to reflect on the possibility of giving birth to a disabled child. Rhetorically, it can also provide them with a readily available narrative for why they might want to refuse diagnostic testing. Despite the fact that the risk of miscarriage after amniocentesis has decreased significantly over time so that the risk is very, very small, many women still choose to forego diagnostic testing on the basis of not wanting to put the baby at risk. As a result, existing testing procedures also protect the mother from potentially having to make a choice that she doesn't want to make.

In a few years' time, there will be no readily available narratives for women to refuse diagnostic testing when the MaterniT21 test becomes routinized. It is likely to become as ordinary as other blood tests and thus unremarked in the experience of obstetrical management of pregnancy. As a consequence, more women may be placed in situations that they are unprepared for, rhetorically, ethically, and practically.

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