

RESPONSIBLE GENETICS: EXAMINING RESPONSIBILITY IN LIGHT OF
GENETIC BIOTECHNOLOGIES

By

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To my loving grandparents, Reba and Calvin,
To Mom and Dad for teaching me to be good for something,
and
To my wife, Rachel, infinitely loving and supportive

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TABLE OF CONTENTS

	Page
DEDICATION	iii
ACKNOWLEDGEMENTS	iv
INTRODUCTION	x
Thesis and Significance of Project.....	xi
Outline of Project.....	xiii
 Chapter	
I. THE PROMISES AND CHALLENGES OF THE NEW GENETICS	1
Contextualizing Genetics and Genetic Medicine.....	5
Novelty	5
Exceptionalism.....	8
Determinism.....	14
Interlude: Thinking More Clearly about Genetics and Genetic Health	19
Health and Disease.....	20
Genetic.....	23
The Utility of Genetic Health and Disease Concepts.....	25
Emerging Genetic Technologies.....	26
Predictive Genetic Testing.....	26
Preimplantation Genetic Diagnosis.....	34
Summary.....	40
 II. SPEAKING OF RESPONSIBILITY: STATEMENTS ON RESPONSIBILITY FROM MEDICAL PROFESSIONALS AND RELIGIOUS CARE PROVIDERS	 44
A Note on Focus Group Transcripts	47
Insights from Physician, Nurse, and Genetic Counselor Focus Groups	49
Clergy Members Speak: Notes from Hospital Chaplain and Ministerial Focus Groups	54
Institutional Responses to the New Genetics	59
Statements from Medical Professional Organizations	59
The American Medical Association.....	59
The American Nurses Association.....	63
The National Society of Genetic Counselors.....	67
Religious Institutional Responses to the New Genetics: Jewish and Christian Denominational Statements.....	69

Summary.....	80
III. UNDERSTANDING RESPONSIBILITY: PREVALENT DISCUSSIONS OF RESPONSIBILITY IN RELIGIOUS, PHILOSOPHICAL, AND BIOETHICS SCHOLARSHIP	84
A Brief Word on Responsibility	90
Jonsen’s Basic Patterns of Responsibility	91
Attribution of Responsibility.....	91
Appropriation of Responsibility.....	95
William Schweiker’s Typology of Responsibility.....	99
Agential Theories of Responsibility: Immanuel Kant.....	100
Social Theories of Responsibility: Stanley Hauerwas.....	104
Dialogical Theories of Responsibility: H. Richard Niebuhr.....	109
Responsibility in Bioethics Scholarship.....	113
The Influence of Principlism.....	113
Early Discussions of Responsibility: Garrett Hardin and George Agich.....	115
Responsibility and Genetics: Anders Nordgren and Guido Pennings.....	117
Summary.....	122
IV. TOWARD AN UNDERSTANDING OF RESPONSIBILITY GROUNDED IN STATUS AND INTEGRITY	126
Moral Agents Speak: Challenges in the Clinic.....	130
Judith Butler: <i>Giving an Account of Oneself</i>	134
The Modern Subject	134
Butler on Subjectivity and Responsibility	137
John Silber’s Status Responsibility.....	142
William Schweiker: Responsibility as a Matter of Integrity	151
Summary: Responsibility as a Matter of Status and Integrity.....	157
V. PREDICTIVE GENETIC TESTING AND PGD IN LIGHT OF RESPONSIBILITY.....	161
Responsibility and Genetics: Predictive Genetic Testing.....	163
Responsibility and Genetics: Preimplantation Genetic Diagnosis (PGD)....	169
Implications of Status and Integrity-Informed Responsibility for Medical Practice	180
Implications of Status and Integrity-Informed Responsibility for Bioethics.....	185
Summary.....	195
Appendix	
A. CASE STUDY SAMPLES.....	199
Prenatal Testing	199
Predictive Testing	199

BIBLIOGRAPHY 201

INTRODUCTION

This project arose out of my involvement with the Religion and Genetics study group at Vanderbilt University. Led by Professors Larry Churchill and Ellen Wright Clayton and sponsored by Vanderbilt's former Center for the Study of Religion and Culture, the study group consisted of ethicists, attorneys, physicians, genetic counselors, nurses, scholars of religion, and graduate students (including myself). Very broadly, our interests were in the manifold ways that genetic knowledge shaped our understandings of health and disease, healing and enhancement, human nature, and human relationships. These fundamental issues have deeply religious dimensions to them. Further, the language used to discuss genetics is often imbued with religious meaning. In the opening chapter of this dissertation, I provide examples of individuals, including scientists, proclaiming DNA (deoxyribonucleic acid) to be the "secret of life" and the "language of God." To a significant degree, religious perspectives and genetic knowledge simultaneously shape one another. The symbols associated with genetics in popular discourses are frequently saturated with religious meaning. At the same time, increased genetic knowledge and newfound genetics-based technologies bring many of those fundamental religious issues to the forefront of debates about how genetics shapes human self-understanding.

In early 2007, the Religion and Genetics study group conducted a series of 13 focus groups with members of the caring professions—physicians, nurses, genetic counselors, chaplains, and Christian ministers. Nine of the focus groups consisted of medical professionals (physicians, nurses, genetic counselors) and four involved hospital

chaplains and Christian ministers. We were interested in their experiences dealing with genetics-related issues in the course of their work and asked them to reflect on their experiences and to recall any especially memorable instances. I observed three of these focus groups and assisted with data analysis based on the transcripts from each focus group. In my work with the study group, I was intrigued by the ways in which participants, particularly the ministers, spoke about matters of responsibility in relation to genetics-based technologies. The ways in which they framed their moral experiences were also noteworthy.

I noticed that some of these individuals spoke about their moral distress and the distress of their congregants in the language of identity-conferring commitments, self-understanding, and integrity. Their challenges were not framed as matters of decision-making but as challenges related to living a life of integrity in light of difficult, often tragic, circumstances. Many times, there were no difficult decisions to make and yet their moral distress remained. References to responsibility often followed this trajectory, going well beyond the language of free, responsible choice. These individuals spoke of responsibilities that arose by virtue of the particular identity-conferring commitments that they held as fundamental to their self-understanding rather than out of any specific choice that they had made.

Thesis and Significance of Project

Turning to literature in religion, philosophy, and bioethics, I discovered that this way of thinking about responsibility is grossly underappreciated in academic scholarship. In particular, bioethics, as an emerging field of study, lacks a sufficiently robust

theoretical account of responsibility. Much of analysis of responsibility in these fields presupposes decision-making contexts and voluntaristic accounts of moral agency. It also fails to attend to the unique contours of the contextualized moral experiences of individuals. As a result, responsibility is construed primarily as a matter of making free, autonomous, voluntary decisions. In this dissertation, I argue that a voluntaristic and intentional account of responsibility must be supplemented by a vision of responsibility that acknowledges the ways in which an agent's roles and status may give rise to specific responsibilities in the context of the clinic—responsibilities that the agent does not intentionally and autonomously choose, but responsibilities for which the agent will nonetheless be held accountable.

This project contributes to bioethics scholarship on responsibility by developing a robust theoretical account of that concept that is attentive to the ways in which people involved with genetics-related issues frame their moral distress. To do so, I draw heavily on scholars of religion and philosophy, namely Judith Butler, John Silber, and William Schweiker. Specifically, I contend that this supplemental account of responsibility must emphasize two salient features that are often ignored in discussions of responsibility: 1) Responsibility entails the acceptance of obligations borne from one's status, regardless of one's acceptance of the status itself—whether one is a medical professional, a potential carrier of a genetic anomaly, a parent, or a member of a religious community; and 2) While responsibility promotes the movement toward greater integrity in one's life, that movement paradoxically involves recognizing and incorporating uncertainty and loss of control into that life. This paradox is especially evident in light of biotechnologies like PGD and predictive genetic testing, which purportedly provide a person with greater

control and certainty about the biological conditions of her life or the future life of her offspring, though they often highlight the ways in which agents lack certainty and self-control.

On a more practical level, in its turn to scholars of religion, philosophy, and rhetoric, the theoretical arm of this project provides a foundation for responding to the challenges posed to clinicians, counselors, patients, and families in the context of the clinic. It demonstrates the fruitfulness that attitudes of humility and openness to unique modes of being in the world have for considering what responsibility demands in a given set of circumstances. Along these lines, this project also highlights ways in which uncertainty inevitably rears its head in the clinic, even when dealing with genetic technologies that offer a person the ability to supposedly “take charge” of her health. Such boasts, I suggest, are profoundly misguided due to the type of information that genetic testing provides as well as the significant degree of uncertainty and unknowability that rests at the very heart of human existence. Finally, with its emphasis on the giftedness of human being, this project affirms the notion that humans are not fully self-creating masters of our own fate. In this way, it opens up deeply religious questions for individuals in the clinic as well as for scholars of bioethics.

Outline of the Project

Chapter one, “The Promises and Challenges of the New Genetics,” presents an overview of dominant themes in the public perception of genetics following the completion of the Human Genome Project. Specifically, I examine themes of novelty, genetic exceptionalism, and genetic determinism. I argue that while genetic technologies

provide us, in some instances, with novel ways to express human power and agency, much of the talk about the novelty of genetics is overstated. I also assert that statements about the exceptional nature of genetic information and the determinative nature of a person's genes are likewise overstated. This misunderstanding gives the impression that technologies like predictive genetic testing and PGD offer us certainty and control than they actually provide. I also clarify basic concepts of *health*, *disease*, and *genetic* to demonstrate how those concepts are more dynamic than we typically believe. Finally, I provide an overview of what predictive genetic testing and PGD entail as well as the ethical challenges that these technologies create for clinicians, patients, and family members.

In chapter two, I turn to the transcripts of the focus groups described above and highlight the ways in which individuals in the caring professions speak about responsibility in light of genetics-related issues. This chapter also provides evidence that responsibility is a critical moral concept for how people and institutions think about ethical challenges related to genetics. I then examine the codes of ethics of the American Medical Association, the American Nurses Association, and the National Society of Genetic Counselors to demonstrate how those institutions draw on the language of responsibility to describe the appropriate work of members of those professions. Similarly, I examine survey responses and doctrinal statements from Jewish and Christian denominations, highlighting the interesting ways that they speak of responsibility in relation to genetics-based issues. Key questions for this chapter include: How do people speak of responsibility? With what concepts or values is that term associated? Are there common features among the various articulations of responsibility? Where are the key

differences? How are these differences relevant for how one understands oneself in relation to genetic biotechnologies?

In chapter three I contextualize the themes that emerge from those focus group transcripts and institutional statements. I turn to scholarship on responsibility in both philosophy and religious studies, relying heavily on the typologies of Albert Jonsen and William Schweiker to organize that scholarship. Specifically, I discuss Albert Jonsen's patterns of attributions and appropriation of responsibility. I then turn to the work of theological ethicist William Schweiker, who has also developed a typology for theories of responsibility, classifying those theories as agential, social, or dialogical. I appeal to representative examples of each type of theory: Immanuel Kant (agential), Stanley Hauerwas (social), and H. Richard Niebuhr (dialogical). In doing so, I have selected the quintessential modern philosopher (Kant), someone who eschews any attempt to render "the Christian story" into the supposedly universal language of modernity (Hauerwas), and someone who described his work as an example of "Christian moral philosophy" (Niebuhr). I conclude by turning to ways in which responsibility has been cursorily examined in bioethics. In providing these overviews, I demonstrate how most of that scholarship on responsibility construes responsibility as a matter of autonomy, presupposing a voluntaristic account of moral agency and a context of decision-making.

Chapter four initiates the constructive turn in this project. Here, I develop the robust account of responsibility described above, paying special attention to the importance of integrity and status for what responsibility entails. I also briefly return to the focus group transcripts in order to show how many of the moral agents who deal with issues related to genetics actually see their work as a matter of integrity rather than

appropriate decision-making. To make this constructive move, I turn to the works of Judith Butler, John Silber, and the constructive work of William Schweiker. I explore Butler's *Giving an Account of Oneself* to render problematic the very notion of an "autonomous self" who is in control of her own life and can take full responsibility for herself. I also highlight the ways in which Butler argues that we are nonetheless called to responsibility—to give an account of ourselves—even though a full account is always beyond our grasp. I articulate John Silber's notion of "status responsibility" and show how it is beneficial for thinking about one's moral responsibility in relation to her genetic constitution. As it will be demonstrated in chapter three, most theories of responsibility hold that control or authority is a crucial component to assigning or accepting responsibility. That is, a person can only be responsible for actions, events, or entities he or she can control. Silber calls such assumptions into question and offers a way in which an agent can think of responsibility for those things to which she is related but over which she has no authority or control. Finally, I turn to William Schweiker's account of responsibility as a matter of integrity. For Schweiker, responsibility promotes an agent's movement toward greater integrity and self-understanding. Even though I contend full self-understanding is never achievable, I construe the moral life as a constant quest for greater self-understanding and integrity.

Finally, chapter five returns to the earlier discussions of the challenges posed by predictive genetic testing and PGD. I examine those challenges in light of the vision of responsibility I advocate in chapter four. I demonstrate how this underappreciated way of thinking about responsibility clarifies some of the ethical challenges that arise from these technologies and their increasing presence in the clinic. I show how the source of moral

distress is not necessarily uncertainty about what choices a person should make—for some the choice is all too clear—but rather in understanding oneself and being able to give an account of the responsibilities that an agent does not choose but for which she will still be held responsible. I also examine how technologies like predictive genetic testing and PGD actually reinforce my assertions about the ever-presence of uncertainty and the limits of self-knowledge. Those limits, I maintain, are oftentimes sources of moral distress for those agents who come face-to-face with uncertainty in the context of the clinic.

CHAPTER I

THE PROMISES AND CHALLENGES OF THE NEW GENETICS

In both public discourse and within medical contexts, genetics is frequently approached with a deep sense of awe, if not outright reverence. At the popular level, we find mention of DNA (deoxyribonucleic acid) as being “the secret of life” or “the language of God.”¹ Advances in this field have spurred a renewed interest in those questions that we hold to be fundamental, personal, and deeply religious—questions of human nature and personal identity: What does it mean to be a human being? What does it mean to be *me*? How did I become the person that I am today? In what aspects of my life do I have control? In what ways am I at the whim of chance? Genetics also follows in a tradition of sciences that are used to explain human traits and behaviors. We hear of certain aspects of life being “in our genes” and thus outside the domain of our design or control. We also hear promises of new biotechnologies that will allow us to gain greater

¹ See Francis S. Collins, *The Language of God: A Scientist Presents Evidence for Belief* (New York: Free Press, 2006); James D. Watson and Andrew Berry, *DNA: The Secret of Life*, 1st ed. (New York: Alfred A. Knopf, 2003). Interestingly, both Watson and Collins are research scientists who have played crucial roles in the development of the field of genetics. Watson, of course, is famous for discovering DNA’s helical structure in 1953, along with the help of Francis Crick, Rosalind Franklin, and several others. Francis Collins was the original director of the National Human Genome Research Institute, the group that originally led the charge to complete the Human Genome Project in the 1990s. As I argue later in this chapter, such language of genetic exceptionalism is not consistent with what scientific research has revealed about the function of DNA and its role in producing the traits that comprise a human being. To have influential scientists like Watson and Collins drawing on such language, however, only serves to further entrench many of the misguided popular notions surrounding DNA.

access to those previously uncontrollable aspects of our lives, exercising profound levels of choice and control over the genetic constitution of our offspring. In this way, genetics also raises serious questions about the nature of responsibility.

Concerns about the ethical implications of genetics and genetic biotechnologies have persisted in scholarly circles for over forty years, though these concerns are now finding a home within public discourse. This movement into public consciousness was driven largely by the development of the Human Genome Project (HGP) in October 1990. At that time, the United States Department of Energy (DOE) and the National Institutes of Health (NIH) joined forces to create an initiative designed to sequence the three billion nucleotide base pairs and to identify the 20,000-25,000 genes that comprise the entire sequence of human DNA.² The Project brought together hundreds of scientists from across the country, and one of the HGP's goals was to make its findings readily accessible to other researchers for further work. Recognizing the potential for the HGP to create controversy, the DOE and NIH also earmarked 3-5% of their annual HGP budget to analyzing the ethical, legal, and social issues (ELSI) raised by the Project and the technologies it could spawn.³ While the HGP was initially a government-sponsored initiative, private research firms (such as Craig Venter's *Celera Genomics*) quickly joined in the efforts. The combination of scientific curiosity and a healthy competition among

² United States Department of Energy Office of Science, "About the Human Genome Project." <http://www.ornl.gov/sci/techresources/Human_Genome/project/about.shtml> (accessed April 8 2009).

³ United States Department of Energy Office of Science, "Ethical, Legal, and Social Issues—Genome Research." <http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml> (accessed June 24 2009).

researchers led to the completion of the HGP in late 2003, roughly two years ahead of schedule. Perhaps the greatest catalyst for the HGP and its rapid completion was its incredible *translational* potential, that is, the potential for HGP discoveries to move from the scientist's bench to the patient's bedside in the form of new medical technologies.

Though the “new genetics” long carried promises of personalized medicine, pharmacogenomics, and a battery of echnologies designed to contribute to medical care, the fervor surrounding those promises reached a fever pitch as the HGP came to fruition. In popular media, we hear of a “genetic revolution” in medicine, with visions of genetic interventions for nearly any imaginable condition.⁴ We hear of a future in which “designer children” with pre-selected traits will be increasingly common. With these images becoming routine, people now often discuss genetic technologies and their implications popular media, public policy arenas, Sunday School classrooms, and around family dinner tables. To a significant degree, those discussions are warranted. Genetic biotechnologies are becoming common components of “Western” medical care, particularly in prenatal and neonatal medicine. The proliferation of these technologies indicates that medical practitioners (with some exception) find them to be beneficial and that the ethical issues they raise are acceptable challenges for medical care. Thus, it seems that some of those fundamental questions—Can we do this? *Should* we do this?—have already been answered affirmatively. As a result, questions about the ethical import of genetics in medicine have now shifted to an examination of how genetic information and technology can be utilized in medical contexts. Here again we are confronted with

⁴ For example, see Gina Kolata's "A Revolution at 50; Genetic Revolution: How Much, How Fast?" *New York Times*, February 25, 2003, Science section.

questions of responsibility: How can we responsibly use genetic information in medical care? What does it mean for a responsible person to have access to these newfound attempts at greater control? What are the responsibilities of care providers? Of patients? To whom are those responsibilities owed?

This dissertation is an analysis of responsibility in light of two specific technologies that have arisen as our understanding of genetics has increased: predictive genetic testing and preimplantation genetic diagnosis (PGD). This chapter describes these two technologies and details the intellectual context within which they have developed. In doing so, I illustrate how this larger intellectual framework places great emphasis on the “gene” as a concept for understanding human health, behavior, and disease. I also note the ethical challenges that these technologies pose to individuals involved in their use. My concern with the popular understandings of genetics and genetic technologies is due to the significant gap in understanding between scientists and the lay public. Though the human genome consists of thousands of genes and billions of nucleotides, it is a microscopic, sub-cellular phenomenon. Typically, those who are qualified to wear the priestly vestments—the white lab coats of physicians and scientists—have a much more nuanced understanding of what genetics actually entails. The transition from technical, scientific idiom to language that the layperson can understand is fraught with potential misunderstanding. Attempts to “translate” the work of the physician or scientist are bound to result in “mistranslation” as the process of simplification inevitably leaves out crucial details while drawing on imagery (DNA as a “code” or “book,” for example) whose own limits are rarely acknowledged. Popularized understandings of genetics, though often riddled with inaccuracies, are nonetheless

powerful forces that shape the tenor of current debates on the place of genetics in the medical clinic. To ignore the power of those views would be to neglect one of the sources of many of the perceived ethical challenges that genetic biotechnologies pose to physicians, counselors, patients, and other care providers.

This “popular” understanding of genetics that I describe is grounded in three distinct but related concepts: novelty, exceptionalism, and determinism. In the following sections, I describe some of the ways in which these concepts fuel public perceptions of genetics. I also illustrate ways in which those three concepts fall well short of accurately portraying the history and science of genetics and genetic technologies. In doing so, I endorse accounts of genetics and genetic information that are less sensationalized and truer to scientific data. Such accounts would not only be more factually accurate but would also promote a more robust response to the ethical challenges that genetics and genetic technologies like predictive testing and PGD pose to patients and care providers alike.

Contextualizing Genetics and Genetic Medicine

Novelty

If we relied on their portrayal in popular media (magazines, film, television), we might believe that genetics and genetic biotechnologies are new phenomena. We would see frequent references to the “new genetics” or a “genetic revolution.” Recall, for example, the cover of the January, 17, 1994 *Time* magazine that depicts a man with outstretched arms, adorned with DNA’s double-helix and the caption “Genetics: The

future is now.”⁵ The 1997 science-fiction film *GATTACA* (a reference to DNA’s nucleotide base pairs) portrays a not-too-distant future in which upper and upper-middle class families use technologies akin to PGD to select the “best” possible traits for their offspring. If we relied on this imagery for our primary understanding of genetics, we would have to believe that we are in uncharted territory, laden with previously unknown challenges and possibilities for our futures. In other words, we would think that genetics and genetic technologies were novel components of both medicine and our self-understanding.

Of course, the history of genetics and the concept of a “gene” extend well beyond the work of the HGP, even long before the 1953 discovery of DNA’s helical structure. What scientists now describe as “a specific sequence of nucleotides in DNA or RNA... usually on a chromosome and that is the functional unit of inheritance controlling the transmission and expression of one or more traits by specifying the structure of a particular polypeptide” has also become the site at which the theories of Darwinian evolution and Mendelian inheritance have merged.⁶ Thus, the “gene” has become the biochemical unit for explaining the mechanisms by which traits are passed from generation to generation and for describing how various species are related to each other. Even as early as 1902, scientists like Archibald Garrod were searching for such a sub-cellular explanation for the presence of inherited traits (especially diseases or disorders). Around that same time, Danish botanist Wilhelm Johannsen was the first to coin the word

⁵ Dena S. Davis, “Genetics: The future is now,” *Time*, January 17, 1994.

⁶ *Webster’s New World Medical Dictionary*, ed. William C. Shiel, Jr. and Melissa Conrad Stöppler, 3rd edn. (Hoboken, NJ: Wiley Publishing, 2008), s.v. “gene.”

“gene,” to describe units of Mendelian inheritance.⁷ As research progressed throughout the 20th century, we have arrived at a contemporary view of the “gene” as a mutable unit of inheritance that specifies the production of amino acids (the biochemical building blocks of proteins).⁸ What should be noted here, however, is that this particular understanding of the “gene” has been a long time coming. Quite simply, the gene is not a recent discovery, contrary to how it may be portrayed in popular culture. Rather, as the work of scientists like Garrod and Johanssen demonstrate, researchers have long suspected that something akin to the gene must exist. That process of discovery, however, may be better understood as a process of gradual and incremental refinement rather than sudden discovery. Thus, to portray genetics as something novel to our contemporary context is fundamentally misguided.

Further, it should be noted that genetic information has long been utilized in the medical context, long before any contemporary discussions of a “genetic revolution” arising from the work of the HGP. For example, chorionic villus sampling (CVS)—first developed in 1968—is a prenatal diagnostic tool that tests for a range of genetic abnormalities in a fetus by examining the genetic material from chorionic villi (which is identical to the genetic material of the fetus).⁹ In the United States, newborn infants are

⁷ Lenny Moss, *What Genes Can't Do*, Basic Bioethics (Cambridge, MA: MIT Press, 2003), 28 ff.

⁸ For a brief history of the development of the gene, see the 3rd chapter of Matt Ridley's *Genome: The Autobiography of a Species in 23 Chapters* (London: Fourth Estate, 1999). See also Evelyn Fox Keller's *The Century of the Gene* (Cambridge, MA: Harvard University Press, 2000).

⁹ Jan Mohr, "Foetal Genetic Diagnosis: Development of Techniques for Early Sampling of Foetal Cells," *Acta Pathol Microbiol Scand* 73, no. 1 (1968).

routinely screened for phenylketonuria (PKU), a condition for which early dietary intervention can drastically improve one's health outcomes. Those tests are based on knowledge of human genetics. To speak of a "genetic revolution" in medical care is therefore hyperbole. What has changed most about the place of genetics in clinical settings is the ever-increasing degrees of specificity and multiplicity that these technologies now possess. New tests are available that provide us with more information about our health status, our futures, and the genetic constitution of future offspring. While I maintain that it is beneficial to temper our discussions of genetics by resisting the language of novelty as much as possible, it should be noted the levels of knowledge and control that new genetic technologies purportedly offer is indeed at a new level. In other words, genetics has been a component of medical care for quite some time. The newfound levels of knowledge, control, and power that those technologies provide us, however, may indeed be unlike anything we have previously witnessed.

Exceptionalism

Another theme fueling many popular understandings of genetics is often called genetic exceptionalism. The language of genetic exceptionalism is at work in the earlier remarks about the reverential attitude that many people have toward genetics. Within the framework of genetic exceptionalism, people speak about genetic material and information as if there is something qualitatively unique about genes that make them somehow special or different.¹⁰ As a result of those unique features, genetics warrants

¹⁰ Thomas Murray first coined the phrase "genetic exceptionalism" to describe this perspective. See his "Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information?" in *Genetic Secrets: Protecting*

special consideration that we rarely give to other biochemical entities, processes, and technologies.¹¹ For example, consider the words of former President Bill Clinton in his June 26, 2000 press conference announcing the completed first draft of the HGP's findings: "Today we are learning the language in which God created life. We are gaining ever more awe for the complexity, the beauty and the wonder of God's most divine and sacred gift."¹² Former Director of the National Human Genome Research Institute, Dr. Francis Collins, recently wrote a book (which has a strand of DNA emblazoned across its cover) about science and religion entitled *The Language of God*.¹³ These examples demonstrate ways in which genetics can be imbued with powerful symbols and metaphors that portray that genetics as special, worthy of reverence, and even sacred. Further, such reverential language is rare—if not downright foreign—when speaking about other bodily materials and processes. We do not describe neuronal networks, the cardiovascular system, or waste removal with such sacred, special language. In the light of exceptionalism, genetics becomes the fundamental explanatory model for understanding numerous aspects of human existence. Picking up on the reverential

Privacy and Confidentiality in the Genetic Era, ed. Mark A. Rothstein (New Haven, CT: Yale University Press, 1997).

¹¹ Ronald M. Green and A. Michael Thomas, "DNA: Five Distinguishing Features for Policy Analysis," *Harvard Journal of Law and Technology* 11, no. 3 (1998).

¹² "June 2000 White House Event," Office of the Press Secretary, 26 June 2000. The White House: Washington, D.C. 21 April 2009. <<http://www.genome.gov/10001356>>.

¹³ Collins, *The Language of God*.

themes in the two examples above, Dorothy Nelkin and M. Susan Lindee even assert that DNA has become popular Western culture's "secular equivalent of the Christian soul."¹⁴

Claims about the exceptional nature of genetic material and information do not rely solely on religious or theological language, although the examples indicate that such claims are often bolstered by such appeals. Beyond the obvious reference to God in the metaphor that Clinton and Collins have drawn upon, there is a significant element of non-religious symbolism present in the "language of God" metaphor—the very reference to *language*. Genetic material is often portrayed through the use of textual and linguistic symbols; the very concept of the genetic "code" is a prime example of reliance on such communicative imagery. In these references, genetic material is described as that component of the body that both *contains* (like a book) and *communicates* (like a language or code) the information necessary for our very existence as human beings. For example, Audrey Chapman (among others) compares DNA to a "blueprint" with the "instructions" for assembling the amino acids and proteins that comprise the human body.¹⁵ Anders Nordgren has examined texts in behavioral genetics for their metaphorical content and found abundant descriptions of DNA as "programs" or "books" that "control" or "respond."¹⁶ In her study rebuking such appeals to communicative imagery, Lily Kay argues that their influence has been all the more potent because of

¹⁴ Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York: Freeman, 1995), 2.

¹⁵ Audrey R. Chapman, *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science* (Minneapolis: Fortress Press, 1999), 4.

¹⁶ Anders Nordgren, "Metaphors in Behavioral Genetics," *Theoretical Medicine and Bioethics* 24, no. 1 (2003).

resonance with the religious symbol of the “book of life.”¹⁷ Within biological sciences, textual symbols appear to be uniquely associated with genetic material in particular, thereby supporting the idea that genetic material is uniquely special in a way that other biological materials are not.

Following this prevalent textual understanding of the human genome, we might conclude that the genetic “code” has become the new “Western canon” for the late modern or post-modern era. Biologist Scott Gilbert and his colleagues claim that “Introduction to Biology” courses have usurped the foundational status in colleges that previously belonged to courses on “Western Civilization.”¹⁸ Living in an era where the notions of a “canon” and “Western civilization” are unceasingly critiqued, enrollments in courses on this topic are on the decline in American university systems. Yet, most students *will* take an introductory biology course. Gilbert and his colleagues suggest that by taking over that foundational position from Western civilization classes, biology has now become the lens through which human culture, history, political relations, and behavior are explained. When our genetic sequence becomes the primary “text” for this course, genetic material then comes to be understood as providing the biochemical basis for a wide range of human traits, including specific physical characteristics, intellectual capacity, behavioral tendencies, and health status.

¹⁷ Lily E. Kay, *Who Wrote the Book of Life?: A History of the Genetic Code*, Writing Science (Stanford, Calif.: Stanford University Press, 2000). See especially chapter 7, “In the Beginning Was the Wor(l)d?”

¹⁸ Scott F. Gilbert and the Biology and Gender Study Group, “Mainstreaming Feminist Critique into the Biology Curriculum,” in *Doing Science + Culture*, ed. R. Reid and S. Traweek (New York: Routledge Press, 2000), 199-220.

The claims of genetic exceptionalism have also made a significant impact in public policy arenas. Worried about the prospect of employers and insurance companies using genetic information as exclusion criteria against potential employees and customers, former President George W. Bush signed into law H.R. 493, the Genetic Information Nondiscrimination Act (GINA) in May 2008.¹⁹ The law prohibits the use of information about genetic predispositions to disease as exclusionary criteria for employment and insurance coverage. Supporters of GINA hope that this protection will ease people's fears about potential genetic discrimination, allowing people to feel more comfortable with pursuing genetic tests as part of their healthcare plans and leaving open the possibility of personalized genetic medicine. The very existence of GINA (which had been debated in Congress for over a decade) indicates the perception of policymakers that genetic information requires unique legislative protections above and beyond measures that are already in place for a person's medical record (like the Health Insurance Portability and Accountability Privacy Law, HIPAA).

From a public policy perspective, legislation like GINA might be necessary if the claim of genetic exceptionalism is true, that is, if there are indeed good reasons for treating genetic information as qualitatively different from other types of information. Legal and bioethics scholar Mark Rothstein has identified seven arguments that advocates of genetics-specific laws provide in support of such legislation (in other words, seven reasons why genetic material and information warrants special protection):

“(1) Genetic information has implications not only for the individual but also for family members; (2) genetic information may have implications

¹⁹ *Genetic Information Nondiscrimination Act of 2008*, Public Law 110-233, 110th Congress, 2nd session, 21 May 2008.

for reproduction and characteristics of future generations; (3) genetic information may be predictive; (4) genetic information often carries stigma, and the misuse of genetic information has led to eugenics, racism, and genocide; (5) genetic information is regarded as unique by the public; (6) there are other ‘special’ categories of medical information for which separate protections have been adopted, including HIV/AIDS and mental illness; and (7) the political reality is that there is greater support for genetic nondiscrimination than for more general and sweeping laws.”²⁰

Ultimately Rothstein finds each of these arguments to be unpersuasive. He notes that the supposedly unique characteristics described in 1-3 are not unique to genetic information but could be equally applied to socioeconomic factors and family history. The issue of stigma, he argues, does not indicate anything unique about genetic information and could best be addressed through public education on the genetic science and medicine, not through legislation. The idea that *because* people hold genetics to be unique it should therefore receive unique treatment is a self-fulfilling prophecy, while the analogy in 6 does not hold because unlike information about one’s HIV/AIDS status, genetic information cannot be easily isolated in a patient’s medical record. As for the political impetus for supporting genetics-specific laws, Rothstein argues that general discrimination laws would diminish the stigma attached to genetic information whereas laws like GINA may actually perpetuate such stigmatization and empty claims of genetic exceptionalism.

Another motivating force underlying the support of genetics-specific legislation is the idea that because genetic information is unique to individuals and can therefore be used for identification purposes, its privacy must be protected (even within the already-

²⁰ Mark A. Rothstein, "Genetic Exceptionalism & Legislative Pragmatism," *Hastings Center Report* 35, no. 4 (2005), 27-33; quote on 30. See also Rothstein’s “Policy Recommendations” in *Genetics and Life Insurance: Medical Underwriting and Social Policy*, ed. Mark A. Rothstein (Cambridge, MA: MIT Press, 2004).

private medical record). James Evans and Wylie Burke readily note, however, nearly everything in a person's medical record is "identifying" to a significant degree.²¹ They also note that "genetic risk" for a particular disease is rarely different from other forms of risk (family history, socioeconomic status, diet, lifestyle, etc.). Why then do the calls for genetics-specific protection remain? Evans and Burke suggest that legislation informed by genetic exceptionalism persists for two significant reasons: "genetics is at the heart of our most profound relationships" and the "cultural belief that genetics largely determines who we are (despite many observations to the contrary)."²² That is, people tend to view genetics as constitutive of who we are as human beings, both as relational creatures (I have *these* parents rather than *those* parents, *these* siblings rather than *those* siblings, etc.) and as specific individuals with unique physical and character traits. Here, Evans and Burke suggest that views of genetic exceptionalism are bolstered by a perspective known as genetic determinism. It is thus necessary to examine what that idea entails.

Determinism

Broadly speaking, genetic determinism is the notion that a person's genetic constitution is determinative of his or her physical, mental, and even psychological constitution. In the supposed struggle between "nature" and "nurture," a person's given genetic "nature" rules the day. We hear the language of genetic determinism in remarks about a person's appearance, talents, or traits being "in his/her genes." When physicians and laypeople alike refer to "the gene" for a specific disease, deterministic thinking is

²¹ James P. Evans and Wyle Burke, "Genetic Exceptionalism. Too Much of a Good Thing?," *Genet Med* 10, no. 7 (2008), 500-501.

²² *Ibid.*, 501.

again at work. Although deterministic thinking is not unique to considerations of genetics, it has become the focal point for such perspectives in the late 20th and early 21st centuries. Where brain size was once considered to be “the” reason that men were (supposedly) more intelligent than women and Caucasians were (supposedly) more intelligent than Africans, today those sexist and racist claims are often made with reference to apparent differences “in the genes” of these different groups.²³ Recall the controversy that arose in late 2005 when then-President of Harvard University, Lawrence Summers, suggested that research in behavioral genetics may hold the key to explaining why women are underrepresented in the fields of mathematics and the sciences. Such deterministic thinking often provides people with a perceived genetic basis for one’s fate and future possibilities—potentially limiting those possibilities altogether.

Messages of genetic determinism permeate popular discourse on genetics in American culture. For instance, consider the research that was sensationalized as a search for a “gay gene.” In July 1993, *USA Today* published an article with the headline “Is there a Gay Gene? Key evidence: More maternal kin are gay.”²⁴ Soon after, other popular news magazines followed suit.²⁵ These articles drew upon research published in the journal *Science* that indicated that a portion of the X chromosome in males (the sex

²³ For numerous examples of genetics used to justify racist and sexist claims, see Nelkin and Lindee, *The DNA Mystique*, ch. 6, pp. 102-126. See also Diane B. Paul’s *Controlling Human Heredity: 1865 to the Present* (Atlantic Highlands, NJ: Humanities Press, 1995).

²⁴ Kim Painter, “Is There a Gay Gene? Key evidence: More maternal kin are gay,” *USA Today*, 16 July 1993, Sec. A1.

²⁵ For example, see Sharon Begley’s article “Does DNA Make Some Men Gay?” in *Newsweek*, Vol. 26 Issue 4 (26 July 1993), 59 and Anastasia Toufexis’ “New Evidence of a ‘Gay Gene,’” *Time*, Vol. 146 Issue 20 (13 November 1995), 95. The latter article cites 1995 research in *Nature Genetics* that seems to confirm the 1993 *Science* article.

chromosome inherited from one's mother), when it contained specific markers, *may* influence a man's sexual orientation. The *Science* article noted with "a statistical confidence level of more than 99 percent that at least one subtype of male sexual orientation is genetically influenced."²⁶ The key word in this phrase is *influenced*. Previous studies had shown that sexual orientation is not genetically *determined*, as there are numerous cases of identical twins who share identical genetic sequences and yet have different sexual orientations. Nonetheless, this study sponsored by the National Cancer Institute demonstrated that *for some men*—usually those men who had homosexual uncles and cousins in their mother's family—statistics indicate that there is a genetic predisposition toward likewise identifying themselves as homosexual men.

Why then did such popular news articles consistently refer to the "gay gene?" Media initially presented this research with an air of determinism, although in carefully reading these articles (as well as the scientific research on which they are based), it becomes apparent that it would be inaccurate to speak of a genetically-*determined* homosexuality. Instead, we find that "more likely, inheritance and experience together shape sexual orientation."²⁷ Dean Hamer, principal investigator on these studies, explicitly notes, "from twin studies, we already know that half or more of the variability in sexual orientation is not inherited. Our studies try to pinpoint the genetic factors, not to negate the psychosocial factors."²⁸ Nonetheless, by connecting homosexual

²⁶ Dean Hamer, et al, "A Linkage between DNA Markers on the X Chromosome and Male Sexual Orientation," *Science*, Vol. 261, No. 5119 (16 July 1993), pp. 321-327. Sexual orientation in this study was measured according to the Kinsey scale system.

²⁷ Begley, "Does DNA Make Some Men Gay?"

²⁸ Hamer, quoted in Toufexis, "New Evidence of a 'Gay Gene.'"

orientation to a genetic factor, these studies seemingly demonstrate that homosexuality “is not ‘a deviant choice and [the result of] a lack of will. It is at least partly a biological orientation, as important to one’s constitution as eye color.’”²⁹

Motivations for simplifying the complex relationship between genes, environment, behavior, and experience may be purely pragmatic: “One reason is that people like to read and buy books and magazines that tell them something definite about their origins, nature, and, perhaps, their future.... there is a pragmatic interest for publishers to present *definite* explanatory and predictive claims that seem to pertain to each of us individuals.”³⁰ Besides the obvious commercial interests that promote simplified, deterministic portrayals of genetics, there are other factors at work. Perhaps it is ignorance on the part of the non-scientist reporter or perhaps an intellectual laziness that favors simple explanations, even at the cost of truthfulness. Political and ideological forces are also at work in deterministic portrayals of genetics, as there may be ideological and prejudiced reasons for promoting deterministic thinking.

Lenny Moss has argued that this prevalent idea that “genes constitute information for traits (and blueprints for organisms)” is based on the conflation of a deterministic view of genes as predictive of an organism’s phenotype (the observable characteristics of an organism) with an “epigenetic” view of genes as “developmental resources” that serve as templates for RNA and protein synthesis.³¹ This conflation, he argues, is enabled

²⁹ Kenneth Paul Rosenberg, quoted in Begley.

³⁰ Neil C. Manson, “Presenting Behavioural Genetics: Spin, Ideology, and Our Narrative Interests,” *Journal of Medical Ethics* 30, no. 6 (2004), 601-604; quote on 603. Italics are Manson’s.

³¹ Moss, *What Genes Can’t Do*, xiv.

through the use of textual images and metaphors, like those that I described above. As a result, there is a strong tendency to think of one's traits as being "written in the genes" that carry the "instructions" for making the proteins that constitute the human body. While it may be possible to separate these two distinct ideas of what constitutes a gene, he argues that their combination perpetuates deterministic thinking about genetics.

It is crucial to note that while researchers have clearly identified numerous monogenic traits or conditions (Huntington disease, for example) for which phenotypic expression is indeed a direct product of one's genotype, such clear-cut certainty is rare in the realm of genetics. In fact, there is a great deal of variability associated with genetics and the move from genotype (genetic constitution) to phenotype. Instead, it is more accurate in speaking of genetic *predispositions* to specific traits or conditions. The movement from genotype to phenotypic expression can be influenced by a host of non-genetic factors, including environment, the epigenetic and biochemical environment surrounding DNA, the translation of DNA to RNA, diet, and various developmental events. In fact, the same sequence of DNA material can be "translated" into different RNA and thereby produce different amino acid products. It would be false to maintain such a fixed, deterministic understanding of what "a" gene can do.

While the science behind arguments against widespread genetic determinism may be difficult for the non-scientist to understand, an easy-to-understand real-world example can illustrate determinism's shortcomings. Consider identical twins. Although they share a common genome, those of us who know sets of identical twins can quickly point to differences in traits—both physical and in their personalities—that enable us to readily

identify which twin is which. To claim that because those twins share the same genetic material they must be identical in every way would be ludicrous to those of us who know them! Thus, it should be apparent that the claims of genetic determinism are oftentimes exaggerated at best, and sometimes altogether incorrect.

Interlude: Thinking More Clearly about Genetics and Genetic Health

To address the ethical challenges posed by emerging genetic technologies like predictive genetic testing and PGD, we must also clarify some of the basic terms that appear in public discourse and in scholarly literature on these topics. While I have already addressed the power of three themes—novelty, exceptionalism, and determinism—and demonstrated how they are often exaggerated in public discourse on genetics, the meanings of the fundamental terms of those debates are often taken for granted. For example, what does “genetic” mean in these discussions? One can appeal to biochemical data in order to point to some identifiable sub-cellular entity that we call “DNA” or a “gene” or a “chromosome” but such appeals provide little insight about what constitutes a “genetic disease” or what “genetic health” might look like. In other words, what makes a condition a “genetic” condition rather than a physiological condition? What difference does “genetic” make here? Does it make sense to speak at all of genetic health and diseases? While an entire dissertation could be devoted to unpacking those questions, I merely intend to prod them in order to reveal the significant ambiguity at the heart of such concepts and the difficulties that this ambiguity creates for discussions of genetic technologies.

Health and Disease

First, consider the very concepts of health and disease. Human beings are, to a great extent, goal-oriented creatures. As Aristotle noted at the beginning of Book One in his *Nicomachean Ethics*, “Every art and every enquiry, and similarly every action and pursuit, is thought to aim at some good; for this reason the good has rightly been declared to be that at which all things aim.”³² Leaving aside questions of what the proper *telos* of human life might be, I want to follow Aristotle and suggest that the art of medicine has its own particular goals that are typically couched in the language of health promotion and disease prevention. As H. Tristram Engelhardt (among others) has noted, however, health and disease are both descriptive and evaluative concepts.³³ As a descriptive concept, health is decidedly ambiguous, typically articulated in relation to equally ambiguous notions of physical, mental, and social well-being (which merely pushes the bump around in the rug, so to speak).³⁴ “Health” generally describes the ability to live and successfully interact with the world, though again, what such success entails is not

³² Aristotle’s *Nicomachean Ethics* (trans. W.D. Ross) in Aristotle, *The Basic Works of Aristotle*, ed. Richard McKeon, (New York: Modern Library, 2001), Book 1, paragraph 1.

³³ H. Tristram Engelhardt, “The Concepts of Health and Disease,” in H. Tristram Engelhardt, Arthur L. Caplan, and James J. McCartney, *Concepts of Health and Disease: Interdisciplinary Perspectives* (Reading, MA: Addison-Wesley Publishing Company, 1981), 31-45.

³⁴ The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” In defining health in this way, it also becomes a heuristic goal, one to which persons should strive but one that is ultimately unattainable. See the Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

easily agreed upon. Disease, on the other hand, describes conditions that thwart one's health. Engelhardt notes that the concept of disease can be descriptive in both an ontological sense (referring to some material *entity* that causes a disease) as well as in a physiological sense (referring to the state of being diseased).³⁵ We can thus speak of disease in relation to both material conditions (such as germs or viruses) as well as one's actions that contribute to his or her state of disease.

As evaluative concepts, the labels of health and disease are value judgments, ways of expressing that something is significant, worthy of praise or blame, worth seeking and promoting or avoiding and eradicating. As value judgments, assigning those labels is thus a context-dependent and dynamic process. What is considered to be a "disease" in one time and context may be of little concern or even considered to be healthy and beneficial in other contexts. Masturbation, for example, was considered to be a disease by Western cultures in the 18th and 19th centuries, thought to contribute to a host of degenerative conditions as well as other deviant behaviors. Nowadays, it is largely considered to be an acceptable component of one's sexual activities and is rarely (if ever) the purview of physicians. In fact, some people might argue that it can serve as a "healthy" outlet for one's sexual energy. Further, because it is no longer considered to be a disease, masturbation is no longer seen as a condition for which a physician can provide treatment. In this way it has lost its status as an object of medical concern, perhaps making the use of health and disease labels seem a bit odd in this specific context. Of course, we can also readily think of conditions that are considered to be diseases in almost any culture, some condition that is so adversely significant that it would be called

³⁵ Engelhardt, "The Concepts of Health and Disease."

a disease in nearly any context. What I mean to emphasize here, however, is that “disease” itself is not always a static concept.

Examples of the dynamic, malleable nature of health and disease can be found in relation to supposed “genetic” conditions, as well. Sickle cell anemia is a condition in which a person’s red blood cells are sickle-shaped due to abnormally shaped hemoglobin proteins in the cells. That “abnormality” is caused by a single nucleotide mutation on the short arm of chromosome 11p15.5, on the “hemoglobin beta gene.” In order for the condition to manifest, each of the two chromosomes 11p15.5 must possess the mutation in question (that is, sickle cell is a homozygous condition).³⁶ Sickle cell anemia is much more prevalent in people of African ancestry and is today considered to be a condition that requires treatment. Left unchecked, sickle cell anemia can contribute to a host of other complications, including stroke and significant organ damage. However, the sickle-shaped red blood cells have been demonstrated to protect individuals from contracting malaria, a parasite prevalent throughout much of Africa. In fact, at one point it may have been *advantageous* to carry the genetic mutation that causes sickle cell anemia due to its protective abilities. These days, we see the debilitating effects of sickle-cell anemia and rightly consider it a disease that is to be treated. But again, context matters—even (especially?) regarding what constitutes healthy and diseased states of being. As contexts shift, so too do the meanings we associate with particular behaviors and modes of existence. To reify health and disease would be to ignore the dynamic nature of those

³⁶ National Center for Biotechnology Information, “Anemia, sickle cell.” *Genes and Disease, Blood and Lymph Diseases*.
<<http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=gnd&part=anemiasicklecell>>
(accessed June 29, 2009).

concepts and give a false sense of security about what is appropriate in a given situation.

Genetic

Health and disease are not the only relevant concepts that are subject to such ambiguity, however. Even the very idea of what counts as “genetic” is up for debate. At times “genetic” refers to the material contained in cells that we call DNA. At other times “genetic” refers to the phenotypic expression of what that DNA has encoded. As a descriptor, the adjective “genetic” implies something about the origin of the concept in question, be it health, disease, or information (to give but a few examples). Neil Manson states that the semantics of “genetic” “have subtly altered from ‘pertaining to origins’ to ‘pertaining to heredity’ to ‘pertaining to the material which we think is causally important in heredity’ ...[to] ‘of or pertaining to DNA.’”³⁷ But thinking of “genetic” in this way does not necessarily specify what that modifier entails in any given instance, particularly as it is used to describe states of health and disease. In calling a disease a *genetic* disease, is one asserting that one’s DNA is itself in a state of disease? Or, is the physical manifestation of a genetic product—which is significantly shaped by non-genetic factors—the genetic disease in question?

Physicians in contemporary American medicine will agree that Huntington disease is clearly worthy of the label of “disease” and is often the paradigmatic example of a genetic disease. But how are such assertions defended? David Magnus has identified three ways in which ideas of “genetic disease” are defended, though he finds

³⁷ Neil C. Manson, "What Is Genetic Information, and Why Is It Significant? A Contextual, Contrastive, Approach," *Journal of Applied Philosophy* 23, no. 1 (2006), 1-16; quote on 9.

each approach to be lacking.³⁸ The first approach to defining genetic disease is the “causal approach” in which a disease is considered to be a genetic disease if one’s genetic constitution is the “direct cause” of the disease (as in the case of Huntington disease). However, Magnus argues that this way of thinking of genetic disease suffers from a “selection problem”: phenotypic expressions of traits or conditions (or diseases) are rarely the product of one’s genetic makeup but arise from the confluence of genetic and non-genetic (environmental, developmental, etc.) factors; diseases like Huntington are the exception rather than the rule. How does one identify *which* factor is most important in the development of a condition or disease? The second approach to identifying genetic diseases is a statistical approach in which phenotypic differences in a given population can be explained by genetic differences in that same population. This approach, however, focuses only populations and not individuals and, according to Magnus, simply pushes the “selection problem” back to the level of population classes: what is the proper population to sample and with whom should they be contrasted? The last approach Magnus identifies is the “manipulation approach” to identifying genetic diseases, in which a disease may be called “genetic” if genes are identified as the factor “most easily manipulated to prevent or treat disease.”³⁹ However, genetic therapy is still in its infancy. Paradigm cases of “genetic disease” like Huntington would not qualify as genetic diseases under this last rubric because no gene therapies are currently available in the medical treatment of disease (though this may eventually change).

³⁸ David Magnus, “The Concept of Genetic Disease” in *Health, Disease, and Illness: Concepts in Medicine*, eds. Arthur L. Caplan, James J. McCartney, and Dominic A. Sisti, (Washington, D.C.: Georgetown University Press, 2004), 233-242.

³⁹ *Ibid.*, 236.

The Utility of Genetic Health and Disease Concepts

So where does all of this ambiguity leave us? Must we abandon the very ideas of genetic health and disease? As in the discussions of novelty, exceptionalism, and determinism, I do not necessarily want to lose the concepts of genetic health and disease altogether as I move forward in this dissertation. Instead, I want to encourage restraint in deploying those concepts. Just as human beings seek to exercise control over the natural world through powerful manipulation, so too do we strive for that control through the ways in which we use our words. While it will be helpful to temper our grandiose pronouncements about the “genetics revolution,” we must nonetheless recognize that the lens of genetics provides one way in which to understand many debilitating conditions from which we suffer, and it may very well be appropriate to use concepts like “genetic disease”—particularly if technologies like predictive genetic testing and PGD can use genetic data to predict and prevent conditions like cystic fibrosis or Huntington disease. Genes *do* establish many of the boundaries within which we live, creating possibilities for interacting with the world in specific ways while limiting our access to other options. In some cases—carrying the genetic abnormality for Huntington disease, for example—those genes are in fact determinative insofar as they limit one’s ability to exercise his or her agency in the world, which is a critical component of nearly any understanding of health.

However, as we explore predictive genetic testing and preimplantation genetic diagnosis, it will be important to remember just how dynamic the concepts of health and disease can be. In speaking of “genetic enhancement” a person makes a value judgment about genetic states of affairs, so such references should not be looked upon with an air

of certainty about what is worth seeking and worth avoiding. Rather, we should be open to the possibility that the judgments we make about what is desirable and what is to be eradicated are not always grounded in universal standards but are instead built on moving ground that shifts as times and cultures shift. Further, we should be open to the possibility that the scientific data on which we base many of these judgments are open to revision (as in the case of masturbation or the shifting etiology of ulcers). Part of the dynamic nature of the concepts of health and disease is due to new information that researchers uncover. That research can call into question ideas that we previously held to be evident. Such recognition these various limits may be the first step toward responsibility in relation to genetic biotechnologies like the ones described below.

Emerging Genetic Technologies

Predictive Genetic Testing

Earlier in the chapter I mentioned PKU screening, one example of large-scale genetic testing that became a routine component of medical care in the United States well prior to the HGP. With the completion of the HGP, however, researchers have been able to identify genetic markers associated with over 900 diseases and conditions, several of which are initially asymptomatic but manifest later in life, and these discoveries are indeed a novel dimension of the science of genetics. As a result, people can now undergo genetic testing for such late-onset conditions before ever experiencing any symptoms of the condition in question, hence the label “predictive genetic testing.” Currently, testing exists for a wide range of diseases and conditions, from monogenic autosomal dominant

diseases like Huntington to breast cancer susceptibility, eye color, and even testing for one's susceptibility to developing alcoholism.⁴⁰ From a technical standpoint, these tests generally work through one of three methods: by directly sequencing the DNA of the patient, by testing for abnormal protein levels that would indicate an alteration in the DNA that codes for the proteins associated with a certain condition, or by directly attaching biochemical markers to specific sections of DNA in order to obtain a visual representation of a possible alteration in the tested section of DNA.

Predictive genetic testing raises compelling ethical challenges, particularly as a result of the ways in which predictive genetic testing is different from traditional medical diagnostic tests (like testing blood and tissue samples).⁴¹ First, typical medical tests reveal something about a patient's current condition—elevated white blood cell counts are typically indicative of infection or the presence of some pathogen, for example—while predictive genetic tests seek to forecast a patient's future condition. For this reason, there is a greater degree of certainty for most medical tests that is lacking for predictive genetic testing. After all, nearly any attempt to forecast the future is subject to change due to numerous variables: environmental factors, dietary changes, changes in habits, exercise levels, stress levels, etc. Second, the direct correlations we find in other tests—viewing tumor cells in a biopsy that indicate a specific form of cancer, for example—are usually replaced in genetic tests with statistical probabilities regarding a

⁴⁰ The Genetics & Public Policy Center has identified some interesting traits for which someone can receive direct-to-consumer genetic testing, including athletic performance, hair loss, gout, restless legs syndrome, and periodontal syndrome. See the above "Direct-to-Consumer Genetic Testing Companies" below.

⁴¹ James P. Evans, Cécile Skrzynia, and W. Burke, "The Complexities of Predictive Genetic Testing," *BMJ* 322, no. 7293 (2001), 1052-1056.

person's susceptibility to developing a certain disease or condition. Finally, predictive genetic testing cannot determine with a significant degree of accuracy when an individual will develop a condition for which she tests positive. With blood assays, however, those tests indicate whether or not a particular pathogen or condition is *already* present. Thus, predictive genetic testing often lacks the certainty that can be provided by other clinical tests.

Others have expressed fears that employers and insurance companies may use information from predictive genetic tests to deny employment and insurance coverage to those whose tests indicate a genetic anomaly.⁴² While legislation like GINA may ease some of those fears, there is nevertheless a risk of stigmatization for those who undergo predictive genetic testing, as well as concern about the psychological well-being of those who are found to carry some genetic anomaly. What might it be like to live knowing that one carries a significant risk of developing a lethal condition—but without knowing precisely when that condition will manifest itself? Further, what if there are no available treatments for that condition? While predictive genetic testing may provide someone with information about his or her genetic constitution, is that information valuable if he or she cannot act on it and it carries with it such potential for psychological harm and public stigmatization?

Predictive genetic testing also raises questions about one's relations to others, particularly one's family. Evans, Skrzynia, and Burke have suggested that this testing

⁴² For example, see E. V. Lapham, C. Kozma, and J. O. Weiss, "Genetic Discrimination: Perspectives of Consumers," *Science* 274, no. 5287 (1996), 621-624; E. T. Matloff and others, "What Would You Do? Specialists' Perspectives on Cancer Genetic Testing, Prophylactic Surgery, and Insurance Discrimination," *Journal of Clinical Oncology* 18, no. 12 (2000), 2484-2492.

raises these issues because the results of a genetic test may reveal something about the genetic constitution of a person's family members.⁴³ While I grant that one component of their argument is correct—blood samples and tissue biopsies reveal something about *individual* patients while genetic testing says something about the shared genetics of the patient and her family—I find their argument to be largely overstated. It seems to me that the family history that a physician takes of her patients reveals similar information that is considered medically relevant, namely patterns of susceptibility to particular diseases or conditions. I see no significant difference in the type of information that is revealed when a patient mentions that hypertension runs in her family rather as opposed to receiving the results of a genetic test for hypertension susceptibility. Either way, the patient—and her family—is at risk for developing hypertension and should take the appropriate cautions.

There are instances, however, where predictive genetic testing poses unique challenges to those who utilize it. Consider the example of Katharine Moser, whose decision to utilize genetic testing for Huntington disease was documented in the *New York Times*.⁴⁴ Ms. Moser's grandfather had suffered from the disease and at age 23, she decided to undergo genetic testing to discover if she carried the genetic markers that cause the incurable disorder. Her test came back positive, indicating that she would eventually develop the disease that struck her grandfather, a great uncle, a cousin, and an aunt. The story recalls some of the major changes in Ms. Moser's life following her testing, but what is particularly interesting here were the ramifications of Ms. Moser's

⁴³ Evans, Skrzynia, and Burke, "The Complexities of Predictive Genetic Testing."

⁴⁴ Amy Harmon, "Facing Life with a Lethal Gene," *New York Times*, March 18 2007.

test for her mother. Katharine's mother did not want her daughter to receive the test, nor did she want to have the test herself. Following the test, Ms. Moser and her mother became estranged. In a heated custody battle between her mother and one of her aunts, the topic of Huntington disease was raised. Through those court proceedings, Ms. Moser's mother came to learn—unwillingly—of her own status as someone who would eventually develop Huntington disease.

Ms. Moser's mother had insisted that she did not want to know her chances of developing the disease, but through her daughter's testing she could not avoid learning about her status as a person who will eventually develop Huntington. Ms. Moser's case illustrates some of the difficulties associated with undergoing predictive genetic testing: What can one do with that information, particularly if one learns of an incurable lethal genetic anomaly? Does one have a right *not* to know about one's genetic status? In cases where predictive genetic tests would might reveal such life-changing information that impacts more than one person, must all potentially affected people agree to the testing? What does this do to how we understand confidentiality?

In cases like Ms. Moser's, a person interested in predictive genetic testing typically visits a physician, a genetic counselor, and sometimes even a psychologist. These care providers work to ensure that the person understands what genetic testing reveals about her health and raise awareness about the possible ramifications of undergoing testing. They can even urge a person to forego genetic testing if it is clear that he or she has not given the matter careful consideration. These days, however, if someone is interested in pursuing predictive genetic testing, she does not even need to leave her own home. Companies offering direct-to-consumer genetic testing are now

becoming booming businesses, allowing a person to simply swab the inside of her cheek, mail the sample to the company providing the test, and receive test results in the privacy of her own home—all for just a few hundred dollars. In fact, the Genetics & Public Policy Center has identified *forty* such companies (as of May 2009), including the cleverly named *23andMe* and *Suracell*.⁴⁵

Bringing genetic testing into people's homes is certain to raise ethical challenges for patient/customer and physician alike. The American College of Medical Genetics has been quick to note that “the consumer should be fully informed regarding what the [direct-to-consumer genetic] test can and cannot say about his or her health.”⁴⁶ Picking up on earlier points, it should be noted that because these tests provide the patient/customer with statistical probabilities regarding their susceptibility to developing the disease or condition(s) in question, these tests often do not provide the diagnostic certainty that patients/customers may seek. *23andMe*, for example, readily states on its website that they do not “sequence your entire genome or perform predictive or diagnostic tests.”⁴⁷ They currently offer genetic testing for 116 conditions, and with 30 of those conditions (including Crohn's disease, BRCA cancer mutations, earwax type, and HIV/AIDS resistance), the customer receives a “clinical report” that provides an

⁴⁵ Genetics & Public Policy Center, “Direct-to-Consumer Genetic Testing Companies.” <<http://www.dnapolicy.org/recourses/DTCcompanieslist.pdf>> (accessed June 26, 2009).

⁴⁶ American College of Medical Genetics Board of Directors, “ACMG Statement on Direct-to-Consumer Genetic Testing, 7 April 2008.” <http://www.acmg.net/AM/Template.cfm?Section=Policy_Statements&Template=/CM/HTMLDisplay.cfm&ContentID=4157> (accessed May 11, 2009).

⁴⁷ 23andMe, “23andMe Help—Why can't 23andMe diagnose me?” <<http://www.23andme.com/you/faqwin/nodiagnosis/>>. Retrieved 26 June 2009.

estimate of whether one's "genetic risk" for a condition is above or below "average risk" as well as the "heritability" rate for the condition, which can be as little as 1% in some cases. For the other 86 conditions, one instead receives a "research report" that contains the same information, only with a notice that not enough "scientific consensus" has been built to include that information in the aforementioned "clinical report." *23andMe* does not provide tests for monogenic conditions or for other conditions for which genetic constitution can in fact be determinative.⁴⁸

Direct-to-consumer predictive genetic tests are aimed at empowering individuals to take charge of their own health by "personalizing" medicine according to a person's genetic susceptibility to specific diseases or conditions. However, we may want to ask some pointed questions about what personalized medicine in the age of genetic testing entails: Are many of these tests necessary? Is the information that they provide of any real value? While the old Baconian adage "knowledge is power" motivates the movement toward putting personalized genetic "information" in the hands of customer/patients, we should still recognize that predictive genetic testing (and DTC genetic testing in general) can cause headaches for customers/patients and physicians alike. Without the assistance of a genetic counselor or physician, can the average person interpret information from these tests in any meaningful way? Does the lack of an "expert" in that process promote certain misconceptions about the power of genetics for shaping and predicting a person's future? While knowledge about genetic susceptibility to particular conditions may indeed empower a person to make better decisions about

⁴⁸ This information and more is available at the *23andMe* website: <http://www.23andme.com/> (accessed 30 June 30, 2009).

how to live his or her life, basing such decisions on misunderstood or incorrect information might actually *disempower* that person from being able to live his or her life on the basis of sound knowledge.

Nonetheless, predictive genetic testing—whether it takes place in the clinic or in someone’s home—may be a worthwhile endeavor for many people, provided that they are cognizant of what the test results actually indicate about their genetic constitution. The certainty that so many of us crave is all too elusive except in the rarest of instances. In those rare cases (such as that of Ms. Moser) a person may find that having the information provided by a predictive genetic test is itself a form of therapy. He or she can incorporate that information into his or her self-image and live a rewarding life in accord with that new image. Even when lacking that certainty, just knowing that one has an increased risk of developing some future condition can be an impetus for one to reorient his or her new life in a beneficial way. In these ways, predictive genetic testing can be of value.

Despite the anxiety that can come about using predictive genetic testing and despite the various other challenges that such testing creates, it is also clear that in some cases predictive genetic testing can be a beneficial diagnostic tool for patients and physicians alike. As this dissertation moves forward, I will make the case that thinking of predictive genetic testing in the language of *responsibility* provides an avenue for navigating the bumpy terrain between certainty and probability, between self-control and self-alienation, and between acceptance and dread. There is no doubt that this type of genetic testing has its limitations; the way in which it has become a mass marketed product only serves to further complicate matters. However, there is also little doubt that

predictive genetic testing is here to stay. The key, it seems, is to think about how to *responsibly* incorporate predictive testing into a person's medical care. This question—and the challenges I have described here—will be revisited later in this dissertation.

Preimplantation Genetic Diagnosis (PGD)

Preimplantation genetic diagnosis (PGD) is another example of a genetic technology that is becoming an increasingly routine component of medical care. From a technical perspective, PGD is a combination of the molecular biology of genetic testing with the reproductive technology of in vitro fertilization (IVF). In this process, multiple embryos are created in vitro from the germ cells (sperm and egg) of those who are seeking reproductive assistance.⁴⁹ When the embryos have matured to a size of six to ten cells (just prior to the blastocyst stage of development), an embryonic cell is removed from each embryo. The excised cells are then tested for potential genetic anomalies, just as that process was described in the previous section. The embryos that are discovered to contain a genetic anomaly are either discarded or frozen, while the embryo(s) that is/are deemed to have the “best” genetic constitution is selected for implantation. A 2001 report indicates that PGD carried a 24% pregnancy rate, a similar rate to that of assisted reproductive techniques that do not involve such excision.⁵⁰ PGD is an expensive

⁴⁹ Of course, eggs or sperm could also come from donors, though that practice seems rare in relation to the use of PGD.

⁵⁰ International Working Group on Preimplantation Genetics, “Preimplantation Genetic Diagnosis: Experience of 3000 Clinical Cycles,” Report of the 11th Annual Meeting of the International Working Group on Preimplantation Genetics, Vienna, Austria, 15 May 2001. *Reproductive Biomedicine Online* 3, no. 1 (2001): 49-53.

procedure that is usually not covered by insurance programs, adding approximately \$3000-\$5000 to the cost of a cycle of IVF.

PGD has been used since 1990, when it was first implemented to test for aneuploidy (having other than 46 chromosomes) in embryos of low prognosis infertility patients, or in testing for single-gene and X-linked conditions in at-risk patients.⁵¹ One of the seemingly attractive aspects of PGD is that it provides an alternative to pregnancy termination for potential parents who are at risk of passing inheritable genetic disorders to their children, allowing those potential parents to avoid conventional prenatal testing (namely CVS and amniocentesis) and any subsequent discussions about abortion if the fetus was discovered to possess some genetic disorder.⁵² In Great Britain, PGD is utilized to test embryos for over 70 diseases and conditions, some of which are gravely painful and certainly lethal (β -thalassemia, for example). Other conditions for which potential parents can use PGD in Great Britain include Huntington disease, BRCA-1 breast cancer susceptibility, and hemophilia.⁵³ Interestingly, some of the conditions for which PGD is used in Great Britain include conditions that are non-lethal, manifest later

⁵¹ Ibid.

⁵² Heather Draper and Ruth Chadwick, "Beware! Preimplantation Genetic Diagnosis May Solve Some Old Problems but It Also Raises New Ones," *Journal of Medical Ethics* 25, no. 2 (1999), 114-120. Draper and Chadwick are quick to note that although PGD sidesteps the issue of abortion, it does nothing to placate the concerns of those who hold that life begins at conception and that embryos are thus human life worthy of protection. It may be attractive, however, to those people who distinguish between actively destroying life and failing to save life.

⁵³ In Great Britain, PGD is regulated by a governmental agency, the Human Fertilisation and Embryology Authority. A list of conditions for which PGD is available in that country is available online: "Preimplantation Genetic Diagnosis (PGD): Conditions licenced by the HFEA, January 2009." <<http://www.hfea.gov.uk/69.html>> (accessed June 23, 2009).

in adulthood, and have readily available clinical treatments available. Additionally, it should be noted that PGD cannot be used to diagnose congenital conditions like spina bifida or anencephaly.

In the United States, PGD is not regulated as it is in Great Britain. The only limitations to the conditions for which PGD can be used are the availability of genetic tests for a given condition and the willingness of a clinician to perform PGD for a specific condition. Hypothetically, one could thus use PGD to seemingly test embryos for potential athletic performance, eye color, sex, and/or susceptibility to food allergies and migraines (among a host of other testing possibilities). That is, PGD can be utilized for not merely for karyotyping and testing for inheritable genetic disorders, but also for genetic susceptibility, late-onset conditions (like Huntington disease), human leukocyte antigen (HLA) matching for producing a donor for an existing person in need, gender selection, and even for non-medical conditions.⁵⁴ Quite simply, the possibilities are almost endless, provided one can afford the procedures and find a willing clinician.

For this reason, PGD is often portrayed as the quintessential “genetic boogeyman” that casts its shadow over ethical discussions concerning the place of genetics in medicine. It brings the ideas of “playing God,” “controlling human destiny,” and “fabricating man” to the forefront of those discussions. Particularly with the rise of in vitro fertilization and the blossoming of genetics as a scientific discipline, theologians and philosophers have expressed serious concern about the perceived encroachment of human power and direction into the realm of reproduction (beyond the basic procreative

⁵⁴ John A. Robertson, "Extending Preimplantation Genetic Diagnosis: The Ethical Debate. Ethical Issues in New Uses of Preimplantation Genetic Diagnosis," *Hum Reprod* 18, no. 3 (2003), 465-471.

act).⁵⁵ Leon Kass, for example, has argued that the gradual movement from IVF to PGD, genetic engineering, and the prospect of human cloning in the name of reproductive freedom and genetic health actually leads to a dehumanization of the procreative process altogether.⁵⁶ From this perspective, children become little more than products, parents become customers, and clinicians become the manufacturer and supplier of the desired product.⁵⁷ So this line of argument goes, PGD—and other reproductive and genetic biotechnologies—remove much of the mystery from procreation and turn the whole process into a sterile, depersonalized and dehumanizing affair. PGD also removes much of the mystery and perceived giftedness from the procreative endeavor—a theme that will be revisited in the final chapter of this dissertation.

Similarly, PGD raises the typical “line-drawing” questions that are prevalent in public policy discussions. For example, why might it be okay to use PGD to test for cystic fibrosis but not for sickle cell anemia? What about sex selection? If treatments are currently available for a given disorder or disease, should a person nonetheless opt against implanting an embryo that possesses the genetic markers for that disease? If a lethal disease manifests itself later in adulthood, should a person choose not to implant an affected embryo—or might the years of (presumably) healthy life prior to the onset of

⁵⁵ For example, see Ronald Cole-Turner, *The New Genesis: Theology and the Genetic Revolution*, 1st ed. (Louisville, KY: Westminster John Knox Press, 1993); Ted Peters, *Playing God? Genetic Determinism and Human Freedom*, 2nd ed. (New York: Routledge, 2003); Paul Ramsey, *Fabricated Man: The Ethics of Genetic Control* (New Haven, CT: Yale University Press, 1970).

⁵⁶ Leon R. Kass, "Triumph or Tragedy? The Moral Meaning of Genetic Technology," *American Journal of Jurisprudence* 45, no. (2000), 1-16.

⁵⁷ Along these lines, Draper and Chadwick (1999) suggest that PGD transfers reproductive power from women to the physicians and clinicians who actually have the final say about which (if any) embryos are implanted.

disease be considered a “life worth living” by clinicians and potential parents? John Robertson even raises the possibility of eventually being able to use PGD to select embryos based on their potential sexual orientation.⁵⁸ Should that be permissible? In asking the basic question of where the proverbial line out to be drawn—or if it should be drawn at all—we should recognize that the various positions on those questions “illustrate a balancing a number of considerations, including the moral status of the embryo and fetus, the limits of professional authority, the limits, if any, of our respect for personal autonomy, and the impact of individuals with disabilities on the family and society.”⁵⁹ The way in which those considerations should be balanced, however, is certainly up for debate and would go a long way toward determining the conditions under which PGD is an acceptable diagnostic tool for potential parents to utilize.

Finally—and related to this issue of acceptability—I cannot discuss PGD without recognizing the specter of eugenics that hovers over these discussions. Many individuals and disability rights groups view such “line drawing” as discriminatory. If an embryo possesses the genetic markers for a given susceptibility or condition (such as deafness), any decision to *not* implant that embryo may be seen as an affront to those people who already have the condition in question, tantamount to asserting that living with that condition would be a life “not worth living.” This only serves to further increase the level of stigmatization that individuals living with a particular disability or condition might face. Further, in this process of establishing boundaries between “acceptable” and

⁵⁸ Robertson, "Extending Preimplantation Genetic Diagnosis: The Ethical Debate. Ethical Issues in New Uses of Preimplantation Genetic Diagnosis."

⁵⁹ Jeffrey R. Botkin, "Ethical Issues and Practical Problems in Preimplantation Genetic Diagnosis," *Journal of Law, Medicine, and Ethics* 26, no. 1 (1998), 17-28; quote on 22.

“unacceptable” states of existence, there is a definite compulsion to actively pursue the “best” or “most acceptable” avenue in the name of disease prevention, health promotion, and human progress. However, recalling the prior discussion about the dynamic nature of health and disease labels, we should approach this process of discernment with caution. What some individuals view as “disability” may be seen as “diversity” by others, and to use technologies like PGD to eliminate diverse elements of human existence would be to act unjustly and *inhumanly* toward our fellow humans.

Clearly PGD presents patients and clinicians with a variety of ethical challenges, particularly around our understandings of what constitutes a “life worth living” and what we view as diseased and disordered states of being. Complicating these discussions is the fact that PGD is currently a “boutique” diagnostic test, not covered by insurance programs and available only to those who are able to afford its hefty price tag. Thus, issues of class and socioeconomic status permeate every discussion of PGD. Here, the question of responsibility becomes all the more important: Are clinicians and potential parents responsible to/for anyone beyond themselves when they undergo PGD and use that information to decide which embryos to implant for pregnancy? Are there larger societal implications for those actions, and if so, to what degree should those implications be taken into account when acting on the basis of PGD results? These are just some of the questions posed to us when we consider the use of PGD in light of responsibility. As I will demonstrate later, however, PGD also poses challenges to the very ways in which we understand what “responsibility” entails. As I will later argue, the pursuit for greater control and certainty about a person’s life (or the life of her offspring) is oftentimes a

worthy pursuit. To think that PGD provides us with full control and certainty, however, is misguided.

Summary

In this opening chapter, I have suggested that genetic biotechnologies are becoming an increasingly routine component of medical care. Two such technologies—predictive genetic testing and preimplantation genetic diagnosis—raise a host of challenges to our moral frameworks and how we think about ideas of health, disease, and responsibility. To establish the historical and intellectual context within which discussions of genetics and genetic biotechnologies take place, I have used this chapter to provide an overview of dominant themes that permeate those discussions—specifically novelty, genetic exceptionalism, and genetic determinism. I argued that while many of the genetic biotechnologies making headlines these days are new, genetic information has long been used in the context of the clinic. While I found many of the claims of genetic novelty and exceptionalism (for example, genetics as “the book of life” or the “language of God”) to be greatly exaggerated, I pointed out that technologies like PGD and predictive genetic testing do indeed raise unique challenges that must be addressed. Finally, while I noted that views of genetics as being determinative of a person’s existence are overly simplistic and downright false, I also asserted that one’s genes *do* establish some limitations to a person’s possible modes of existence.

Additionally, I noted that many of the basic notions on which discussions of genetic biotechnologies are based—genetics, health, and disease, specifically—are sometimes misconstrued as static concepts. “Genetic,” for example may describe either

the DNA material *or* the phenotypic expression of the genome's products. To speak of "genetic health" therefore, one must be clear about whether one is applying the label of "health" to one's genetic constitution or to the way in which those genes phenotypically manifest themselves. I also asserted that the very labels of health and disease are both descriptive and evaluative (normative). In describing someone as healthy or diseased, one makes a claim about that person's ability to live and interact in the world. As evaluative concepts, health and disease provide ways of expressing what activities or states of being are to be pursued or avoided, promoted or eliminated. Because health and disease are evaluative concepts, however, we must recognize that they are also dynamic concepts whose contents are provided by the specific contexts and times in which they are used. What is considered diseased in one context may be insignificant—or even considered healthy—in another context. Thus, I urged us to exercise extreme caution when attaching labels of health and disease to issues of genetics, particularly because we are still learning more and more each day about the role that genes play in shaping various aspects of our lives.

Finally, I turned to the two specific examples of genetic biotechnologies in action—predictive genetic testing and PGD—in order to articulate what those processes entail and to highlight some of the ethical challenges that they pose to clinicians, patients/customers, and society at large. Predictive genetic testing, I argued, is limited in the type of information it can provide. Even if a person tests 100% positive for a lethal condition, predictive genetic tests cannot tell that person when the condition will manifest. Second, these tests deal largely with statistics and probabilities rather than certainty. Thus, predictive genetic tests cannot tell someone about their specific case, but

only about the disease rates for populations sharing the indicated genetic markers with that individual. In other words, while a predictive genetic test can tell me that I have a 72.5% chance of developing a particular condition, it cannot tell me if I am part of that 72.5% or if I may be part of the 27.5% of the population who does not develop the condition in question. Additionally, predictive genetic testing has expanded into direct-to-consumer products, readily available for individuals to use with little or no counseling or expertise. In this expansion, tests now exist for a wide array of conditions and susceptibilities—including hair loss and athletic performance (!)—leading me to question what constitutes “medically valuable” information. Lastly, others have noted that predictive genetic tests challenge how we understand our relationships to others, particularly other members of our family. The case of Ms. Moser clearly brings some of those issues to light.

With PGD, I noted the broad but pervasive challenge that PGD represents yet another example of human beings attempting to “play God” by inserting new levels of precise intentionality into the process of reproduction. From this perspective, PGD is a tool that may be used to create “designer babies” and dehumanize the reproductive process by striving to eliminate the mystery and giftedness that accompanies human reproduction. Along these lines, I also noted some of the ethical challenges associated with discerning what might constitute an acceptable use of PGD. That is, the task of “drawing the line” between acceptable and unacceptable uses of PGD—if such a line is to be drawn at all—is typically dependent upon our shifting understandings of health and disease. Through the process of line drawing that often belongs to the realm of public policy discussions, PGD also brings to the forefront issues of discrimination and

stigmatization that must be addressed, particularly if PGD is to be used to select against conditions for which treatments or accommodations already exist.

As I have already noted, I will probe many of these challenges later in the dissertation by focusing on the idea of responsibility. The decision to focus on responsibility, as the following chapter will indicate, is with good reason. Clinicians, care providers, and other caring professionals readily draw on the concept of responsibility in their discussions of genetics and genetic biotechnologies. The following chapter is dedicated to understanding how those people talk about genetics and responsibility, and as I will argue, they do so in a manner that provides valuable insights for rethinking and confronting many of the challenges I have described above. They also point to interesting ways in which we can reconsider what responsibility actually means for us, sometimes challenging dominant views of responsibility as a matter of autonomous, rational, free choice.

CHAPTER II

SPEAKING OF RESPONSIBILITY: STATEMENTS ON RESPONSIBILITY FROM MEDICAL PROFESSIONALS AND RELIGIOUS CARE PROVIDERS

I have suggested that responsibility is an important concept for understanding the ethical challenges posed by genetics and genetic technologies in the medical context. Tools like predictive genetic testing and preimplantation genetic diagnosis (PGD) are becoming more common in the clinic, or in our very homes, as is the case with predictive genetic testing. In the spirit of ethics as a form of critical inquiry, it will be necessary to examine questions about how these genetic innovations should be implemented. Here, it is crucial to listen to the voices of those people who often confront those questions through their work, people serving in caring professions: physicians, genetic counselors, nurses, chaplains, and religious ministers who counsel congregants dealing with these issues. Turning to those voices, it is apparent that responsibility is an important concept for moral understanding in this context

The Religion and Genetics study group at Vanderbilt University conducted a series of focus groups with members of the caring professions named above. The ministers involved were all Christian ministers, with separate focus groups geared toward mainline Protestant ministers and evangelical ministers.¹ As noted, “responsibility”

¹ Vanderbilt University’s Religion and Genetics study group, “Religion and Genetics Focus Groups” (IRB #061052, first approved 3 November 2006). I can access and utilize these transcripts for my work without subsequent IRB approval, provided that I have the permission of the study’s principal investigator, Dr. Ellen Wright Clayton. Doctor Clayton has granted me that permission.

emerged from many of those sessions in a significant way and without provocation. While the focus group transcripts by no means provide a full data set for drawing conclusions about how these groups care for their patients and congregants, they nonetheless attest to the power of responsibility for informing how care providers understand their work in such settings. Additionally, in this chapter I will examine the published statements of medical professional organizations (American Medical Association, National Society of Genetic Counselors, American Board of Genetic Counseling, and the American Nursing Association) and religious denominations in order to demonstrate how responsibility also functions as a crucial concept for ordering institutional responses to how its members should conduct themselves in their work. The medical professional statements are readily available online. The religious denominational statements I examined were taken from Rebecca Rae Anderson's *Religious Traditions and Prenatal Genetic Counseling*.²

It should come as little surprise that the positions taken in these numerous statements are as diverse as the focus group participants and the religious and medical professional organizations that I discuss throughout the chapter. I should note that their statements about responsibility are my primary concern in this chapter, not the stances that these individuals and groups take regarding the morally licit or illicit character of genetic biotechnologies. Hence, I will only draw on those positions when they are

² Rebecca Rae Anderson, *Religious Traditions and Prenatal Genetic Counseling*, Notebook format (Omaha, NE: Munroe Meyer Institute and University of Nebraska Medical Center, 2002).

relevant to how responsibility is articulated in light of issues of genetics and genetic technologies.

As much as possible, I aim for this chapter to be an expression of the perspectives that these care providers offer in their own words. Thus, analysis of the statements, focus group transcripts, and any other documents will be rooted in grounded theory, particularly in the in vivo coding strategies articulated by Corbin and Strauss.³ Further, I follow this method because the Religion and Genetics group initially adopted it during the design and development of their study. In grounded theory, the coding process takes place in three basic stages: open, axial, and interpretive coding. In open coding, I broadly examine the materials for instances where “responsibility” emerges as a theme of interest. This stage of coding relies on the concepts that are specifically mentioned by study participants, hence the term “in vivo coding.” Next, through axial coding I examine the concepts that surround uses of the term “responsibility” in order to identify common or interesting themes that may emerge from the data. Finally, through interpretive coding I can relate that data back to questions about what responsibility means and what responsibility requires in relation to genetics and genetic technologies.

Drawing on grounded theory analysis provides space for themes to emerge from the data without manipulating that data to suit my own predetermined ends; thus I am not testing any hypotheses about those discussions. As I stated, I want—as much as possible—for the participants to speak for themselves. This approach also provides space for situating those emergent expressions of responsibility within larger social and

³ Juliet M. Corbin and Anselm L. Strauss, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 3rd ed. (Los Angeles, CA: Sage Publications, Inc., 2008).

religious frameworks that may provide the specific content of that concept. While those frameworks often remain implicit in our discourses, I aim to make them explicit; grounded theory makes that task possible. In other words, grounded theory provides the necessary tools to highlight those previously unacknowledged presuppositions upon which discussions of responsibility rest. For example, when someone asserts that she is “responsible to God for the decisions I make,” a variety of unstated presuppositions give meaning to that statement: a view of God that holds people accountable for specific personal decisions, that she can know that God holds her responsible, and that there are consequences for failing to be responsible to God (to give but a few examples). By identifying some of those presuppositions I can then utilize these statements to flesh out a more substantive account of responsibility later in this dissertation. Further, I can also turn to prevalent views of responsibility in ethics and bioethics in order to demonstrate how they are often blind to some of the themes that emerge from the institutional statements and focus group transcripts.

A Note on Focus Group Transcripts

The transcripts discussed in this chapter are from a series of 13 focus groups conducted by Vanderbilt University’s Religion and Genetics study group in early 2007. The study group, an interdisciplinary collection of ethicists, genetic counselors, physicians, and nurses, sought to learn about how members of “caring professions” (physicians, nurses, genetic counselors, hospital chaplains, and Christian ministers) articulated and understood their experiences in dealing with issues of genetics during the course of their work. With the exception of the genetic counselor focus groups,

participants were recruited through investigator contacts and the process of “snowball sampling” in which initial participants were asked to recommend others who may be interested in participating in this research.⁴ Genetic counselors were recruited through the American Society of Genetic Counselors and participated via telephone. As a result of these recruiting methods, focus group participants were largely from the middle Tennessee area, again with the exception of these genetic counselors. Focus groups were between 3-6 members in size.

The focus groups lasted up to two hours and were conducted by a member of the Religion and Genetics group while one or two members of the group observed, taking notes on verbal and non-verbal communications. The moderator would describe the study and present the participants with two of four possible case studies: a 40-year old woman (Debbie) who is 16 weeks pregnant and has been referred for ultrasound and amniocentesis; a 35-year old father (Jeff) of two who watched his mother suffer through Huntington disease and is considering predictive testing for himself; a 9-year old boy (R.J.) who develops Becker muscular dystrophy (BMD), a genetically-based condition he inherited from his mother (Susan); and a 30-year old woman (Laura) diagnosed with multiple endocrine neoplasia type 2A (MEN 2A) whose father refuses DNA testing for the condition despite the presence of some of its symptoms. The ministerial groups focused solely on the cases of Debbie and Jeff, while clinicians were not limited in this way. Participants were then asked a series of open-ended questions regarding their experiences caring for patients/congregants where issues of genetics have arisen. They

⁴ Emily C. Hansen, *Successful Qualitative Health Research: A Practical Introduction* (Sydney: Allen and Unwin, 2006).

were also asked to reflect on the case studies and offer their own responses to the cases, though we encouraged participants to speak as much as possible about their own personal experiences with these matters. The case studies of “Debbie” and “Jeff” will be attached as an appendix to this dissertation.⁵

Insights from Physician, Nurse, and Genetic Counselor Focus Groups

Of the 13 focus groups conducted, nine of these sessions consisted of medical care providers (physicians, nurses, and genetic counselors). Each focus group had between three and six participants (excluding facilitators and observers) and was conducted in person, with the exception of the genetic counseling focus groups that were conducted via teleconference. In all, seven physicians, eight nurses, and 15 genetic counselors participated in these focus groups. In their discussions, participants rarely drew on language of responsibility to describe their activities or to recall specific instances where religious issues were raised by their work as caring professionals. In fact, the word “responsibility” was not used at all among the participants in the physician focus groups, which is interesting considering that the American Medical Association (AMA) crafted a significant “Code of Ethics” for physicians in which responsibility plays a key role in framing the ethical nature of the physician’s work. One nurse and two genetic counselors used the language of responsibility to describe their experiences, and their discussions will be examined here. I chose not to focus on presumed surrogates for

⁵ A thorough account of the methods for this study can be found in Virginia L. Bartlett and Rolanda L. Johnson, "God and Genes in the Caring Professions: Clinician and Clergy Perceptions of Religion and Genetics," *Am J Med Genet C Semin Med Genet* 151C, no. 1 (2009).

responsibility (duty and obligation, for example) because I did not want to assume that I knew what “responsibility” would mean for these focus group participants.

When those individuals spoke of responsibility, the theme of *control* consistently emerged alongside that concept. In fact, control (or a lack thereof) informs each of the statements made in this section. Consider the statement below from a nurse who was describing her involvement with a patient facing very difficult circumstances. Here, responsibility appears to be equated with control, and as such, it may be deferred to someone or something else. In other words, the nurse senses that by deferring responsibility for her health care to God, the patient signals that she no longer has control over her health outcomes:

Nurse 1: “This was a very young patient; she was about 29 years old, who had developed heart failure as a result of pregnancy-related complications. And she had given up, and in the process of giving up, she basically deferred all the responsibility for her own health care to God: “If God wants me to be well, I will be well. If God wants me to live to see tomorrow, I will see tomorrow.” Basically, she externalized all the control for her health care based on her faith, and that’s a very difficult thing to contradict, because I think on a lot of levels, that’s a way for them to gain control of their emotions and of their emotional reactions. It’s so stressful to deal with that they don’t want to, so they defer to the object of their religious faith, and in that situation, we spent a lot of time with her, talking about the importance of sticking to their therapeutic regimen, relying, you know, on supportive networks, and helping her identify factors in her daily care that she could control: taking of her medications, you know; doing her daily weights; those kinds of things. So it wasn’t that I was attempting to contradict what she said, but I was trying to re-frame it, rather than deferring all of the responsibility to God. There are some things that you can still do, that you have control of.”

In the exchange below between two nurses, one nurse equates responsibility to control in the form of causality. The patient views herself as being an active contributor to her present health status, noting that her eating, drinking, and smoking habits “corrupted” her status of being made in the image of God:

Nurse 1: “One patient comes to mind who had a congenital dyslipidemia that was a family trait on her mother’s side. And we talked about that, and her sense was that this—you know, she was made in God’s image, which, in her mind, was a perfect relationship, but that nothing in this world is perfect, and so, the building blocks of God’s creation are corrupted by the nature of this world and things that happen within this world, which I thought was sort of interesting. And what she did was then sort of bring in the fact, ‘Well, you know, I smoke; you know, I was a heavy drinker. You know, these are all things that I did in this world. This was not part of God’s creation, and even though I had this tendency to have, you know, high blood fats, you know: the way that I ate, living on McDonald’s and pizza, you know. It was something that I—I corrupted the situation by what I did in this world.’ So I thought that was kind of an interesting thing.”

Nurse 2: “Did she name Adam and Eve?”

Nurse 1: “No. No, she didn’t.”

Nurse 2: “Collaborators in this?”

Nurse 1: “She didn’t. She didn’t. But she clearly put the onus on herself, as being responsible for that, and corrupting God’s creation. Interesting.”

In another focus group session, one genetic counselor recounted her work in a Catholic hospital, specifically her experiences with a patient facing the choice of terminating her pregnancy. Here, the counselor expresses a feeling of lacking control when the patient makes an unexpected decision regarding her care, and once again we find that responsibility is articulated in relation to the ideas of decision-making and control:

Genetic Counselor: “In a lot of the cases where there’s a fetal anomaly or they get a diagnosed condition, sometimes the issue of, you know, spiritual assessment will come up, and there, I have offered patients the options to speak with our peri-natal grief support person...the nurse that is RTS trained...RTS is, it’s kind of a peri-natal loss training program...Resolve Through Sharing...and I’ve also offered for patients to speak with a chaplain person and we’ve only had one person in all of my time, here, ever take me up on the offer to speak with a chaplain. And interestingly that patient ended up terminating her pregnancy. You know, it was kind of counter-intuitive to me, I thought, you know, what I thought

her decision would be ended up being completely different from what it was and you know, that was kind of a puzzling situation for me where I expected the patient to make a decision and they ended up with a completely different (?). That comes up a lot, actually, I'm finding out. That no matter what support services, or what resources I offer to patients, it seems like they are going to make their decision how they're going to make it. And I don't think it means that we shouldn't be offering them the resources and the grief support, to talk with a chaplain or a grief support specialist, but I've realized not to feel like I have so much responsibility for the decision that patient makes. And, I think that's something that I've learned in the past few years. It's difficult for me when patients make the decision to terminate but I can't take responsibility for that."

Finally, another genetic counselor in the same focus group speaks of her responsibilities "as a counselor," in other words, her *professional* responsibilities. Though this mention of responsibility is in line with the other statements that render it in language of control and choice, it is worth noting that the counselor's appeal to responsibility occurs in her description of her own anxiety. She draws a distinction between her "responsibility as a counselor" and her religious and familial backgrounds, noting how they seemingly pull her in different directions on the issue of abortion. Though responsibility may appear to be synonymous with duty or obligation in her statement, she is discussing *her* responsibilities. In other words, responsibility informs her self-understanding of her work as a counselor:

Genetic Counselor 3: Yeah, but what if it were? Abortion to used to not be legal and now it....

Genetic Counselor 2: Right but what I'm thinking of is what is their legal right to do and my responsibility as a counselor and where I do or do not draw the line as my responsibility as a counselor as long as what their choice is is legal and my religious beliefs, I've had to sort through, through the years, because I still do have a problem with that is a life...that is a life that is being taken and I take that very, very seriously...very seriously...and I still struggle with that issue but I also would fight for their right to make that decision because and part of that doesn't come just from my religious beliefs and that's concern about that child. Part of that comes from my familial background that I have a sister

with Down Syndrome who was born 40 years ago when there was nothing to do for those children. And I watched my mother attempt to kill herself twice over having produced that abnormal child and over having a husband who said that child could not be his because he wasn't capable of producing an abnormal child...so I've seen what it can do to a whole family and so it's not just a decision about that child...it's a decision about the whole family unit and so it's not just my religious beliefs. It's where I come from from a family perspective that I would fight for their right, regardless of whether I think what they're doing is right, as long as it's legal, and I as a counselor, whether I agree with what they're doing or not, have worked through the point that I can support that decision and I can say to them, I know that you are doing what you believe is right because one of the research studies I did, because it's one of the things that couple's need to hear the most is, you're doing the right thing. Well, I can't always say you're doing the right thing but I can say I know you have struggled with this decision and thought it through and I know you are doing what you feel is best for you...this is the best decision you can make for you.

In sum, relatively few of the medical professionals spoke about responsibility during these focus groups, but when they did it was typically in relation to notions of decision-making and control. In lacking control over a patient's decision-making process, the care provider feels that she lacks responsibility for that decision. In other words, one gains responsibility by having some form of control. Especially in the final statement, we see that responsibility is also linked to a person's particular role as a professional (in this case, as a genetic counselor). This should come as little surprise, given that focus group participants were asked to reflect on their work as professionals dealing with issues of genetics and religion. Further, as we examine the medical professional codes of ethics later in this chapter, we shall find a similar emphasis on professional role-based responsibilities.

Clergy Members Speak: Notes from Hospital Chaplain and Ministerial Focus Groups

Medical clinicians are not the only caring professionals who encounter genetics-related issues in their work. Both within and outside the clinic, pastoral care providers seek to comfort and assist patients who face challenging medical circumstances in their own lives or in the lives of family members. The Religion and Genetics study group also conducted four focus groups of Christian ministers and hospital chaplains. One focus group was devoted solely to hospital chaplains, while one focus group consisted of “mainline” Protestant ministers and two focus groups centered on “evangelical” Christian ministers. Each focus group consisted of three or four participants. In all, 13 religious professionals participated in the focus groups (10 ministers and three chaplains). As described above, participants were provided a set of case studies to consider in order to launch discussion. Participants were then asked to reflect on their own experiences providing care for patients and congregants. In these focus groups, participants drew on the language of responsibility more frequently than did the clinicians I previously described. All three chaplains, one mainline Protestant minister, and three evangelical ministers referenced responsibility in their remarks (five, one, and nine times, respectively), although the facilitator made the first mention of responsibility in brief remarks in each instance. In another focus group of evangelical ministers, one minister raised the issue of responsibility on his own.

In the chaplaincy focus group, participants spoke of role-related responsibility. However, the chaplain’s statement below ties parental responsibility to possessing

knowledge, even if that knowledge is unactionable. In other words, knowledge is a requirement for responsibility:

Chaplain 2: “You know, if it matters that he has this, and thereby, his children may also have that possibility, then he would probably want to, as a parent, responsible parent, might choose to go ahead with the testing, even if it wasn’t going to benefit him, in terms of treatment options, so he would know what their status would be, I would think.”

At another point during the chaplaincy focus group, participants turn their attention to patients using the language of God’s will to understand themselves and their circumstances. In this particularly revealing exchange, two of the chaplains note that while some people may see a reliance on such views as an “abdication of responsibility,” others may find such recourse to be comforting and a very different way of understanding what it means to be responsible. It may be that recognizing one’s lack of control may in fact be a hallmark of the type of responsibility of which they speak:

Chaplain 1: “It’s a security of knowing that even though I don’t understand why, somebody’s in charge. This isn’t just a fickle world that—I don’t understand why God is doing this to me, but I trust that God is in control. And I may be angry with God for giving me cancer or whatever, but ultimately, God’s in control, and that’s been my experience of the sense of payoff, is there’s a sense of security; there’s a sense of orderliness, in the midst of what otherwise might feel like a chaotic, unordered world.”

Chaplain 2: “In watching that, it often looks like an abdication of responsibility.”

Chaplain 1: “Yeah.”

Chaplain 2: “When you watch people walk through that, you go, “Gosh! It looks as though they’ve given up any sense of responsibility for themselves or for the folks around them, but it can be a very comfortable place to be, if you think you’re just rolling with it, and God, again, will do what God chooses to do. It seems, again, and can look, irresponsible to outsiders, particularly, I think sometimes, medical personnel who aren’t familiar with that kind of thinking.”

A discussion among evangelical ministers echoes a similar point as they discuss responsibility in the case study of Debbie, the 40-year-old pregnant woman who is asked about undergoing amniocentesis. In the case study, Debbie defers to “God’s will” in her responses, as she is hesitant to accept the risks involved with the procedure. She suggests that it will be God’s will if she has a child with Down syndrome, just as it will be God’s will if her child is born without that condition. Note how the exchange moves quickly from a question about Debbie’s responsibility to a discussion of how her theological worldview informs her self-understanding and her interpretation of her specific circumstances. Interestingly, one of the ministers echoes the sentiment that Debbie’s movement away from making a decision is an abdication of her responsibility, but another minister frames the issue quite differently. Instead of Debbie struggling with what is the “responsible” decision to make, this minister interprets her hesitance to make a decision as a signal of her attempt to live in accord with her faith-based experiences. Her struggle is not with making a particular decision—whether or not to undergo amniocentesis—but rather with understanding her current situation in light of her theological worldview:

Minister 1: “What are you saying? Backing away from a decision or backing away from...because she ultimately has to make a decision.”

Minister 2: “Right.”

Minister 1: “Nothing is a decision.”

Minister 2: “Right.”

Minister 1: “So, are you saying she’s backing away from a decision as far as her own human responsibility or help me to follow on what you were saying.”

Minister 2: “Yeah, it just seems like she’s struggling with and she, yeah, I agree. She’s making a decision by not making a decision. She’s going to just see what happens.”

Minister 3: “I think she’s also dealing with, as she looks at the genetic counselors scenarios that have been given to her, I think, I think the first thing that she is acknowledging here is the fact that what is her faith experiences up to this point and how do they fit into the context of the four scenarios and I think that, I think what I’m finding today, more and more people are operating off of that premise to begin with than off of the situation. In other words, what is my faith based experience and therefore my decisions are coming off of that faith based decision. Ah, and that’s particularly true with what I would call core church attenders and members.”

This link between God’s will and human responsibility ran throughout the evangelical ministers’ focus groups. Participants grappled with what it means to be a responsible human moral agent in light of a worldview in which God is still “in control” and actively participating in the affairs of the world. In elaborating on this point, one participant drew on an enlightening metaphor—a ship at sea. Though his focus is on the relationship between human freedom and God’s control, his response is directed to a prompt regarding the nature of responsibility in light of that tension. In the statement, the minister concedes that human beings have freedom to act to a certain degree, but we lack control over the overall trajectory of our lives. That trajectory, according to this minister, is the purview of God. As a result, responsibility remains for individuals even when they lack total control over their lives:

Facilitator: “Well, so speaking with this God’s will claim, my grace is the notion of sovereignty and...Bruce raises the notion of responsibility so my sense is this sort of tension...how do you hear that tension with your congregants or folks that you are ministering too? How do they experience that tension?”

Minister 2: “Well, I hear people, I don’t know if they use the word God’s will but they ah, during prayer, you know, they say, ‘Lord, (?) but if it’s in your sweet will, you know, I ask that this occur and that occur.’ You

know, they want to be where where God wants them to be on there but they still know, that, you know, we can tug on the heart of God through (?). I heard somebody say one time that God's will is like an ocean liner that's going from here to Germany and that while I'm on it, I've got all the freedom; I can do whatever I want to do. I can play shuffleboard, I can exercise, I can eat, I can do what I want to but that ship is going to Germany, not going some place else so God's will is at work and all, saying we're going this direction but I think within sight of that we have, there is some of that freedom that is in there working in you know, different areas."

What we find in these various statements is both a harmony and a discord with what the medical professionals said about responsibility. On one hand, there is a recognition that one's status as a parent or professional or church member gives rise to and informs certain responsibilities. On the other hand, some of these clergy members made overtures toward a vision of responsibility in which people struggle not with making difficult decisions, but rather with discerning how best to live out their fundamental commitments amid a challenging set of circumstances. In other words, the question of responsibility for these clergy and their congregants is not "What decision should I make?" but rather "How can I live in accord with my commitment to the idea that God is in control?" As I will later show, this is a very different approach to thinking about responsibility, but it is one that may be fruitful for probing the ethical challenges that genetics and genetic biotechnologies pose to care providers, patients, families, and others who confront those issues in the course of medical care.

Institutional Responses to the New Genetics

Statements from Medical Professional Organizations

The focus group transcripts are certainly helpful for eliciting what individual members of the caring professionals say about responsibility in light of genetic issues. However, as some of those statements suggested, responsibility is not merely a personal value or commitment; it often carries social and institutional connotations. Thus, it will be helpful to turn to the official statements of religious denominations and medical professional organizations in order to see how these institutions speak of responsibility. Further, the institutional perspectives can carry significant weight for public policy discussions and for setting expectations and standards for members of these caring professions, even if the personal views of individual professionals may differ from the institutional statements. Specifically, I turn to the Codes of Ethics for the American Medical Association (AMA), the American Nurses Association (ANA), and the National Society of Genetic Counselors (NSGC).

The American Medical Association

The American Medical Association (AMA) has developed an extensive Code of Medical Ethics over the course of its 160-year existence, going well beyond simple recitation of the Hippocratic oath. The AMA Code is designed to provide “standards of conduct which define the essentials of honorable behavior for the physician.”⁶ For this

⁶ American Medical Association, Council on Ethical and Judicial Affairs, “Principles of Medical Ethics” in “AMA Code of Medical Ethics,” 2001 Version. <<http://www>.

reason, the AMA Code offers both general principles and specific suggestions for guiding the conduct of AMA physician members in a variety of circumstances.

Just as the physician's role is multi-dimensional, so too does the AMA Code address the physician's relationship to her patients, other physicians and health professionals, hospitals, and society at large. Not surprisingly, responsibility becomes one of the conceptual lenses through which those relationships are understood. For example, physicians are called to "recognize responsibility to patients first and foremost, as well as to society, to other health professionals, and to self."⁷ AMA members are urged to recognize that "ethical obligations typically exceed legal duties" and that "in exceptional circumstances of unjust laws, ethical responsibilities should supersede legal obligations."⁸ Here, obligation, duty, and responsibility appear to be used interchangeably, indicating that responsibility carries connotations associated with bearing some obligation or possessing a duty. Further, even in this brief statement we see that the AMA makes a distinction between what the law demands and what is "ethical," with the ethical being of greater importance.

Responsibility also plays a crucial role in describing the physician-patient relationship for the AMA. The Code states that "patients share with physicians the responsibility for their own health care."⁹ However, sharing in responsibility does not

ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.shtml> (accessed August 20, 2009).

⁷ Ibid.

⁸ "Opinion 1.02—The Relation of Law and Ethics" in the AMA Code.

⁹ "Opinion 10.01—Fundamental Elements of the Patient-Physician Relationship," AMA Code of Medical Ethics.

mean that the physician and patient share in the same activities, nor do they share in power: “Such a partnership does not imply that both partners have identical responsibilities or equal power.”¹⁰ In this partnership, the physician is instructed to provide healthcare services while the patient is asked to be honest about her medical history and condition, to tell the physician of medical issues in a timely manner, and to treat the physician with respect. While the activities of the physician and patient are distinct, they nonetheless share a common goal: the promotion of health. By sharing a common goal, the physician and patient both become responsible for their efforts in reaching that goal through collaboration.

Interestingly, the AMA Code goes into much greater detail about the source of the patient’s responsibilities for her healthcare. Presumably, the fact that a physician is responsible to her patients is taken for granted by the AMA and needs little explanation regarding the source of that responsibility; instead the AMA Code details how the honorable physician should respond to a wide variety of specific issues. As for the patients’ responsibility, the AMA holds the following:

“Like patients’ rights, patients’ responsibilities are derived from the principle of autonomy. The principle of patient autonomy holds that an individual’s physical, emotional, and psychological integrity should be respected and upheld. This principle also recognizes the human capacity to self-govern and choose a course of action from among different alternative options. Autonomous, competent patients assert some control over the decisions which direct their health care. With that exercise of self-governance and free choice comes a number of responsibilities.”¹¹

¹⁰ “Opinion 10.01—Patient Responsibilities,” AMA Code of Medical Ethics.

¹¹ Ibid.

This brief statement provides the most robust articulation of the AMA’s understanding of responsibility. A patient’s responsibility, according to the AMA, is grounded in the principle of autonomy. Notice the themes that the AMA associates with patient autonomy: integrity, self-governance, decision-making, self-governance, and free choice. It is through the patient’s capacity to “self-govern and choose a course of action” that she comes to bear some of the responsibility for her health care. The combined emphasis on integrity and choice is particularly revealing in this case. Integrity carries connotations of “wholeness” or “completeness” as well as a consistent commitment to particular values or principles. In the context of decision-making, integrity means being able to give an account of decisions and actions in order to demonstrate how they are commensurate with how a person understands herself, that is, how those decisions and actions are my own. And it is through being able to choose for myself—especially in making a decision that is commensurate with my self-understanding—that I share in the responsibility for my health care.

As for the role of genetics in medical care, the AMA Code covers 11 “social policy issues” but only mentions responsibility in two of their opinions—gene therapy and genetic engineering.¹² Here, both references are to “the standards of medical practice

¹² The “social policy issues” for which the AMA has issued opinions in their Code of Medical Ethics are as follows: patenting human genes (Opinion 2.105), gene therapy (2.11), genetic counseling (2.12), genetic engineering (2.13), disclosure of familial risk in genetic testing (2.131), genetic testing by employers (2.132), insurance companies and genetic information (2.135), genetic information and the criminal justice system (2.136), ethical issues in carrier screening of genetic disorders (2.137), genetic testing of children (2.138), and multiplex genetic testing (2.139).

and professional responsibility.”¹³ In both cases, what the standards of professional responsibility entail in those specific situations is not elaborated. A section of the AMA Code titled “Opinions on Professional Rights and Responsibilities” covers an array of topics (accreditation, physician health and wellness, gender discrimination in the medical profession, medical testimony, among other topics) that arise in the day-to-day activities of a medical professional; presumably these are the types of professional responsibilities to which the Code refers in its discussion of genetics-based issues. This section of the AMA Code articulates both the rights and attendant responsibilities that are vested in the role of physician: By accepting that role, one accepts the responsibilities listed therein. Yet, the AMA Code does not make note of any other responsibilities that arise for the physician in situations that specifically concern genetics. In this way, genetic biotechnologies are no different for the physician than other forms of biotechnology: all must be used within the limits of professional responsibility.

The American Nurses Association

The American Nurses Association (ANA) also established a Code of Ethics, one that was initially drafted in 1985 with an extensive revision culminating in 2001. There are nine provisions in the ANA Code, and unlike the AMA Code that was designed with physicians in mind, the Nurses’ Code does not pore through lists of specific situations that may warrant ethical consideration on the part of the professional. As such, there are no specific provisions in the ANA Code that are geared toward issues of genetics and

¹³ “Opinion 2.11—Gene Therapy” and “Opinion 2.13—Genetic Engineering” in the AMA Code of Medical Ethics.

genetic biotechnologies. Instead, the ANA Code was established for the following purposes: “It is a succinct statement of the ethical obligations and duties of every individual who enters the nursing profession; it is the profession’s nonnegotiable ethical standard; [and] it is an expression of nursing’s own understanding of its commitment to society.”¹⁴ With these goals in mind, the ANA Code is an articulation of the ethical dimensions of the nursing profession, one that carries with it an explicitly normative component.

Like the AMA Code of Ethics for physicians, the ANA draws heavily on the language of obligation, duty, and responsibility in detailing the ethics of the nursing profession. In fact, the words “responsible” and “responsibility” appear 62 times in this brief statement. In the ANA Code we find that “the nurse’s primary commitment is to the patient, whether an individual, family, group, or community.”¹⁵ However, the nurse must not forget to take care of herself: “The nurse owes the same duties to self as to others, including the responsibility to preserve integrity and safety, to maintain competence, and to continue personal and professional growth.”¹⁶ While the AMA physician’s code emphasizes respect for both patient and professional, the ANA code for nurses repeatedly stresses the guiding force of the “inherent dignity” of everyone involved in the clinical encounter.

¹⁴ American Nurses Association Board of Directors and the Congress of Nursing Practice, “Preface to the ‘Code of Ethics for Nurses with Interpretive Statements.’” Adopted July 2001.
<<http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses/AboutTheCode.aspx>> (accessed September 4, 2009).

¹⁵ “Provision 2” of the ANA Code of Ethics for Nurses.

¹⁶ “Provision 5” of the ANA Code of Ethics for Nurses.

Responsibility also plays a key role in establishing and protecting the “professional boundaries” of nursing. Nurses are told that they have a “professional responsibility” to retain personal boundaries when working with patients and families so that the work of the nurse is not jeopardized by those interactions. Further, the very profession of nursing is “responsible and accountable for assuring that only those individuals who have demonstrated the knowledge, skill, practice experiences, commitment, and integrity essential to professional practice are allowed to enter into and continue to practice within the profession.”¹⁷ Nursing educators “have a responsibility” to ensure that this level of competency is achieved by a student prior to entering the profession and nursing administrators are “responsible for” assessing nurses’ competency and assigning them duties commensurate with their level of competency. Finally, once she has entered the nursing world, the nurse herself “has a responsibility” to uphold the standards of her profession and to report unethical or incompetent behavior on the part of her colleagues.

Ultimately, responsibility is the bedrock of the nursing profession’s understanding of itself and its activities. Individual nurses “bear primary responsibility for the nursing care that their patients receive and are individually accountable for their own practice.”¹⁸ In this section of the Code, the ANA provides its clearest understanding of what responsibility entails for the nursing profession: “Responsibility refers to the specific accountability or liability associated with the performance of duties of a particular role.

¹⁷ “Provision 3.4 Standards and Review Mechanisms” of the ANA Code of Ethics for Nurses.

¹⁸ “Provision 4.1 Acceptance of Accountability and Responsibility” of the ANA Code of Ethics for Nurses.

Nurses accept or reject specific role demands based upon their education, knowledge, competence, and extent of experience.”¹⁹ The Code then elaborates on responsibilities that are specific to certain nursing roles, such as the individual registered nurse and the nursing administrator. This understanding of responsibility is commensurate with others we have seen throughout this chapter, particularly as it is understood in terms of accountability and role-related activities.

One final component of the ANA Code of Ethics is worth mentioning here. Earlier there was a reference to the nurse’s responsibility to “preserve integrity.” In the provision that addresses this responsibility there is a significant emphasis on moral self-respect and character. This section reiterates the nurse’s responsibility to participate in the development of assessment criteria and her responsibility to maintain competence, but preserving moral-self respect and character goes beyond these professional and procedural matters. The Code states, “Nurses have both personal and professional identities that are neither entirely separate, nor entirely merged, but are integrated. In the process of becoming a professional, the nurse embraces the values of the profession, integrating them with personal values.”²⁰ Part of this integration includes a responsibility to “express moral perspectives, even when they differ from those of others, and even when they might not prevail.”²¹ The nurse is also called to express her conscientious objection to professional activities that are not in line with her personal perspective, though she is also called to seek a compromise rooted in integrity whenever possible.

¹⁹ “Provision 4.3 Responsibility for Nursing Judgment and Action” of the ANA Code of Ethics for Nurses.

²⁰ “Provision 5.3 Wholeness of Character” of the ANA Code of Ethics for Nurses.

²¹ Ibid.

Clearly this is a recognition of the tension created when a nurse's "personal" and "professional" identities come into conflict. In this way, perhaps it is also a recognition of a tension similar to that identified by participants in the clergy focus groups, one in which a person seeks to live in accordance with her self-understanding in light of a given set of circumstances.

The National Society of Genetic Counselors

Finally, the National Society of Genetic Counselors (NSGC) established its own Code of Ethics, designed to "clarify and guide the conduct of a professional so that the goals and values of the profession might best be served."²² The NSGC Code is based largely on Beauchamp and Childress' articulation of four principles of biomedical ethics: respect for autonomy, beneficence, nonmaleficence, and justice.²³ Like the other codes described here, the NSGC Code not only covers the values that are to be upheld by genetic counselors, but it also offers guidance for their relationships with clients, colleagues, and society. The NSGC Code is not intended to be exhaustive of the genetic counselor's obligations in every circumstance, but is open to "ambiguity...allowing the experience of genetic counselors to provide the proper balance in responding to difficult situations."²⁴

²² National Society of Genetics Counselors. "Introduction' to the Code of Ethics." <<http://www.nsgc.org/about/codeEthics.cfm>> (accessed August 21, 2009).

²³ See Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (Oxford: Oxford University Press, 2001).

²⁴ NSGC, "Introduction' to the Code of Ethics."

The NSGC document is quite brief, divided into six sections consisting of explanatory paragraphs and numbered obligations that the genetic counselor should strive to fulfill. In this short space, the NSGC specifically refers to responsibility on five different occasions. In the Code's preamble, the NSGC notes that the Code is an affirmation of the "ethical responsibilities" of its members. While the specific mention of "ethical" here may indicate that there is a distinction between "ethical responsibilities" and other kinds of responsibilities, the Code itself then goes on to describe responsibilities that arise out of the position of counselor, that is, *professional* responsibilities. This relation between the invocation of "ethical responsibility" and the delineation of professional standards suggests that the NSGC views ethical and professional responsibility as inseparable from one another.

Three of the four sections devoted to the work of the genetic counselor (Genetic Counselors Themselves, Genetic Counselors and Their Colleagues, and Genetic Counselors and Society) mention responsibility in some way, though it is curious that the "Genetic Counselors and Their Clients" section does not mention responsibility at all. In these three sections, NSGC members are called to "be responsible for their own physical and emotional health as it impacts on their professional performance." In serving as mentors, counselors are also encouraged to "assure that individuals under their supervision undertake responsibilities that are commensurate with their knowledge, experience and training." They also urged to "participate in activities necessary to bring about socially responsible change" and to "support policies that assure ethically responsible research." In these brief statements we once again find that responsibility is tied to knowledge and experience, but not in a way that suggests that knowledge and/or

experience creates responsibility. Rather, one's "knowledge, experience and training" can provide the contours of one's responsibilities, delineating that for which one may "be responsible" from that which is off limits. The two other statements use "responsible" as a modifier, describing the social change and research that genetic counselors should promote. However, what such responsible social change and research might look like cannot be discerned from the NSGC Code of Ethics alone.

Religious Institutional Responses to the New Genetics: Jewish and Christian Denominational Statements

In 2002, Rebecca Rae Anderson, a legal scholar and prenatal genetic counselor at the University of Nebraska, conducted a survey of 31 Jewish and Christian denominational representatives in the United States regarding relevant aspects of their faith for how they understand issues of prenatal genetics.²⁵ The survey asks questions

²⁵ Anderson contacted all religious denominations in the United States with at least 200,000 members or at least 50 congregations, including Hindu, Jain, and Muslim denominations. Of the 86 religious organizations she contacted, 31 submitted responses to her survey, and of those 31, all were either Jewish or Christian with the exception of the Eckankar religious organization. The following denominations participated in Anderson's survey: Antiochean Orthodox Christian Archdioceses of North America; Christian Reformed Church in North America; Church of Christ, Scientist; Church of God (Cleveland, TN); Church of Jesus Christ of Latter-Day Saints; Church of the Nazarene; Churches of Christ (Non-Instrumental); Community of Christ [formerly Reorganized Church of Jesus Christ of Latter-Day Saints]; Cumberland Presbyterian Church; Eckankar; Episcopal Church; Evangelical Free Church of America; Evangelical Lutheran Church in America; General Association of General Baptists; General Association of Regular Baptist Churches; General Council of the Assemblies of God; Greek Orthodox Archdiocese of America; Lutheran Church—Missouri Synod; Mennonite Church; Orthodox Church in America; Presbyterian Church (U.S.A.); Rabbinical Council of America (Orthodox Judaism); Roman Catholic Church c/o United States Council of Catholic Bishops; Salvation Army; Seventh-day Adventists; Southern Baptist Convention; Union of American Hebrew Congregations (Reform Judaism);

about a range of issues in prenatal care (including prenatal diagnosis) and neonatal care, including questions about religious ideas of ensoulment, the use of prenatal diagnosis, induced abortion for fetal defects, and observances following newborn death.

Representatives were also invited to elaborate on the issues raised and to provide copies of any relevant doctrinal teachings. As a prenatal genetic counselor, Anderson had witnessed firsthand how spiritual ideas or attitudes were frequently operative when patients were immersed in difficult circumstances. She believed that in the counselor's quest to aid patients in understanding complex issues and making tough choices that are consistent with their own self-understanding, genetic counselors should be aware of prevalent religious teachings and perspectives on those issues in order to facilitate that self-understanding. Hence, she conducted and compiled this survey for the benefit of those counselors, though she is quick to note that one should not assume that a person's beliefs are wholly consistent with the teachings of their particular faith tradition.

As one might expect, responses to the survey questions were as diverse as the denominations that participated. For example, when representatives were asked at what point in human development ensoulment takes place or at what point does a unique human being become present, responses ran the gamut from "conception" (the most common response) to "at, or about the time of birth" (Eckankar) to "live birth" to "each individual is eternally the image and likeness of God (Gen: 1:26-27). Therefore, there is no single moment when an individual comes into being" (Church of Christ, Scientist). On this same question, the Presbyterian Church (U.S.A.) even suggests that its members

Unitarian Universalist Association; United Synagogue of Conservative Judaism; Unity School of Christianity; and the Wesleyan Church.

will hold a range of positions, including at the moment of conception, at the fulfillment of criteria developed by Harvard Medical School, quickening, at viability, or even at birth. When asked about the acceptability of prenatal diagnostic testing (maternal serum screening, ultrasound, amniocentesis, CVS, cordocentesis), parents are often encouraged to utilize such testing “at their discretion” while some see such prenatal care as “essential” because “our bodies are a trust from God, [therefore] preservation of life and health are paramount duties” (Conservative Judaism). For others, however, prenatal diagnosis is considered illicit if “undertaken with the intention of aborting an unborn child with a serious defect” (Roman Catholic Church).²⁶

As interesting as these differences may be, it is also important to note the different ways in which these groups speak about responsibility. Of the 31 participating denominations in the survey, 17 specifically draw on the concept of responsibility in their answers while two additional participants mention appropriate “responses.”²⁷ The frequent use of that concept is all the more notable when we see that Anderson does not

²⁶ For a more developed account of the varying responses to the specific issues raised in the survey, see Rebecca Rae Anderson, "Religious Traditions and Prenatal Genetic Counseling," *Am J Med Genet C Semin Med Genet* 151C, no. 1 (2009), 52-61. Roman Catholic quote can be found in the United States Conference of Catholic Bishops' *Ethical and Religious Directives for Catholic Health Care Services* (Washington, D.C.: United States Conference of Catholic Bishops, 2001), p. 27, paragraph 50.

²⁷ These denominations include: Antiochean Orthodox Christian Archdiocese of North America; Church of Christ, Scientist; Church of God (Cleveland, TN); Church of Jesus Christ of Latter-Day Saints; Church of the Nazarene; Eckankar; Episcopal Church; Evangelical Free Church of America; Evangelical Lutheran Church in America; General Association of General Baptists (refer to “respond”); General Association of Regular Baptist Churches; General Council of the Assemblies of God; Lutheran Church—Missouri Synod; Mennonite Church and General Mennonite Conference; Orthodox Church of America; Presbyterian Church (U.S.A.); Roman Catholic Church c/o United States Council of Catholic Bishops; Salvation Army; Seventh-day Adventists; and the Wesleyan Church (refer to “respond”).

use the term “responsibility” at any point in her survey questionnaire. Other participants pick up on related concepts such as “choice” (Church of Christ, Scientist) or “obligation” (Reform Judaism) without specific reference to responsibility. Some denominations mention responsibility only once (Antiochean Orthodox Christian Archdiocese of North America, Church of Jesus Christ of Latter-Day Saints, Mennonite Church and General Mennonite Conference) while others used the term up to 17 times (Evangelical Lutheran Church in America). Two of the participating denominations—the Roman Catholic Church and Seventh-day Adventists—even supplied supplemental doctrinal statements that contained specific emphases on responsibility (“Responsible Parenthood” and “Acceptance of Social Responsibilities,” respectively).

But how do these diverse participants articulate the concept of responsibility in their survey responses and doctrinal statements? One theme that regularly emerged was a connection between responsibility and choice:

“We believe that the human race’s creation in Godlikeness included ability to choose between right and wrong, and that thus human beings were made morally responsible” (Church of the Nazarene).²⁸

“In their personal lives, members of Eckankar seek divine guidance, knowing choices carry responsibility” (Eckankar).

“It may be the morally responsible choice to avoid known risks of serious congenital defects by forgoing procreation” (Seventh-Day Adventists).

In the first statement, responsibility seems to be predicated upon one’s abilities to both discern and choose between right and wrong, which is in turn rooted in “the human race’s creation in Godlikeness.” Thus, a person can be described as “responsible” not simply

²⁸ Church of the Nazarene, “Articles of Faith,” Section 7, paragraph 7, in Anderson’s *Religious Traditions and Prenatal Genetic Counseling*.

because she has the ability to choose but also because she has a moral understanding of her options—she knows right from wrong. In the Seventh-Day Adventists’ statement, “responsible” does not describe the moral agent but rather her choices. From the ECKist perspective, responsibility does not describe the character of an agent or her actions. Rather, it is some identifiable quality that accompanies one’s choices.

Related to this connection to choice, other statements suggest that knowledge is a key component of responsibility, particularly as that knowledge relates to making choices. On one hand, knowledge creates responsibilities such that because a person knows the difference between right and wrong, she is therefore “responsible” for making the appropriate choice. On the other hand, as our knowledge of the world increases, so too does our capacity to interact with the world. It is in those new interactions that we are then faced with new choices—and as some of these statements suggest—new responsibilities:

“We are, to use Philip Hefner’s words, created co-creators with God. That role expands as we know more and can do more....That makes our responsibility for human and other life unavoidable, including our responsibility in begetting children known to be at risk” (Evangelical Lutheran Church in America).²⁹

“The moral responsibility to share important genetic knowledge with a spouse or potential spouse is not a trivial or passing one; it is a radical responsibility which reaches to the core of the relationship (Evangelical Lutheran Church in America).³⁰

²⁹ Hans O. Tiefel, “Individualism vs. Faith: Genetic Ethics in Contrasting Perspectives” in the Evangelical Lutheran Church in America’s *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, Roger A. Willer, ed. (Minneapolis: Kirk House Publishers, 1998); supplemental document to the Anderson survey, 2002.

³⁰ Robert Roger Lebel, “A Geneticist’s Synthesis: Evolution, Faith, and Decision Making” in the ELCA’s *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*; supplemental document to the Anderson survey, 2002.

“The basic Reformed tenet that God alone is the Lord of Conscience undergirds long-standing church policy in support of a woman’s ability and responsibility, guided by the Holy Spirit, to make good moral choices about contraception and abortion within the limits of state and federal law (Presbyterian Church, U.S.A.).

“While gene therapy is still in its infancy, it is our moral responsibility as thoughtful Christians to become aware of its potential to meet human needs, to understand the biological and genetic risks that it entails, and to avoid its misuse. Decisions should be made in accordance with biblical principles” (Seventh-Day Adventists).

Another theme that emerged from the statements was that responsibility is often viewed as inseparable from specific roles—roles that are imbued with levels of power or authority (legitimated power). Whether one is a church bishop, a congregant, or a parent—each of these positions of authority carry with them specific attendant responsibilities. That is, those who possess the authority to engage in certain activities (counseling, protecting unborn children, nurturing one’s family) also have certain responsibilities by virtue of their specific role. Those responsibilities may either direct someone to engage in certain sets of activities rather than others (“protecting the rights of an unborn child” rather than assisting someone seeking abortion, as in the ELCA example below) or they may characterize the ways in which a person participates in his the activities of her role. In other words, certain responsibilities are characteristic of specific authority-laden roles:

“Because of the complexity of the issues, genetic counselors should be encouraged to refer members of the LDS Church to their bishop for consultation. He has the responsibility and the right to divine guidance in helping them understand spiritual issues” (Church of Jesus Christ of Latter-Day Saints).

“It is the responsibility of members of this Church, especially the clergy, to become aware of local agencies and resources which will assist those faced with problem pregnancies” (Episcopal Church).³¹

“We hold that it is the responsibility of parents to protect the rights of an unborn child...” (Evangelical Free Church of America).³²

“...therefore be it RESOLVED, That the Lutheran Church—Missouri Synod in convention urgently call upon Christians... To speak and act as responsible citizens on behalf of the living but unborn in the civic and political arena to secure for these defenseless persons due protection under the law” (Lutheran Church—Missouri Synod).³³

“In those increasingly rare cases where a medical choice must be made between the life of the mother and that of her unborn child, it is morally permissible to favor the mother. This is not because she is a full ‘person’ whereas the fetus is merely ‘potential life,’ for both are equally human. It is rather because of the mother’s place and responsibility within the family, where her nurturing and loving presence directly affects the lives of her husband and other children” (Orthodox Church in America).³⁴

Additionally, many of these statements reveal that responsibility is seen as a deeply personal matter. In the statements below we find responsibility associated with terms like “unconditional commitment” and “dignity” and “intrinsic value,” words and phrases that suggest that there is something so fundamental to responsibility that it may be understood as a hallmark of human existence and interaction with the world around us. With such “unconditional commitment,” a person devotes herself to a particular cause or

³¹ “Statement on Childbirth and Abortion,” in *Resolutions of the General Convention of the Episcopal Church*, General Convention 1988-C047; supplemental document to the Anderson survey, 2002.

³² “Abortion (Declaration for Life and Morality),” Resolution adopted at General Conference, 1977; supplemental document to the Anderson survey, 2002.

³³ “To State Position on Abortion (Overtures 3-02A—3-23),” 1977 Convention Proceedings; supplemental document to the Anderson survey, 2002.

³⁴ *Orthodoxy and Abortion* (Syosset, NY: Department of Religious Education, Orthodox Church in America); supplemental document to the Anderson survey, 2002.

act, creating a bond in which neither the person nor the cause can be wholly understood without reference to one another. That is, one's responsibilities come to define who a person seeks to be:

“Responsible opposition to abortion requires our commitment to the initiation and support of programs designed to provide care for mothers and children” (Church of the Nazarene).³⁵

“Human beings, created in God's image as male and female (Genesis 1:27-28), are persons of intrinsic value and dignity. Human beings live in community, with responsibility and accountability to God, self, and others” (Evangelical Lutheran Church in America).³⁶

“Amniocentesis can on occasion be put to good use...But we deceive ourselves if we suppose that, as a routine feature of medical practice, it can simply assist a couple to prepare themselves for their child's birth. It does exactly the opposite. It sets our foot on a path that is difficult to exit....The technology...prepares us not for the kind of commitment that parenthood requires, an unconditional commitment, but for a kind of responsibility that finite beings ought to reject” (Lutheran Church—Missouri Synod).³⁷

Finally, some statements about responsibility stand out in these documents because they are so unique. While the examples above can be readily organized based on their shared themes, other statements attract attention precisely because they stand out, offering unique insights about how some people construe responsibility:

“God is not responsible for evil, nor is He its cause. Neither is he blameworthy because He created man's nature with the possibility of

³⁵ “1997-2001 Manual, Church of the Nazarene (Kansas City, MO: Beacon Hill Press, 1997), Section 36; supplemental document to the Anderson survey, 2002.

³⁶ “A Social Statement on ABORTION,” adopted at the 2nd biennial Churchwide Assembly of the Evangelical Lutheran Church in America meeting, Orlando, FL, 1991; supplemental document to the Anderson survey, 2002.

³⁷ Excerpted from Gilbert Meilaender's *Bioethics: A Primer for Christians* (Grand Rapids, MI: Eerdmans Publishing, 1996); included in supplemental document to the Anderson survey, 2002.

alienating itself. If He had created human nature without free will, by this imposed condition He would have rendered the created intelligent being purely passive in nature; the creature would simply submit, not having the possibility of doing otherwise, since it would not be free. However, God wished that, after a fashion, we too should be His co-workers in His creation and be responsible for our own eternal destiny. God knows in His infinite wisdom how to transform the causes of evil into that which is profitable for man's salvation. Thus, God uses the consequences of evil so as to make roses bloom from thorns" (Antiochean Orthodox Christian Archdiocese of North America).³⁸

"The Church recognizes that there can be sound reasons for ending a pregnancy through induced abortion... We recognize that conscientious decisions need to be made in relation to difficult circumstances that vary greatly. What is determined to be a morally responsible decision in one situation may not be in another (Evangelical Lutheran Church in America).³⁹

Each of these statements resonates with commonly held views of responsibility.

The Antiochean Orthodox statement is particularly rich. The very first sentence—"God is not responsible for evil, *nor is He its cause*" (emphasis mine)—seems to indicate that causality is not a necessary condition of responsibility, as each clause of that sentence treats responsibility and causality separately. However, the rest of the statement suggests that freedom *is* nonetheless a necessary component of responsibility, enabling us to freely choose "to do otherwise" as we live and work in the world. Next, the ELCA statement suggests that responsible decision-making requires discernment (determination) and that responsibility may be context-dependent. As the last sentence indicates, what is understood as being morally responsible in one context may not be in another. Thus, responsible agents take into consideration the contingent factors of their specific

³⁸ "I Believe:...A Short Exposition of Orthodox Doctrine," <<http://www.ocf.org:80/OrthodoxPage/reading/believe.html>>; supplemental document to the Anderson survey, 2002.

³⁹ ELCA, "A Social Statement on ABORTION."

situations. Even if someone holds certain principles (such as beneficence) as nearly absolute, what is considered to be in accordance with that principle in one situation may be in another context. In fact, the very same act may be seen as responsible (or beneficent, etc.) *or* irresponsible, depending upon the mitigating factors surrounding the action.

From these survey responses, four points are worth emphasizing at this time. First, we should note that responsibility is indeed an important concept for how many of these religious institutions understand themselves and their work in the world. Because these denominations draw on the concept of responsibility to articulate how they understand themselves and their interactions with others, responsibility takes on a keenly moral dimension in these statements. Second, common themes routinely emerged among these statements from even the briefest mentions of that concept. Here, respondents often couched responsibility in language of choice, decision-making capacity (which requires knowledge), inhabiting roles, and in terms that make responsibility integral to one's self-understanding. None of these themes are incommensurable with one another. Finally, in the two unique statements I highlighted, we see recognition that responsibilities may be context-dependent at times. We also notice in one particular statement that responsibility may be associated with causality while nonetheless remaining distinct from that notion. Hence, it may be possible to speak of responsibilities that arise independent of whether one has "caused" those responsibilities to exist. Rather, such thinking opens the door to speak of responsibilities that arise out of being rather than doing.

Finally, the very structure of these institutional statements—for both religious denominations and medical professional organizations—is remarkable in its own right,

particularly in relation to responsibility. As statements of official institutional positions, these documents serve a specific function, outlining some of the positions that members should take and expressing certain expectations that they are expected to fulfill as members of a particular denomination or profession. Beyond providing guidelines and describing responsibilities for members of these institutions, however, such statements may in themselves create responsibilities for these institutions and their members. Here, J.L. Austin's distinction between constative and performative utterances is especially helpful.⁴⁰ Constative utterances, according to Austin, describe states of affairs and report facts that can be verified or disproven. Performative utterances, on the other hand, are not subject to standards of truth and falsehood, nor do they merely describe events. Rather, performative utterances *do* something (or initiate the doing of something). For example, stating the phrase "I promise X" is not a description of an event but is an event unto itself—the very act of promise making. Similarly, it could be that with these public statements that pronouncements like "it is the responsibility of members of this Church" may not be merely descriptions of members' responsibilities but may instead be the instantiation of those very responsibilities. Thus, in declaring that members of these various organizations are to be responsible or have certain responsibilities, those responsibilities are created through those assertions. Through taking an oath of membership or by continuing to be a member of the organization in question, members thereby assent to the responsibilities thrust on them by virtue of belonging to the group.

⁴⁰ See J. L. Austin, *How to Do Things with Words*, William James Lectures (New York: Oxford University Press, 1965); J. L. Austin, J. O. Urmson, and G. J. Warnock, *Philosophical Papers*, 3d ed. (Oxford: Oxford University Press, 1979); and "Performative-Constative" John L. Searle's *The Philosophy of Language*, Oxford Readings in Philosophy (London: Oxford University Press, 1971), pp. 13-22.

Further, this way of thinking about institutional statements is commensurate with the notion that responsibilities are sometimes borne out of the role that one inhabits. As a member of a church or a medical profession, one takes on responsibilities associated with that larger organization, and statements such as the ones mentioned here may be one way in which those responsibilities are articulated to organizational members.

Summary

In this chapter I examined data from focus groups conducted by Vanderbilt University's Religion and Genetics study group. These focus groups, consisting of members of the "caring professions" (physicians, nurses, genetic counselors, hospital chaplains, evangelical Christian ministers, and mainline Protestant ministers), were asked to reflect on their experiences working with patients and congregants dealing with issues of genetics and religion in medical care. Members were also given case studies offering specific examples in order to prompt discussion. For my work, I focused on instances in which participants spoke about responsibility in order to develop an understanding of how these professionals understand what responsibility entails in the context of their professions.

In the medical professional focus groups, participants spoke of responsibility in relation to control. Patients who "gave up control" of their health care decisions were seen as abdicating responsibility, while the focus group participants articulated a sense of lacking responsibility when they were unable to influence their patients' decisions. One participant drew a distinction between her personal attitudes and her responsibilities "as a counselor," that is, her professional responsibilities that are inherent to her work. In the

clergy focus groups, some of the participants echoed this emphasis on professional responsibility. However, talk frequently turned to the issue of “God’s will.” In this light, some clergy acknowledged that what often appears as an abdication of responsibility is in fact a recognition of a tension that permeates human existence: Though we are called to be responsible moral agents, we are in fact not in total control of our lives. Recognizing this lack of control may be the first step toward becoming a responsible moral agent, particularly when one lives with a worldview in which God’s will is still operative.

I also examined the statements of medical professional organizations and religious denominations to identify ways in which these institutions articulate their visions of responsibility. For the medical professional groups, responsibility is often used interchangeably with concepts like “duty” and “obligation.” Particularly in the AMA Code of Medical Ethics, this understanding of responsibility serves as the foundation of the physician-patient relationship. In working together, patient and physician share responsibility for promoting the health of the patient. Further, AMA Code tied responsibility to patient autonomy. Two other themes that emerged in these Codes of Ethics are an emphasis on responsibility for one’s personal well-being (as a member of a particular profession) and the unique responsibilities that arise as a result of the specialized knowledge that is the hallmark of a given profession.

The religious statements I examined are from Rebecca Rae Anderson’s survey of 31 Christian and Jewish denominations in the United States in which she asked representatives to discuss relevant aspects of their faith for issues of prenatal genetics. Representatives were also encouraged to include supplemental statements of faith in order to provide a more robust account of their particular orientations. Responses to this

survey were as varied as the denominations that agreed to participate. Some denominations connect responsibility to matters of choice, such that one makes “responsible choices” or becomes a responsible moral agent by virtue of the choices she makes. Others echoed the familiar sentiments that responsibility is predicated upon the possession of knowledge or one’s particular roles (as a parent, sibling, Christian, etc.). Many respondents also spoke of responsibility as a deeply personal matter, describing it in terms like “unconditional commitment.” Finally, some responses were very unique and were in tension with other statements. One denominational respondent, for example, described responsibility in language that suggests that responsibilities arise independent of causality and instead come from one’s *being* rather than her *doing*. This perspective may be in line with a status-based view of responsibility or ones like those above in which responsibility is inextricably linked to one’s specific roles.

The following chapter seeks to contextualize these various reflections on responsibility by examining prevalent understandings of this concept that are operative in bioethics and ethics discourse. What might be truly unique about some of these statements, and what finds a readily identifiable counterpart in responsibility ethics literature? By turning to ethics and bioethics literature, I intend to highlight ways in which typical scholarship on responsibility tends to neglect some of the most interesting insights articulated throughout this chapter. As a result, these statements can serve as the basis for an updated account of responsibility that is more reflective of the experiences of members of the caring professions. Thus, a new understanding of responsibility may be more suited to address some of the challenges I identified in chapter one that are posed by genetics and genetic technologies in the clinic.

CHAPTER III

UNDERSTANDING RESPONSIBILITY: PREVALENT DISCUSSIONS OF RESPONSIBILITY IN RELIGIOUS, PHILOSOPHICAL, AND BIOETHICS SCHOLARSHIP

In the previous chapter I demonstrated ways in which responsibility is an important concept for the self-understanding and ethical reflection of the caring professions and their individual members. Survey responses from religious denominations and medical codes of ethics attest to the centrality of responsibility as a framework for institutional understanding. Likewise, the focus group transcripts reveal that individuals also draw on that concept when discussing the ethical dimensions of their work in light of genetics and genetic technologies. The examples in the previous chapter do not provide an adequate data set for making definitive statements about the meaning of responsibility for these groups and individuals. They nonetheless provide testimony to the multivalent character of responsibility and its critical importance for moral understanding.

That multivalent character is on full display in both contemporary moral discourse and in everyday conversation (though these categories are by no means exclusive). Responsibility is talked about as something a person *takes* or *accepts*; a person might be *held* responsible. It is both thrust upon and striven for by a moral agent. There are frequent references to the responsible citizen, corporate responsibility, and social responsibility. A person may have responsibilities toward herself, toward her family, and

toward God. As a noun, responsibility is often understood as an obligation or duty that a person must discharge. As an adjective, it describes a moral agent who possesses the positive or praiseworthy trait of being able to reliably discharge those obligations. Or, being responsible may mean being the one from whom a response is demanded, the one who is called upon by the other to give an account of herself. To a degree, the multivalent nature of responsibility is a result of its immense scope of concern. As social scientist Gabriel Moran states, “The relation between the human race and its total environment forms the backdrop of all questions of responsibility.”¹ With this large backdrop and with an ever-increasing expansion of human power and control over our surroundings, it should come as little surprise that we often articulate responsibility in ambiguous—and sometimes contradictory—terms.

Theologian Edward Farley has characterized a related concept—obligation—as an eroding *deep symbol* of modern Western societies.² For Farley, deep symbols are those metaphors and concepts that a community uses to engage in self-criticism and develop self-understanding. In our late-modern or post-modern era, these deep symbols have become disenchanted and dislodged from the larger interpretive master narratives within which they once thrived. Moran similarly describes this dislodgment as the “lack [of] agreement on any rules for our moral language.”³ Alasdair MacIntyre’s entire ethical project is based on the premise that the concepts of our moral language have become

¹ Gabriel Moran, *A Grammar of Responsibility* (New York: Crossroad Publishing, 1996), 14.

² Edward Farley, *Deep Symbols: Their Postmodern Effacement and Reclamation* (Valley Forge, PA: Trinity Press, 1996).

³ Moran, 23.

detached from the rich traditions of inquiry from which they arose.⁴ As a result of this disenchantment and dislodgment, people may still draw on those deep symbols but they do so in ways that are varied and often incompatible (or, for MacIntyre, at the services of one's emotions or personal preferences). In this dissertation I follow Farley's analysis and take responsibility to be a deep symbol—one whose erosion is evident in the ambiguity encircling its usage.

In this chapter I offer an overview of prevalent understandings of responsibility in philosophical, theological, and bioethics discourses. In doing so, I aim to contextualize the statements described in the previous chapter to demonstrate how the perspectives offered here fail to attend to some of the ways in which members of the caring professionals talk about responsibility in light of their work. This chapter is heavily informed by the earlier works of both Albert Jonsen and William Schweiker, two theological ethicists (the former is a pioneer in the work of bioethics) who have developed classificatory schemes for framing discussions of responsibility. Jonsen organizes his systematic review of responsibility according to two patterns that are akin to Weberian ideal types: the attribution of responsibility and the appropriation of responsibility.⁵ Schweiker develops a typology of responsibility based on the locus of

⁴ See MacIntyre's trilogy: *After Virtue: A Study in Moral Theory*, 3rd ed. (Notre Dame, IN: University of Notre Dame Press, 2007); *Whose Justice? Which Rationality?* (Notre Dame, IN: University of Notre Dame Press, 1988); and *Three Rival Versions of Moral Enquiry: Encyclopedia, Genealogy, and Tradition: Being Gifford Lectures Delivered in the University of Edinburgh in 1988* (Notre Dame, IN: University of Notre Dame Press, 1990).

⁵ Albert Jonsen, *Responsibility in Modern Religious Ethics* (Washington, D.C.: Corpus Books, 1968).

judgment and action in assigning and discharging responsibility. He classifies theories of responsibility as being agential, social, or dialogical.⁶

To provide an overview of the contours of responsibility theories in ethics, I unpack what agential, social, and dialogical theories entail by appealing to representative examples of each type: Immanuel Kant (agential), Stanley Hauerwas (social), and H. Richard Niebuhr (dialogical). I have selected the quintessential modern philosopher (Kant), someone who eschews any attempt to render “the Christian story” into the supposedly universal language of modernity (Hauerwas), and someone who described his work as an example of “Christian moral philosophy” (Niebuhr).⁷ While two of these theorists do not place responsibility at the center of their work, they nonetheless provide representative examples of what agential, social, and dialogical theories of responsibility entail for moral agents and communities.

⁶ William Schweiker, *Responsibility and Christian Ethics* (Cambridge: Cambridge University Press, 1995).

⁷ H. Richard Niebuhr, *The Responsible Self: An Essay in Christian Moral Philosophy*, 1st ed. (New York: Harper & Row, 1963), x. The choice of Kant as the representative for agential theories of responsibility may seem a bit odd to those who are familiar with responsibility’s history in our moral language. In fact, Kant never explicitly uses the concept in his writings. However, Kant’s ethical writings lay the groundwork for much of modern philosophy, including subsequent writings on responsibility. Despite Kant not using the term “responsibility” in his writings, I have chosen his work as representative of an agential theory of responsibility for two important reasons. First, many of the crucial themes of Kant’s works (respect for self, autonomy, and intentionality, to name but three) are fundamental to agential theories of responsibility. Second, Kant provides the basis for H.L.A. Hart’s articulation of responsibility. While I do not discuss Hart’s work in detail in this dissertation, I reference him in the following chapter because his work serves as a foil for John Silber and his notion of “status responsibility” [see John R. Silber, "Being and Doing: A Study of Status Responsibility and Voluntary Responsibility," *The University of Chicago Law Review* 35, no. 1 (1967)]. To a great degree, Silber’s status responsibility is the notion that I seek to recover and update in light of genetics and genetic biotechnologies. Additionally, Schweiker includes Kant in his discussion of agential theories of responsibility.

Most importantly for this dissertation, these typologies provide a manageable way to demonstrate not only what these powerful understandings of responsibility emphasize, but also what each tends to neglect. In this review of scholarly literature, I show that responsibility is framed almost exclusively in language that emphasizes intentionality, voluntariness, and contexts of decision-making. Recalling some of the statements from the previous chapter, however, we find that people often speak of responsibility in ways that are independent of such frameworks. Further, the frameworks of intentionality, voluntariness, and decision-making are not necessarily reflective of the ways in which moral agents speak about their moral distress when confronted with issues of genetics and genetic technologies.

Additionally, I examine discussions of responsibility in bioethics literature, with a special emphasis on talk of responsibility in relation to genetics-based issues. With the exception of scholarship in research ethics, little work on responsibility has emerged in recent bioethics literature.⁸ There are a few exceptions, however. Anders Nordgren's

⁸ There is a significant internal debate around what scholars who study these issues should call the area in which they work. However, most of that debate remains unpublished. The Office of Research Integrity (ORI), an office under the U.S. Department of Health and Human Services, has published a guidebook for all researchers who receive federal funding for their research through the National Institutes of Health. The book, authored by Nicholas Steneck, is required reading for those researchers and its title suggests the "official" position of the ORI on the matter of naming the field: Nicholas H. Steneck, *Ori Introduction to the Responsible Conduct of Research*, Updated ed. ([Washington, D.C.]: Dept. of Health and Human Services, Office of the Secretary, Office of Public Health and Science, Office of Research Integrity, 2007). The book reviews nine "core areas" (research misconduct, protection of human subjects, laboratory animal welfare, data management, mentor and trainee responsibilities, conflicts of interest and commitment, authorship and publication practices, peer review, and collaborative science) for which researchers must receive some training regarding ethics and best practices in their work. While this dissertation will not focus on how responsibility is defined here in this work, I should point out that much of the discussions on the "responsible conduct of research" follow the agential, individualistic model of

Responsible Genetics (2001), for example, directs his attention to the moral responsibility of genetic researchers for the outcomes of their work.⁹ Guido Pennings and colleagues have provided the only scholarship on responsibility specifically in relation to preimplantation genetic diagnosis, and like Nordgren, they emphasize the moral responsibility of care providers in that context.

In turning to these bioethics texts, I demonstrate how they also presuppose decision-making contexts and rely heavily on notions of voluntariness and intentionality—partially a byproduct of Beauchamp and Childress’ principlism and its emphasis on respect for autonomy. As a result, bioethics scholarship on responsibility follows the trend of religious and philosophical scholarship that construes responsibility as a matter of free, voluntary, autonomous decision-making. That limited understanding of responsibility, I maintain, fails to attend to some of the fundamental challenges posed by genetics and genetic biotechnologies. It also fails to reflect the perspective of those individuals who deal with these issues firsthand.

Though these various discussions of responsibility are fruitful in many ways, I point to their short-sightedness in order to lay the groundwork for a more robust understanding of responsibility for ethics and bioethics, one marked by the acknowledgement of responsibility that arise from a person’s status, regardless of his or her voluntary, intentional choices. These are responsibilities, I maintain, for which one

responsibility described by Schweiker combined with an appeal to the “scientific community” as both judge and enforcer of these ethical guidelines and their “responsible” implementation.

⁹ Anders Nordgren, *Responsible Genetics: The Moral Responsibility of Geneticists for the Consequences of Human Genetics Research*, Philosophy and Medicine series (Boston: Kluwer Academic, 2001).

can still be held accountable. Moral agents are called to give accounts of themselves—even for aspects of their lives over which they have no control. For this reason, I argue that questions of responsibility are oftentimes questions of integrity, that is, how an agent understands herself, her actions, her values, and her commitments in light of a given context. Moral distress results not only from uncertainty about what choices to make, but also from the struggle to oneself and to live in accordance with a person’s fundamental values in unfamiliar, challenging contexts. To lay the groundwork for these claims, I must first show how responsibility is typically articulated in ethics and bioethics literature.

A Brief Word on Responsibility

As many other scholars have noted, responsibility is a peculiarly late addition to Western moral discourse.¹⁰ Its Latin cognate, *respondeo*, carries connotations of promising an answer or providing an account of oneself to someone else.¹¹ Pascal uses the term in his *Lettres Provinciales* (1656), but Jonsen notes that responsibility’s “philosophical debut” occurs in David Hume’s *Treatise of Human Nature* (1740).¹² Here, Hume asserts that to hold a person morally responsible is to judge that person in light of his or her actions. This adjudication of praise or blame, he argues, is an extension of the indirect passions of love and hatred, a view in accordance with his belief that the passions are the motivating factors behind human action. Similarly, Jonsen states, “The question of responsibility has always been, in moral philosophy, a question about the

¹⁰ Schweiker, 55; Jonsen, 3; Nordgren, 1.

¹¹ Schweiker, 55.

¹² Jonsen, 3.

necessary and sufficient conditions which must exist if a man is truly to be called the author of his actions and justly to be praised or blamed for them.”¹³

In both Hume and Jonsen we see certain elements that ground this understanding of responsibility: accountability, judgment, and clarifying the relationship between a moral agent and her actions. In other words, to be responsible agent is to be able to be able to take ownership of one’s actions and call them one’s own. It is, as the Latin root suggests, to give an account of oneself to the other. As a promise, responsibility is also a duty that a person bears to be faithful in giving that account of herself. With this view in mind, it should be no surprise that responsibility has found a home in legal and political discourses. The language of accountability and judgment is precisely the language we expect to hear in the legal context, the place in which the accuser must state her case, the accused must give an account of herself and her actions, and the authoritative judge and jury weigh those accounts against each other.

Jonsen’s Basic Patterns of Responsibility

Attribution of Responsibility

The resonance with legal matters characterizes the first pattern of responsibility that Jonsen identifies—the attribution of responsibility. He maintains that the attribution pattern is rooted in the fundamental question: “How do we know when we may justly praise or blame, punish or reward a man for what he has done?”¹⁴ He even characterizes

¹³ Ibid., 5.

¹⁴ Ibid., 36.

this question as “the judge’s problem.” In this pattern, responsibility is connected to the notion of fault. Here, “to ask whether a man is responsible is to ask whether the act he performed was his fault.”¹⁵ To say someone is at fault, however, is to rely on two unstated assumptions: that some knowable standard of conduct exists and that the person who is supposedly “at fault” should have been able to attain that standard. For Jonsen, these moments of fault are “moral events” in which an action “contributes or detracts from the human good, however that might be defined, and which comes about through the intervention of the human agent.”¹⁶ When an agent acts in a way that contributes to the human good, she is praised as the one who is responsible for that contribution. On the other hand, when she fails to meet that standard, she detracts from the human good and is “held responsible” for being “at fault.” To describe the basis of this pattern of responsibility as “the judge’s problem” seems all too appropriate.

In the process of attributing responsibility, the agent presents to the judge and jury reasons for which she should not be held responsible—reasons that demonstrate she is not at fault. In that process of reason-giving, the defendant frequently appeals to one of the six elements that comprise Jonsen’s pattern of attributing responsibility: intention, motivation, deliberation, voluntariness, excuse, and character. If the agent can demonstrate her lack in any one of these six elements, then she may not be held responsible for her actions, or she may be held responsible to a lesser degree. After

¹⁵ Ibid., 39.

¹⁶ Ibid., 38.

describing each element, I will provide a series of examples to illustrate what Jonsen refers to in each case.

To articulate the difference between intention and motive, Jonsen draws on John Dewey's distinction between the two oft-conflated concepts. For Jonsen, an agent acts intentionally when she has a particular action in mind and is aware of its potential consequences as well as its relation to relevant norms. In other words, the agent understands what she is going to do and the foreseeable impact of her actions. Motive, on the other hand, is the "personal frame of mind" that addresses the question of why the agent strives after that goal in particular.¹⁷ A person's motive provides her with reasons for her action. A graduate student who writes a dissertation may be motivated by intellectual curiosity and the desire for future employment, for example. Deliberation is linked to both intention and motive, as deliberate acts are those that are "thought about through and through."¹⁸ Deliberation enables the moral agent to consider her goals, her means for achieving those goals, and her reasons for seeking one goal over another. It is an exercise of the agent's intellect that allows her to exercise her will. In describing the element of voluntariness, Jonsen draws on Aristotle to assert that voluntary actions are those that are performed without constraint or ignorance. In acting voluntarily, the agent has the capacity to deliberate and choose for herself her course of action.

Jonsen concludes his discussion the six elements of the pattern of attribution by turning to excuses and character. In making excuses for our actions, a person accepts that an act is wrongful but she seek to eschew responsibility for the act by arguing that the act

¹⁷ Ibid., 45.

¹⁸ Ibid., 49.

is not subject to the “court of moral verdict.”¹⁹ In making excuses, an agent frequently refers to other elements of this pattern of responsibility, arguing (for example) that the consequences of an act were unforeseeable and thus unintended. Finally, Jonsen argues that character is a key element to the pattern of attributing responsibility, particularly as the “judge” weighs the actions and words of the agent who stands accused of some act. According to Jonsen, the judge asks: Does this specific act reflect the person’s habitual conduct? Is it consistent with what we know about a person’s intentions, motives, and deliberations? That is, what inferences can we make about those elements in light of what we already know about a person? Is the person in need of reform (via punishment), or does this one act appear to be an isolated incident?

A concrete example will help flesh out these notions. Consider a person on trial for killing her neighbor. In crafting her defense, she may deny any involvement in the murder in question. Or, she may admit to her involvement in the death of her neighbor, but will argue that she should not be “held fully responsible” because of her apparent lack in any of those six elements. Below are examples of reasons she may give in her defense according to the six elements Jonsen mentions:

Intention: “I didn’t mean to kill my neighbor!”

Motive: “I have no reason for killing my neighbor! I wasn’t mad at her!”

¹⁹ Ibid., 56. In his discussion of excuses, Jonsen also refers to the practice of justification. When we seek justification for our acts, we “accept responsibility” for acting in that fashion but deny the wrongfulness of the particular act due to extenuating circumstances. A person who kills someone who attacks them with a knife, for example, justifies her actions by arguing that her actions were in self-defense. She accepts responsibility for her act but denies that she should be punished. Jonsen treats “justifications” under the sub-heading of excuses but only offers “excuses” as one of the six elements of this pattern. If justifications are a form of excuse, this is not clear in Jonsen’s writing.

Deliberation: “I got caught up in the heat of the moment and stabbed my neighbor!”

Voluntariness: “I blacked out in a fit of rage and apparently stabbed my neighbor!” or “Her husband forced me to kill her!”

Excuse: “Yes, I killed my neighbor but it was an accident!”

Character: “I’ve never acted violently before. I’m not the kind of person who would kill her neighbor!”

In giving the reasons above, the defendant admits that she was involved in her neighbor’s death. While a judge and jury would likely assign some responsibility to the accused because of her admitted involvement, those authority figures may “hold her responsible” to a lesser degree by convicting the defendant of a lesser crime that carries a less severe sentence (reckless homicide rather than manslaughter or first-degree murder, for example)—if any of the reasons above are deemed valid.

Appropriation of Responsibility

It is fitting that Jonsen concludes his analysis of the pattern of attribution with a discussion of character. He notes that the process of becoming a moral agent is one of gradual growth, a view that I share. From this perspective, the agent is cast into a world over which she has little or no control. She is raised by parents who teach her particular values and behaviors, immersed in a culture with established norms of praiseworthy and blameworthy behavior, and “directed toward certain patterns of action (intentions), for certain reasons (motivation), and in terms of certain logic (deliberation).”²⁰ At some point in this process, the individual transitions from a passive recipient of those lessons and values to an active person who can make them her own, someone who can criticize,

²⁰ Ibid., 61.

alter, accept, or reject what she has received. Against the backdrop of her socio-cultural milieu, she begins to shape her own character and direct her own life. In other words, she becomes a moral agent who “accepts responsibility” for the person she has become and strives to be.

Whereas the pattern of attributing responsibility examined moral actions almost exclusively from the perspective of a judge or authority figure who sought to find the grounds for adjudicating praise and blame, the pattern of appropriation is concerned largely with the acting moral agent and her ability to take possession of her own actions, that is, to call her actions her own. In other words, “the pattern of ideas associated with appropriation of responsibility is that pattern which arises when the philosopher thinks about the problem which he and every man has when he faces the challenge to become a self-determining being, master of his fate.”²¹ Questions of unity and character are at the forefront of the pattern of appropriation, while those questions remained in the background in the pattern of attribution.

With its emphasis on character, the pattern of appropriation consists of four elements: the self, consideration, conscientiousness, and commitment. According to Jonsen, these elements work simultaneously in the process of appropriation, not as sequential events that culminate with the agent’s appropriation of responsibility. The first element, the self, seems to be the foundation upon which the other elements depend for their execution. Here, Jonsen follows the work of F.H. Bradley in noting that character helps to explain an agent’s tendencies in action, but it does not explain an action itself. In other words, there must be some volitional agent to put her character into

²¹ Ibid., 63.

action. He claims that it is “the self” who is able to “transcend” what happens to her, what has been formed in her (as character or disposition), and even transcends herself through critical self-reflection. The “problem of appropriation,” according to Jonsen, is “the problem of the self accepting and taking a position toward what happens to it and even toward what it is.”²² In this self-transcendence and self-reflection, the agent must make choices. By making choices that bear witness to the transcendence and critical reflection of the self, the agent comes to “appropriate responsibility.” Such choices, Jonsen argues, bear certain hallmarks. They are made “‘with consideration,’ ‘conscientiously,’ and ‘with commitment.’”²³

Jonsen’s description of the element of consideration bears a striking resemblance to his earlier description of deliberation in the pattern of attribution. To act with consideration is to act with an awareness of alternative possibilities. The agent chooses one course of action over others, making that decision in light of her awareness of the potential outcomes of her decision and her alternatives. Further, consideration entails being able to contextualize actions and alternatives, understanding their impact on one’s life and relations to others, as well as the ways in which those actions will be understood by other members of society. It involves asking the following question: If I choose to perform this action over other possibilities, what does this choice reveal about who I am and who I aim to be? By asking this question, the agent makes advances toward becoming her own judge.

²² Ibid., 64.

²³ Ibid.

Consideration/deliberation is largely an intellectual exercise. The agent can deliberate about nearly any activity in which alternatives exist: “Should I take the expressway or surface roads? Do I want tuna or chicken salad?” However, Jonsen notes that “for situations commonly called moral something more is asked of the agent than technical skill in thinking through and interpreting his action.”²⁴ In “moral” situations the agent must consider rules of judgment, standards of praiseworthy and blameworthy behavior, and she must also hold to those standards and her decisions with consistency. The ability to act in this way, according to Jonsen, is the sign of conscientiousness. The conscientious agent demonstrates “seriousness, constancy, and consistency in both his considerations and his conduct.”²⁵ In addition to understanding how one’s actions relate to standards of behavior judgment, the moral agent should “stick with” her well-considered actions, even in the face of adversity. For Jonsen, this attitude or disposition toward constancy is the hallmark of conscientiousness.

The final element of the pattern of appropriation is commitment. In the moral life, the agent engages in the process of consideration and then determines a course of action that is expressive of those considerations. In other words, the agent makes choices. Commitment, for Jonsen, “suggests the active engagement of the person to a course of action, to a cause, or to a way of life.”²⁶ In this way, the agent’s choices do not signal an end to the deliberative process, but rather mark the final steps toward becoming an agent who can appropriate responsibility for herself. In commitment, the agent calls

²⁴ Ibid., 66.

²⁵ Ibid., 67.

²⁶ Ibid.

choices and actions her own. Though he recognizes that Sartre's existentialism may overstate the case, Jonsen points to Sartre to demonstrate the foundational nature of commitment for the possibility of appropriating responsibility as a moral agent: "If it is only by choice, by commitment in absolute freedom, that the self and the world come into existence, then the self is totally responsible, totally and incontestably the author of being."²⁷

William Schweiker's Typology of Responsibility

Jonsen's patterns of attribution and appropriation describe two ways in which responsibility is thrust upon the moral agent, whether she is "held responsible" by an authority figure or she "takes responsibility" for herself and her actions. However, these patterns offer little substantive guidance for agents navigating the moral life. "To be responsible is to be held accountable for your actions" or "Being responsible means being able to stand by your actions" reveals little about what responsibility actually entails. Instead, those patterns highlight responsibility's origins. Theological ethicist William Schweiker has also developed a typology for theories of responsibility, classifying those theories as agential, social, or dialogical. Like Jonsen, Schweiker also examines responsibility in light of the primary moral actors (judge and agent for Jonsen, and the agent, community, and dialogue partners for Schweiker, respectively). However, Schweiker's typologies provide more substantive accounts of what it means to "be responsible" according to each theory. As he later moves to the constructive element of his work (which will be discussed in the following chapter), Schweiker maintains that

²⁷ Ibid., 68.

each of these three types of responsibility are helpful for thinking about what it means to be responsible; no theory is sufficient by itself. He then argues for an integrated theory of responsibility. For now, it is important to note how he classifies prevalent understandings of responsibility.

Agential Theories of Responsibility: Immanuel Kant

Jonsen's patterns of appropriation and attribution fit within the framework of agential theories of responsibility. Like the pattern of appropriation, agential theories emphasize the work of the individual moral agent. They place great emphasis on the relationship between the agent and her acts; her causal agency determines her moral responsibility. As described in the pattern of attribution, if an agent did not "cause" the act in question, or if she did so under extenuating circumstances, then she may not be held responsible. Schweiker identifies two forms of agential theories of responsibility, which he calls "strong" and "weak" agential theories. For strong agential theories, the principle for judging acts (as moral/immoral, praiseworthy/blameworthy) rests in the "self-legislating capacity" of the moral agent.²⁸ For weak agential theories, the principle of judgment is grounded elsewhere, such as in social practices or religious ideals. However, whether it is the agent who judges herself to be responsible or whether she is judged to be responsible by her society's judicial institutions, that judgment is based on the ontologically real responsibility that is derived from her causal agency. In other words, the starting point for moral assessment within both strong and weak agential theories of responsibility is the relationship between the moral agent and her actions.

²⁸ Schweiker, 78.

Schweiker then turns to representatives of both strong and weak agential theories: Immanuel Kant and Paul Tillich, respectively. His selection of Kant may seem peculiar considering that Kant never explicitly develops an account of responsibility in his writings. However, Schweiker views Kant's work as providing the foundation upon which strong agential theories of responsibility rest, as his entire philosophical project depends upon his formulation of the rational, self-legislating moral agent. Schweiker describes Kant's vision of autonomy as a form of "responsibility for self" and thereby interprets his work as a contribution to analysis of responsibility.

In the *Grounding for the Metaphysics of Morals*, Kant turns his transcendental method from matters of epistemology to ethics to inquire into the conditions that make morality possible. For Kant, the basis of morality is our sense of duty or obligation; duties are what separate the human from the beast. One hallmark of duties is their conflict with inclinations or desires. After all, if a person wanted to do something, it would not be a duty. So while the rational capacity tells agents that duties exist, sensory experiences compel the agent to act contrary to those duties. That rationality, universally held by all moral agents, also provides the basis for the universal moral law. Being innate (that is, prior to our experience), the moral law is both universal and categorical, hence the label "categorical imperative." As a categorical (rather than hypothetical) imperative, the moral law is applicable at all times, regardless of the context or the ends that one desires. Two formulations of the categorical imperative are worth mentioning here: "Act only according to that maxim whereby you can at the same time will that it should become a universal law," and "Act in such a way that you treat humanity, whether

in your own person or in the person of another, always at the same time as an end and never simply as a means.”²⁹

To act in this way, the moral agent must not be wholly subject to her desires or to the pressures of the world around her—she must have freedom as a precondition of moral agency. She must have freedom *from* the influence of her impulses and sensuous desires but she must also have freedom *to* discover the universal moral law and enact it. This freedom is an exercise of autonomy, according to Kant, as the moral agent frees herself from the bonds of sensuous desire and can exercise her rationality, legislating her actions without the influence of those desires. The moral agent, now free, recognizes the universal moral law described above and, acting with a “good will,” she acts from her sense of duty to that law. As Schweiker states it, “What ought objectively to determine the will is law while its subjective determination is pure respect for this practical law.”³⁰ For Kant, this feeling of pure respect for the moral law is an effect of the law rather than its cause, providing moral agents with “a conception of a worth that thwarts self-love.”³¹ It is the agent’s good will—that which compels her to act from pure respect for the moral law and not merely in accordance with the moral law—that is the only “good without qualification” for Kantian ethics.³²

²⁹ Immanuel Kant, *Grounding for the Metaphysics of Morals*, 2nd ed., trans. James W. Ellington (Indianapolis: Hackett Publishing Company, 1983), § 421 and § 429, respectively.

³⁰ Schweiker, 81.

³¹ *Ibid.*

³² *Ibid.*

Schweiker interprets Kant's moral project as a contribution to responsibility ethics because, like subsequent theorists of responsibility, Kant aims to draw connections between causative and evaluative judgments. Kant works to show how the moral agent can be a "free cause" in the world; it is from her freedom that questions of responsibility may arise. Schweiker rightly notes,

"But the question of responsibility, given Kant's construal of freedom, is whether or not an agent is responsible for the maxim on which she or he acts. An agent is only secondarily responsible for the consequences of an action; she or he is properly responsible, morally praised and blamed, with respect to the motive for acting."³³

Many of the ideas that comprise in Jonsen's pattern of attribution find their early expression in the work of Kant. There is a concern with the relationship between causal and evaluative judgments, such that a moral law is judged to be valid when it is an expression of the moral agent's free, rational, autonomous capacity. There is also an explicit reference to motive and an implicit understanding that responsible moral agency requires deliberation. Additionally, autonomy and intentionality are necessary components of responsible moral agency. Finally, Schweiker notes that responsibility assignment is a secondary activity within the Kantian schema—the assignment of responsibility depends on living a life that is an authentic expression of the true nature of the autonomous moral agent. In other words, responsibility is a secondary principle at best, subordinate to the autonomous, rational capacity of the moral agent.

³³ Ibid.

Social Theories of Responsibility: Stanley Hauerwas

Where agential theories of responsibility (exemplified by Kant) emphasize the self-legislating capacity of the moral agent, social theories emphasize the influence of social roles and practices for shaping the outlook of the moral agent. Schweiker quotes Peter French in describing this phenomenon, noting, “In short, the content of the self is a pattern of relations within a community.”³⁴ From this perspective, the identity of the moral agent develops via a social process of becoming acculturated to the social roles and practices of the community in which she exists. This is a claim about both identity and moral duty for the moral agent, as that duty also arises from the agent’s social relations and the functions of her specific social roles that she inhabits. In other words, the moral agent’s duties arise from who she is insofar as she is identified by her various roles—her profession, family roles, memberships in specific communities or organizations, etc. The agent’s own identity is formed through the social practice of describing the agent’s roles and its associated responsibilities. Therefore, Schweiker notes, “If we can specify the rules for description, or, more properly, the rules for praising and blaming agents, we can fulfill all that can or need be said about conditions for moral agency and responsibility.”³⁵

Like agential theories of responsibility, social theories also come in strong and weak varieties. Strong social theories of responsibility are concerned primarily with the process of assigning responsibility to agents in a community. On the other hand, weak social theories emphasize identity formation rather than responsibility assignment. In other words, weak social theories interpret responsibility as one of the mechanisms

³⁴ Peter A. French, *Responsibility Matters* (Lawrence: University Press of Kansas, 1992), 61; quoted in Schweiker, 87.

³⁵ Schweiker, 87.

through which both individual and community identity are constituted. Schweiker identifies Stanley Hauerwas as a representative of weak social theories of responsibility since Hauerwas' primary ethical consideration is not "What ought I do?" but instead "How can I live in accordance with the Christian story as revealed through the work of God in Christ?" For Hauerwas, Christian identity can only be understood from within the narrative that the Church tells about God's redemptive work in Christ (For Hauerwas, the definite article is important.). Any moral ought that can be discerned arises out of that narrative and the Church's faithful retelling of that story—not from any appeals to human "nature" or supposed universal principles. On this point, Hauerwas notes, "For the Christian seeks neither autonomy nor independence, but rather to be faithful to the way that manifests the conviction that we belong to another. Thus Christians learn to describe their lives as a gift rather than an achievement."³⁶ This perspective is definitely a stark contrast from the Kantian who views the moral life as an autonomous endeavor.

One of Hauerwas' most pressing critiques of modern liberal Protestant ethics is that it has assumed the conceptual categories and framework of Enlightenment thought, thereby diluting and distorting the message of the story of God's love in Jesus Christ. As a result, "being Christian simply became a way to indicate what the society generally regarded as decent."³⁷ That story, he argues, cannot be told in the language of modernity. Instead, he seems to follow Alasdair MacIntyre's retrieval of Aristotle and Aquinas,

³⁶ Stanley Hauerwas, "Character, Narrative, and Growth in the Christian Life" (1980); Reprinted in Stanley Hauerwas, *A Community of Character: Toward a Constructive Christian Social Ethic* (Notre Dame, IN: University of Notre Dame Press, 1981); Stanley Hauerwas, John Berkman, and Michael G. Cartwright, *The Hauerwas Reader* (Durham, NC: Duke University Press, 2001), 224.

³⁷ *Ibid*, 227.

claiming that “the language of virtue and character is especially fruitful in providing moral expressions appropriate to Christian convictions.”³⁸ As noted above, when we rely on the modern language of autonomy, so his argument goes, we fail to appreciate that our lives are gifts. To strive for autonomy is to enslave ourselves rather than to seek the freedom that accompanies dependence on the one who has given us that gift of life. As he notes, “The self can be held to have sufficient coherence to deal with the diversity of our moral existence only if that self is formed by a narrative that helps us understand that morally we are not our own creation, but rather our life is fundamentally a gift.”³⁹

In an essay describing the inadequacy of Kohlbergian theories of moral development for accounting for the Christian moral life, Hauerwas quickly notes that one problem Kantian-based theories encounter is in giving an account for how someone can be “held responsible” for acting in a way that “requires moral skills that he has not yet developed.”⁴⁰ To think of responsibility as a matter of character and narrative, he argues, addresses that challenge. He claims that within a Kantian framework, holding someone responsible becomes a way of encouraging moral growth—we grow as moral agents by being held responsible by others. However, this creates other another problem: This “public morality” or “public responsibility” (to borrow Hauerwas’ terminology) seems unjust when holding someone responsible for something she could not avoid, but to render responsibility relative to the character of each individual moral agent would seemingly undermine that public morality or public responsibility. However, to seek

³⁸ Ibid.

³⁹ Ibid., 233.

⁴⁰ Ibid., 229.

recourse in the view of the “impartial moral agent” is to altogether lose sight of the developing moral agent.

Not surprisingly, Hauerwas’ response to those challenges is to interrogate the assumptions on which the idea of public morality is based. He states, “I assume that no moral theory is capable in principle of closing the gap between what I should do (my public responsibility) and what I can or have to do (my own responsibility).”⁴¹ Instead of developing an account of moral development that connects “personal responsibility” with “public responsibility,” Hauerwas provides account in which the agent’s appropriation of public responsibility contributes to “the story of that people.”⁴² That story, he claims, is more fundamental than the agent’s own standpoint, therefore, “To claim responsibility for (or to attribute responsibility to) the agent is to call for an agent to be true to the narrative that provides the conditions for the agent to be uniquely that agent.”⁴³ Responsibility thus provides the means to live in line with “a narrative that charts a way for us to live coherently amid the diversity and conflicts that circumscribe and shape our moral existence.”⁴⁴ It compels the agent to call her actions her own, even when she acts unknowingly or unreflectively. In being held responsible by the community that shares in the narrative, her character develops.

In sum, social theories of responsibility—as exemplified by the work of Stanley Hauerwas—portray responsibility as a social endeavor, not as an ontologically “real”

⁴¹ Ibid., 232.

⁴² Ibid.

⁴³ Ibid.

⁴⁴ Ibid., 245.

moral fact waiting to be discovered. That is, one cannot learn for herself what it means to be responsible: she learns to be responsible only through being held responsible by others. Praise and blame are social activities determined by the norms (or narrative) of the particular community of which the agent is a member. Responsibility becomes a matter primarily focused on the developing character of the moral agent and her relation to the norms and narrative(s) of her community, with relatively little focus on isolated individual decision-points.

Great difficulty arises for these social theories of responsibility when a person seeks to understand why one community's norms/narrative(s) are more valid than those of another community, or why some versions of that narrative are authoritative at the exclusion of other versions. Further, social theories of responsibility, insofar as Hauerwas is a representative example, tend to assume that there is one narrative, one set of norms, or one community that organizes the world of the moral agent. However, I maintain that moral agents act in multiple roles with different, sometimes competing or incommensurable, norms of responsible action. That is, moral agents find themselves living within more than one narrative. Which "story" or set of norms should organize the agent's world? This question, I argue, is frequently the source of moral distress for many moral agents facing difficult circumstances. Finally, within pluralistic settings like the clinic, moral agents frequently encounter others with different sets of social norms—and yet they must work together to overcome the challenges that brought them together. Social theories of responsibility offer little guidance for engaging in that process in a manner that fosters mutual respect for the various moral agents involved in such endeavors.

Dialogical Theories of Responsibility: H. Richard Niebuhr

The final classes of responsibility theory that Schweiker describes are dialogical theories of responsibility. These theories typically characterize human life as a matter of responsive encounter with the “other” (human, non-human, or intrapersonal). Schweiker describes two basic varieties of these dialogical theories: those that hold responsibility to be “the first principle of ethics” (Niebuhr, for example) and those that hold the response of the other to be “the answer to the problem of the human good” (Barthian divine command theology).⁴⁵ Schweiker interprets these theories as attempts to bridge the challenges posed by agential and social understandings of responsibility. While agential theories of responsibility focus largely on the responsibility of the agent (particularly how she can call her actions her own) and social theories emphasize the ways in which moral identity is socially formed, dialogical theories of responsibility suggest that the moral agent is actually *constituted* by the encounter with the other—a social act that makes moral agency possible, all the while challenging the very notion of the self-acting, self-legislating moral agent.

H. Richard Niebuhr suggests a way of thinking about the moral life that contrasts with deontological ethics that portray moral agency as a matter of rule-following and teleological ethics that cast the moral agent as one who strives after self-determined ends.⁴⁶ “All life has the character of responsiveness,” he claims.⁴⁷ That is, the moral agent is engaged in dialogical (or *trialogical*) relations with others who act upon her and

⁴⁵ Schweiker, 94.

⁴⁶ The labels and depictions of “deontological” and “teleological” ethics are those of Niebuhr, not the author’s own.

⁴⁷ Niebuhr, *The Responsible Self*, 46.

call for a response.⁴⁸ This encounter becomes the moment in which responsibility is enacted:

“The idea or pattern of responsibility, then, may summarily and abstractly be defined as the idea of an agent’s action as response to an action upon him in accordance with his interpretation of the latter action and with his expectation of response to his response; and all of this is in a continuing community of agents.”⁴⁹

This brief statement highlights the four elements of Niebuhr’s pattern of responsibility: response, interpretation, accountability, and social solidarity. Responsible action, Niebuhr states, is a response to the actions of others upon the agent. Action that may be called “moral action” is interpreted action. Not only do agents interpret the action of others upon themselves, they also interpret their own action and anticipate how the other will in turn respond to their response. Hence, responsible moral action is action for which the agent is held accountable. Moral actions anticipate where the “conversation” of action may be headed as well as the significance that the larger conversation may have. These actions do not occur in isolation, however. They require the presence of other beings with whom the agent may interact and who may interpret the agent’s actions. That is, moral actions occur within a social context and are understood within that social context. Hence the fourth element of Niebuhr’s theory of responsibility

⁴⁸ For Niebuhr, it may be more appropriate to speak of *trialogical* relations between the agent, the other, and God. This point goes back to Niebuhr’s relational value theory in which God is the One Absolute that relativizes all other values. As God is the center of value, a person’s fundamental relationship is her relation to God such that she exists only in God. Further, because relational value theory asserts that God relates to all things, God is a participant in each responsive encounter. As noted below, God acts in all actions upon the moral agent, so the agent is called to respond in all actions as she would respond to God, hence the *trialogical* structure of the responsive encounter.

⁴⁹ *Ibid.*, 65. Sex-exclusive language is Niebuhr’s.

is social solidarity. Moral actions must be able to demonstrate continuity with one another in order to be understood. Other beings within a community come to know the agent through her actions, and those actions must be connected with one another so that others may interpret them as *her* actions.

Because God is the One Absolute that relativizes all other values and is related to all things, the scope of the moral community extends well beyond any particular locale with its distinctive mores; the moral community is universal. Here, God is always an interlocutor. When the moral agent recognizes this ever-present relation to God, she sees that she is held accountable to God in all her actions. Hence, Niebuhr also asserts, “Responsibility affirms: ‘God is acting in all actions upon you. So respond to all actions upon you as to respond to his action.’”⁵⁰ With the social, relational, and theocentric dimensions to responsible action in mind, Niebuhr contends that this responsible action is *fitting* action. As Niebuhr explains in his development of relational value theory, fitting action is action that is good-for-being, both reflectively and reflexively. Additionally, Niebuhr describes fittingness much more literally, noting that responsive action is fitting when it “fits” into the process of response and interpretation mentioned earlier. Such fittingness is possible through recognition of an agent’s place within the universal community as well as through a recognition of the timefulness of her own moral agency. The agent then seeks to make her action responsive by “fitting” it into those contexts,

⁵⁰ Ibid., 126.

much like a sentence fits into and contributes to a paragraph, which in turn further adds to a chapter of a book.⁵¹

This discussion of fittingness is premised upon a particular claim about God, one that is revealed in and through Christ: God is a life-affirming God. For Niebuhr, that which promotes the well-being and meets the needs of a being may be called “good.” If fitting action is both action that is good for a being as well as action that “fits” within the context of the universal community with the Universal Other (God) at its center, then one may conclude that the universal community of which God is the center is a community that intends for a being’s needs to be met. Once the agent recognizes this characteristic of the universal community of which she is a part, she sees that responsible action is action that promotes the well-being of others. Even when she is called upon to conduct herself in various roles (wife, mother, employee, church member, etc.) by the different communities of which she is a part, responsible action is that which nonetheless responds to the One in all the many. That is, despite being called upon to respond in different situations through different actions, her integral selfhood can be achieved only because she is responsible to the Absolute One in her actions, a possibility recognized only in faith to the One for whom being and value are co-extensive. For Niebuhr, writing a work of Christian moral philosophy,” we have faith that God’s intentions are ultimately life-affirming and integrity-establishing rather than destructive, but this “faith” is not the same as “hoping” that God is life-affirming. Christians claim to witness this life-

⁵¹ For more on relational value theory, see H. Richard Niebuhr, *Radical Monotheism and Western Culture*, with Supplementary Essays (New York, NY: Harper, 1960). See also “Value-Theory and Theology” in *The Nature of Religious Experience: Essays in Honor of Douglas Clyde Macintosh*, eds. Eugene Garrett Bewkes and Julius Seelye Bixler (New York, London: Harper & Brothers, 1937), 93-116.

affirming and integrity-establishing character of God in and through Christ. That is, Christ is revelatory of God's patterns of action in this world. He is the revelation within the Christian's internal history that illuminates and makes the rest of our lives intelligible and promotes self-integrity.

Responsibility in Bioethics Scholarship

The Influence of Principlism

Any discussion of the foundational moral concepts used in bioethics must begin with Beauchamp and Childress' *Principles of Biomedical Ethics*.⁵² Regardless of one's opinion of the value of a principle-based approach for confronting ethical challenges, their classic articulation of bioethics foundational principles—respect for autonomy, beneficence, nonmaleficence, and justice—has become a cornerstone for bioethics discourse, one whose influence can be detected in debates on abortion, stem cell research, physician-assisted suicide, and a host of other topics. In this principle-based framework, ethical challenges are interpreted as moments in which a person struggles to balance or prioritize a set of principles that are to be respected. Or, those challenges may be seen as a struggle in determining which principles are operative in a given set of circumstances. A brief example will illustrate this approach. Consider potential parents who approach their clinician about utilizing PGD to select the sex of their next child. Must the clinician respect the autonomous choice of those potential parents, even if the clinician sees no

⁵² Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (Oxford: Oxford University Press, 2001).

clear health benefits to using PGD in this way? Or, should concerns about justice override the autonomous choice of the potential parents? Is conceding to the wishes of a patient a beneficent act? This is a very helpful framework for analyzing ethically contentious issues in the clinic, but I should note that it is only one of many approaches to bioethics analysis, albeit an especially powerful approach.

Although Beauchamp and Childress advocate striking a balance among the ethical principles at work in a given situation, respect for autonomy is the most frequently cited principle by clinicians and ethicists alike.⁵³ As they articulate this principle, respecting autonomy entails respecting “the autonomous *choices* of persons.”⁵⁴ In other words, their vision of autonomy is rooted in a context of decision-making. They note, “To respect an autonomous agent is, at a minimum, to acknowledge that person’s right to hold views, to make choices, and to take actions based on personal values and beliefs.”⁵⁵ At this point, examinations of autonomy frequently delve into issues of informed consent, capacity, competence, and who counts as an autonomous agent. For my purposes here, however, I simply want to call attention to the overarching emphasis on matters of free choice. This emphasis on autonomous, intentional decision-making pervades the dominant principle-based approach to bioethics analysis, well beyond matters where issues of autonomy are at stake.

⁵³ Performing a keyword search in the PubMed database, for example, I found 27,045 citations for “autonomy,” 3011 for “nonmaleficence,” 2974 for “beneficence,” and 16,222 for “justice.” PubMed.gov Database, U.S. National Library of Medicine, National Institutes of Health. <<http://www.ncbi.nlm.gov/sites/entrez>> (accessed March 2, 2010).

⁵⁴ Beauchamp and Childress, 57. Emphasis mine.

⁵⁵ Ibid., 63.

Early Discussions of Responsibility: Garrett Hardin and George Agich

With that emphasis on autonomous, intentional decision-making, the principle-based approach to bioethics also informs discussions of responsibility in bioethics literature. In an early attempt to wrestle with the challenges posed by the “new genetics,” biologist Garrett Hardin briefly appeals to “genetic responsibility” in his assessment of those challenges. He states, “We must admit that if there is one thing a person is not responsible for, it is the genes that were passed on to him. No one has the opportunity to pick his parents.... But should we not be responsible as transmitters of errors?”⁵⁶ He then offers an example of a hemophiliac man who reproduces despite passing the condition to subsequent generations. Hardin’s analysis of the example, however, is limited to a discussion of conflicts between individual freedom and social costs. He also assumes that the man in the example knows the risks involved with procreating and yet chooses to do so in spite of the future social costs of his decision. In other words, he assumes that the man makes an autonomous, informed decision. Hardin also fails to elaborate on what “genetic responsibility entails. Does responsibility in this light refer to a duty to *not* pass on one’s genes or a duty to accept the full burden that comes along with that process? On these questions, Hardin offers no response.

In another early essay, George Agich notes the potential benefits that a focus on responsibility has for “medical ethics” scholarship on a variety of topics. It provides benefits, he suggests, “by raising to prominence not only the social and organizational structure of health care, but also the manifold senses in which individual moral agents

⁵⁶ Garrett Hardin, “The Moral Threat of Personal Medicine” in Mack Lipkin and others, *Genetic Responsibility: On Choosing Our Children's Genes* (New York: Plenum Press, 1974), 85-91; quote on 88.

and groups are accountable for their actions.”⁵⁷ By focusing on responsibility, medical ethics turns its attention away from idealized case studies of physicians and patients trying to “solve” a particular problem and toward the ways in which medicine is actually practiced—within specific organizational structures marked by a managerial mentality and by the input of numerous care providers. Following the work of Richard Zaner, Agich argues that the relationship based on responsibility elucidates one of the very cornerstones of the clinical encounter: “Illness or affliction compels response. The response solicited is not abstract or general but particular, and involves the interaction of individuals—an interaction which is sustained by a social and institutional context or practice.”⁵⁸ He also articulates the four features of responsibility in this context: accountability, liability, rationality, and the absence of negligence. In describing these four features, he draws on the same language that we find in Jonsen’s patterns of appropriation and attribution: rational deliberation, knowledge, intention, causal connection, and punishment.⁵⁹ He notes, “Liability involves reference to an agent’s knowledge and intention, as well as the causal connection between the action and its consequences.”⁶⁰ Agich also claims, “Implicit in the notions of accountability and liability is the assumption that a responsible agent will ‘take his responsibility seriously.’ This assumption implies two further features: *rationality* and *absence of negligence*. A

⁵⁷ George J. Agich, “The Concept of Responsibility in Medicine” in *Responsibility in Health Care*, ed. George J. Agich (Dordrecht, Holland: Reidel, 1982), 53-73; quote on 55.

⁵⁸ *Ibid.*, 69.

⁵⁹ These terms come directly from Agich’s description of responsibility. See *Ibid.*, 55-56.

⁶⁰ *Ibid.*, 56.

responsible agent is one who exhibits rational deliberation regarding his actions.”⁶¹ Thus, while he makes the case that responsibility is well suited for probing the ethical complexities of the clinic, he does not offer any new insights about what responsibility might *mean* in this context. Instead, he follows the tradition of treating responsibility as a matter of rational deliberation and being held accountable for one’s actions.

Responsibility and Genetics: Anders Nordgren and Guido Pennings

In his work *Responsible Genetics* Anders Nordgren offers the first sustained treatment of responsibility in relation to innovations in genetics. That treatment is largely grounded in the general trajectory of scholarship on responsibility in philosophy and religious studies. Still, he provides the most substantive analysis of responsibility in relation to genetics and genetic technologies, so his work is worth exploring here. His concern rests primarily with the moral responsibility of genetics researchers for the consequences of their work. Like many other theorists of responsibility, Nordgren views responsibility as a metaphor in the context of morality, as its use in that context corresponds to the two different root meanings of *respondeo* that I previously mentioned.⁶²

His understanding of responsibility is clearly rooted in Schweiker’s typology, as he offers his own “modified social model” that addresses the perceived shortcomings of agential and social views of responsibility. He finds agential models to neglect the social dimensions of responsibility (ascription of responsibility as a social act), to conflate

⁶¹ Ibid.

⁶² See Jonsen *op. cit.* and Schweiker *op. cit.*

moral responsibility with causal responsibility, and to “assume that moral responsibility is a matter of discovery” rather than ascription.⁶³ He also finds the ontology of agential models to be thoroughly lacking, as those models seemingly focus on the isolated moral agent who, as Nordgren notes, is never isolated but is always “socially and biologically constituted and situated.”⁶⁴ Social models of responsibility also fail to adequately take biological conditions into account (a point on which I agree with Nordgren). For Nordgren, social models also tend to neglect the multiple social influences that shape the moral agent, instead typically portraying the social moral agent as merely a member of a given society or institution. For Nordgren, social models also stress the social ascription of responsibility while failing to attend to the ways in which individuals assume moral responsibility by their own choices.

After offering the basic outline of his modified social model of responsibility (which will be described in the following paragraph), Nordgren turns to the dialogical models (which he calls *encounter* models). He criticizes the efforts of Lévinas and Niebuhr, arguing that they offer no guidelines for differentiating between “mere responsibility” and “moral responsibility.” The distinction Nordgren makes between *mere* responsibility and *moral* responsibility goes back to the discussion of metaphors in moral language. Responsibility becomes “moral responsibility” when that term is used metaphorically. “Mere” responsibility, on the other hand, is the concrete form responsibility in which one is called to give an answer or in which one owes something to someone else. He then asserts that “we have moral responsibility in relation to some

⁶³ Nordgren, 5.

⁶⁴ *Ibid.*, 6.

entities” but then fails to substantiate this remark and neglects to articulate who/what can be considered an “entity.”⁶⁵ Based on his interpretation of these models of responsibility, it seems that they leave open the possibility that human beings have a moral responsibility to non-human entities or perhaps even to non-entities (principles like love or justice?). Such possibility is unacceptable in Nordgren’s account of responsibility.

Noting the weaknesses of the agential, social, and dialogical models of responsibility, Nordgren offers a “modified social model” of responsibility marked by the following characteristics:

1. “Causal agency is commonly relevant to moral responsibility but does not in itself determine it.
2. Moral responsibility is ascribed or assumed by communities, social groups, or individuals.
3. Individuals can ascribe or assume a moral responsibility that deviates from established social practice.”⁶⁶

The ability of moral agents to assume responsibility is a great concern for Nordgren. Instances of this “deviation” from the socially ascribed responsibilities borne by the agent make it possible for agents to criticize their own communities, as this deviation helps the agent forge a unique identity that goes beyond social roles and responsibilities. It also means that “at least to some extent, taking responsibility is a matter of individual choice.”⁶⁷ Yet Nordgren’s modified social model implies that responsibility can be either chosen or unchosen, insofar one does not always choose the

⁶⁵ Ibid., 13.

⁶⁶ Ibid., 7.

⁶⁷ Ibid., 11.

communities and social groups of which she is a part. While this unchosen component of responsibility goes largely unnoticed by Nordgren, his model leaves room for the possibility of responsibilities that arise outside of a decision-making context.⁶⁸

When turning to the domain of scientific research, Nordgren provides one more assessment of responsibility worth mentioning here. He distinguishes between the domain, content, and form of responsibility. For Nordgren, the domain of responsibility concerns the linkage between responsibility *for* something and responsibility *to* someone (or a group) in particular. Speaking of the endeavors of scientists, he states, “I call the linkage of a stage of research (*for* which scientists are responsible) with a party (*to* whom scientists are responsible) a ‘domain of responsibility.’”⁶⁹ He argues that the domain of responsibility for scientists is vast because they should be responsible for all aspects of their research and responsible to all parties affected by that research.⁷⁰ The content of responsibility, on the other hand, provides the normative recommendations or standards for a given situation; those contents change according to the specific perspectives or approaches with which moral agents confront that situation. The form of responsibility is the means by which the normative content is implemented by those who are responsible for the situation (scientists in Nordgren’s example). Here we at last come to Nordgren’s recommendations for scientists working in genetics research. I’ll quote him at length:

⁶⁸ It should come as no surprise that Nordgren’s model of responsibility is concerned primarily with chosen responsibilities and chosen social roles considering that his audience consists of scientists working in genetics. After all, those individuals chose to join the scientific community and chose to work in the field of genetics.

⁶⁹ Ibid., p. 53.

⁷⁰ Ibid., p. 91.

“What should responsible scientists do? My general proposals to these scientists—as individuals and as a community—are as follows:

- (1) Use your moral imagination to envision different ethically relevant consequences of research, and to figure out different ways of taking responsibility for these consequences.
- (2) Learn from history, i.e. from earlier, prototypical cases.
- (3) Participate in a dialogue with the general public, politicians and industrialists.
- (4) Integrate ethical reflection with scientific practice by choosing an appropriate form of responsibility, i.e. adequate means of implementing the content of responsibility at different social levels.”⁷¹

Turning specifically to discussions of genetic biotechnologies—in this case PGD—I must highlight the work of Pennings *et al.* that examines the moral responsibility of patients and clinicians in the context of utilizing PGD. Their work is notable because it is the only scholarship that examines new genetic tools through the lens of responsibility. One of the tenets of their argument is that clinicians or physician collaborators should not be “held responsible” for the outcomes of their work in PGD if potential parents “change their mind” and back out of an agreed-upon plan, thereby leading to any number of unintended consequences. Here, they note, “the responsibility of the collaborator is determined by his or her *causal* and *intentional* contribution.”⁷² When potential parents change their mind or intentionally deceive the clinician, “the prior contributions of the clinician are ‘cut off’ by the decision of the patients: their autonomous decision intervenes between the acts of the physician and the possible

⁷¹ Ibid., 84.

⁷² Guido Pennings, Maryse Bonduelle, and Ingeborg Liebaers. "Decisional Authority and Moral Responsibility of Patients and Clinicians in the Context of Preimplantation Genetic Diagnosis." *Reproductive Biomedicine Online* 7, no. 5 (2003): 509-13; quote on 510. Emphasis mine.

harm.”⁷³ Thus, the physician collaborator may be responsible for the conception and pregnancy, but not for the birth of an affected child. This position is rooted in what Pennings calls “the theory of moral responsibility in situations of joint action and causal collaboration,” though he does not elaborate on precisely what this theory entails.⁷⁴

It is also clear that Pennings and colleagues view responsibility in terms of individualism and autonomy. They note that while physicians and clinicians can decide to conscientiously object to collaborating with potential parents who seek to use PGD for reasons deemed condemnable, the appeals to conscientious objection are valid only for the clinician’s own acts. Thus, while she can condemn the intentions of potential parents, she cannot act in a way that hinders those parents from finding other ways to carry out their plans (She cannot destroy the embryos, for example.). In other words, the physician or clinician is only responsible for ensuring that her own actions are morally acceptable, but she has no responsibility for working to avoid the potentially negative outcome she envisions. I am not making a moral judgment about thinking of responsibility in this way: it is certainly a very pragmatic approach and one that many physicians and clinicians would be willing to support.

Summary

In this chapter I provided an overview of prevalent understandings of responsibility in ethics and bioethics literature. I noted the multivalent nature of this concept and some of the ways it has developed since its philosophical debut in the work

⁷³ Ibid.

⁷⁴ Ibid.

of David Hume. Specifically, I utilized the frameworks of Albert Jonsen and William Schweiker to categorize scholarship on responsibility in philosophical and religious ethics. Jonsen's first pattern of responsibility, the attribution of responsibility, is described as the "judge's problem" and is concerned with the way in which praise and blame is accorded to the agent based on her actions. Noting the six elements of this pattern—intention, motive, deliberation, voluntariness, excuse, and character—I showed how the pattern of attribution treats responsibility exclusively as a matter of intentional, rational, voluntary decision-making. The pattern of appropriation, on the other hand, deals with the ways in which the moral agent accepts responsibility for herself and her actions. For Jonsen, appropriating responsibility is a matter of character. This pattern has four elements—the self, consideration, conscientiousness, and commitment. By describing the ways in which these elements operate within the pattern of appropriation, I noted that this pattern also places an emphasis on intentional, voluntary decision-making but does so within the context of an agent's development of character.

Next, I turned to William Schweiker's classification of theories of responsibility in philosophical and religious ethics. His typology consists of three models of responsibility theories: agential, social, and dialogical theories. For each model, I selected one representative figure to examine in detail in order to gain a deeper understanding of what responsibility entails. For agential theories, I explored the work of Immanuel Kant. His work serves as a foundation for many subsequent agential understandings of responsibility, particularly with the emphasis on rational autonomy. Agential theories, Schweiker suggests, are concerned primarily with the relationship between an agent and her action. Social theories of responsibility, on the other hand, are

concerned primarily with the influences of social roles and practices for shaping the outlook of the moral agent. Responsibility is a social matter, to be determined and assigned by and within a given community. Stanley Hauerwas presents a weak social theory of responsibility and offers a way of thinking about responsibility beyond the bounds of autonomous decision-making. However, his account of responsibility is embedded in a view that treats narrative as a monolith; he assumes that agents live within “a” narrative rather than within multiple narratives with potentially different norms of behavior. His treatment of responsibility then becomes problematic when one seeks to draw on it within a context in which people with different operative narratives must work together to resolve a particular issue. To explore dialogical theories of responsibility, I turned to the work of H. Richard Niebuhr. Dialogical theories, Schweiker notes, are rooted in a moral anthropology in which the moral agent is constituted by her relations and encounters with others. For Niebuhr, responsibility is the first principle of ethics because all existence has responsiveness as its form. Responsibility is a matter of interpreting and responding to the actions of the other in a “fitting” way. Dialogical theories, like social theories, offer another way of thinking about responsibility outside of rigid emphases on intentional, voluntary decision-making, although those elements are still present.

Finally, I turned to scholarship in bioethics and explored ways in which responsibility has been articulated in that field, particularly in relation to issues of genetics. Through an examination of the scholarship of Beauchamp and Childress, Hardin, Agich, Nordgren, and Pennings, I demonstrated that bioethics has appropriated a view of responsibility that is largely a matter of intentional, voluntary, autonomous

decision-making. In this way, bioethics has drawn on Jonsen's patterns of attribution and appropriation as well as what Schweiker calls "agential" theories of responsibility. Such emphases are particularly evident in Pennings' work on responsibility in light of preimplantation genetic diagnosis.

What is needed in bioethics, particularly in light of the challenges posed by new genetic technologies, is a different way of thinking about responsibility. As I shall argue in the following chapter, responsibility is not always a matter of intentional, autonomous, voluntary choice. Following some of the voices expressed in the previous chapter, I contend that responsibility is oftentimes a matter of integrity and status. To confront the challenges of genetic technologies like predictive genetic testing and PGD, I claim that we need an account of responsibility that emphasizes two salient features that are often ignored in bioethics discussions of responsibility. First, responsibility entails the acceptance of obligations borne from one's status, regardless of one's acceptance of the status itself. Second, responsibility must promote the movement toward greater integrity in one's life, but that movement paradoxically involves recognizing and incorporating uncertainty and loss of control into that life. While the position I am advocating has resonances with many of the ideas described in this chapter, I will demonstrate why a new framework for responsibility is better able to attend to the challenges of the new genetics.

CHAPTER IV

TOWARD AN UNDERSTANDING OF RESPONSIBILITY GROUNDED IN STATUS AND INTEGRITY

“I am interrupted by my own social origin, and so have to find a way to take stock of who I am in a way that makes clear that I am authored by what precedes and exceeds me, and that this in no way exonerates me from having to give an account of myself.”¹

-Judith Butler, *Giving an Account of Oneself*

In the previous chapter I noted the ways in which dominant understandings of responsibility in ethics and bioethics largely assume voluntaristic accounts of moral agency and contexts of decision-making. With rare exception, responsibility is taken as a matter of freely, voluntarily, rationally making the “right” choices when faced with a given ethical quandary. Even the social and dialogical models of responsibility described earlier contain the elements of voluntariness and decision-making, though in understated forms. However, as the transcripts and statements discussed in chapter two indicate, moral agents often speak of responsibilities or “being responsible” for matters beyond their voluntary choices. Further, when confronted by challenging circumstances, those agents do not always frame their moral experiences with the language of voluntary, autonomous decision-making. For some moral agents, there is relatively little wrestling about what choice to make in a given situation; the appropriate (in their view) way forward is all too clear. Rather, as Hauerwas suggested in the previous chapter, their moral distress arises from the challenges of living a life that is reflective of their self-

¹ Judith Butler, *Giving an Account of Oneself*, 1st ed. (New York: Fordham University Press, 2005), 82.

understanding. Here, to speak of an agent's responsibilities is to speak of those obligations and commitments that give meaning to her life.

This chapter does much of the dissertation's constructive work by articulating a supplementary account of responsibility that is more responsive to the ways in which moral agents frame challenges related to genetic technologies; this account is also more reflective of some of the ways in which those agents speak of their responsibilities. My overall thesis is as follows: Prevalent theories of responsibility operative in ethics and bioethics presuppose a decision-making context, a voluntaristic account of moral agency, and lack a sufficiently robust and contextualized account of moral experience. Such views of responsibility must be supplemented by an account that emphasizes two salient features that are too often ignored in those dominant theories: 1) Responsibility entails the acceptance of obligations borne from one's status, regardless of one's acceptance of the status itself—whether one is a medical professional, a potential carrier of a genetic anomaly, a parent, or a member of a religious community; and 2) While responsibility promotes the movement toward greater integrity in one's life, that movement paradoxically involves recognizing and incorporating uncertainty and loss of control into that life. This paradox is especially evident in light of biotechnologies like PGD and predictive genetic testing, which purportedly provide a person with greater control and certainty about the biological conditions of her life or the future life of her offspring, though they often highlight the ways in which agents lack certainty and self-control.

To develop and support this new vision of responsibility, I first return to the voices of two individuals who have dealt with genetics-based challenges in their work—two participants in the focus groups described in chapter two. Earlier, I highlighted the

various ways in which those individuals and organizations described responsibility in relation to their work. Here, I briefly turn to how two of the focus group participants frame their moral experiences. In doing so, I highlight how the theories of responsibility described in chapter three—with their emphases on voluntary, autonomous choices—fail to attend to the rich nature of those experiences. For this reason, a supplemental account of responsibility must address those experiences if it is to remain a viable concept for moral discourse.

I then turn to the works of Judith Butler, John Silber, and William Schweiker to develop an account of responsibility rooted in notions of status and integrity, an account that is more responsive to the ways in which many moral agents actually interpret the challenges they face. Butler provides a sharp critique of modernity's image of the autonomous self all the while maintaining that responsibility still obtains even when the moral agent cannot fully account for her existence as a moral self. Silber advances a notion he calls "status responsibility," which he describes as "a view which permits of finding men morally wrong and blameworthy for their diseased *condition* or *state of being* in the absence of any morally blameworthy *conduct* that might have been avoided."² This view, I assert, is beneficial for considering the ethical challenges related to genetic technologies like PGD and predictive genetic testing. After all, with so many components of one's very existence supposedly "in the genes" of that person and thus non-selected, non-voluntary, and out of one's control, one will discover that one nonetheless carries specific responsibilities as a result of those very elements. Finally,

² John R. Silber, "Being and Doing: A Study of Status Responsibility and Voluntary Responsibility," *The University of Chicago Law Review* 35, no. 1 (1967), 47-91; quote on 47. Emphases and exist language is Silber's, not the author's own.

the “imperative of responsibility” developed by William Schweiker provides a starting point for considering responsibility as a matter of integrity. This imperative states: “In all actions and relations we are to respect and enhance the integrity of life before God.”³

While I find Schweiker’s work to be too reliant on a decision-making framework, his emphasis on integrity shifts our attention away from isolated decisions and toward the agent whose values are enacted in and through her confrontations with ethical challenges.

Two points must be noted at the outset of my constructive endeavor. First, I am not arguing that a vision of responsibility rooted in status and integrity is exhaustive of what responsibility entails. Many times, responsibility is a matter of freely making decisions and dealing with a particular ethical quandary. What I suggest, however, is that this typical account must be supplemented by a recognition that responsibility is sometimes concerned with more than just making the right choices or about having control over oneself and one’s actions. Second, although the Hauerwasian framework of social responsibility broadly resonates with the theoretical shift I advocate here, his contributions to responsibility theories are unhelpful for sorting through ethical uncertainties in a pluralistic context. While he recognizes that the ethical life is a constant striving for greater integrity, that is, for living in a way that is reflective of the values that one holds dear, his treatment of narrative as a monolithic entity fails to appreciate the manifold nature of moral agency and moral experience, particularly those experiences of agents in the clinical context. In other words, the vision of integrity that flows from his project is constrained by the limits of *the* narrative (note the definite

³ William Schweiker, *Responsibility and Christian Ethics*, New Studies in Christian Ethics series (Cambridge: Cambridge University Press, 1995), 2.

article). For Hauerwas, the moral agent lives in one narrative—one for which there is a “right” telling of that story. As the quotes from the focus group participants in the next section illustrate, agents find themselves living out multiple narratives and values. Genuine ethical anxiety arises from discerning which values take precedent in a given situation. A Hauerwasian view of narrative, responsibility, and integrity fails to appreciate such anxiety. I advocate thinking about integrity as a matter of striking the right balance among an agent’s *multiple* values and commitments so that she can live in a way that enables her to recognize her actions as reflective of who she understands herself to be.

Moral Agents Speak: Challenges in the Clinic

An earlier chapter offered numerous examples of medical professional organizations, religious denominations, ministers, and medical professionals speaking of responsibility in terms that challenge the widely-held view of responsibility as a matter of voluntaristic, autonomous decision-making. While their varied expressions of that concept are noteworthy in their own regard, it is also revealing to listen to how some of these moral agents frame their moral experiences in general, even if they do not speak of responsibility. Consider the words of a genetic counselor struggling with offering information about abortion services to a patient:

Genetic Counselor 2: “Right, but what I’m thinking of is what is their legal right to do and my responsibility as a counselor, and where I do or do not draw the line as my responsibility as a counselor as long as what their choice is is legal and my religious beliefs, I’ve had to sort through, through the years, because I still do have a problem with that is a life...that is a life that is being taken and I take that very, very seriously...very seriously...and I still struggle with that issue but I also would fight for their right to make that decision because and part of that

doesn't come just from my religious beliefs and that's concern about that child. Part of that comes from my familial background that I have a sister with Down Syndrome who was born 40 years ago when there was nothing to do for those children."

Admittedly, the transcription of her remarks is a bit difficult to follow. The counselor describes her struggle reconciling her "responsibility as a counselor" to offer information about terminating a pregnancy to her patient with her personal and religious belief that "that is a life that is being taken." As she indicates, her struggle is not with deciding which responsibilities take precedent—she clearly states that she would "fight for their right to make that decision [to terminate the pregnancy]"—but with being in a position where she is pulled in seemingly different directions. In other words, her challenges do not arise from making a particularly difficult decision, but in the discovery of inevitable tragedy no matter how she responds to her patient. If she offers abortion services to the patient, she fails to uphold her religious convictions; if she refuses to offer those services, she sees herself as failing to fulfill her professional duties. In either case, her integrity becomes, perhaps, tragically challenged.

In another focus group, an evangelical Christian minister recalls his experiences counseling a couple in his congregation. The wife was pregnant and amniocentesis revealed that their future child had Trisomy-18, a condition for which only 5% of children survive beyond their first year of life. Not surprisingly, the minister focuses his discussion on the religious convictions of the couple:

Minister: "And yet, in the case of this family, they both had a strong faith. They came from different backgrounds. She was Catholic in background, so it had a very strong bias for life, as you can imagine. She was a very devout Catholic, who came to be a part of our congregation, and we were very thankful for that. Her husband grew up in a very traditional religious background in the Churches of Christ, and when I say traditional, traditional for the Churches of Christ, at least, in that both of them really

never considered—they never considered abortion as an option, ever, in this entire process, but the real questions for them were, you know, ‘Why did this happen?’ and from a medical perspective, the wife supplied a lot of those answers. You know, she had her training in pediatrics. She was very much aware of what was going on, and the risks that were involved in that, but I think for them, it was really interesting that—the question that really mattered to them is ‘What do we do next? What do we do to make this meaningful?’ Not so much—I mean, the whys were there, but they weren’t there so deeply as ‘What do we do to make this meaningful?’”

A moment later, another minister in the focus group asked him why the parents considered undergoing amniocentesis if they were unwilling to consider terminating the pregnancy. His response is especially revealing:

Minister: “The reason they went, and because that was one of the questions, actually, I had on that, was that they said if—you know, there’s always the possibility ultrasound may not be fully accurate; the amniocentesis will tell them precisely what the chromosomal situation is with this child. They wanted to know, because they wanted to be preparing themselves, their children, and their friends for what was going to happen in the future. They did not want to know to make an option on whether or not to abort that child, but how to prepare people, and to begin right then preparing.”

The minister’s recollections depict a family whose moral challenges did not arise from a particular decision-point or from their causal contribution to the difficult circumstances they face. As the minister clearly states, there was no choice for this family to make. Their religious convictions informed their understanding of their situation and assured them that pregnancy termination was not an option. Instead, the couple’s challenges arose from their attempts to find meaning in a tragic situation and from trying to create a future in which they would be supported for living out those convictions. Again, this was not a struggle about an especially tough decision—it was a struggle over how to best live in accordance with the ideals they hold as fundamental to their self-understanding. In other words, it was the struggle of living a life of integrity.

The statements of the genetic counselor and the minister point to limitations of construing moral challenges solely in the language of autonomous decision-making. In the case of the genetic counselor, her perceived challenge could easily be framed as a matter of choice: Should she offer to her patient information about pregnancy termination or should she withhold that information? But the difficulty she experiences in that moment cannot be fully understood in the language of decision-making. Rather, the genetic counselor describes her moral distress as a tragic conflict between two commitments she holds dear. No matter if she decides to offer or withhold information to her patient, the counselor feels that she falls short of being true to her values (as a counselor or as someone who opposes abortion). While she may have a decision to make, her moral distress is a result of conflicting values. In the evangelical minister's discussion, the moral distress he describes is the product of being involved in a tragic situation, not in any agony over a "problem" that is to be solved by making the appropriate choice.

These sentiments echo the concerns of Edmund Pincoffs, who argued that twentieth century ethics had assumed that its object of analysis is a "problem" or quandary. However, looking back at the history of ethics, thinkers like Aristotle, Kant, and Hegel were not primarily concerned with developing defensible problem-solving methodologies. Any prescriptive guidance (such as the Aristotelian mean or Kant's categorical imperative) those thinkers offered were situated within larger, more robust analysis of the moral life, human agency, and the human condition. However, this more recent understanding of the task of ethics, which he calls "quandary ethics," assumes that ethics deals with "situations in which it is difficult to know what one should do; that the

ultimate beneficiary of ethical analysis is the person who, in one of these situations, seeks rational ground for the decision he must make....”⁴ It attempts to derive universal, abstract principles for decision-making. However, Pincoffs notes that responding to the question “What ought I do?” requires an understanding of who “I” am and what details of that situation are relevant to “my” predicament. Pincoffs claims that “what would be right for anyone in the same circumstances...is not necessarily right for me. Because what I have to take into account as well as the situation is the question of what is worthy of me.”⁵ From this perspective, ethics is about more than problem-solving and decision-making. It is concerned with matters of character, self-understanding, and integrity. However, by focusing on “problems” and “decisions” ethical analysis ignores those more basic issues that moral agents—like the genetic counselor and the family in the minister’s story—struggle with at a given moment.

Judith Butler: *Giving an Account of Oneself*

The Modern Subject

The dominant modes of responsibility described in the previous chapter share an important assumption, though in varying degrees: Talk of responsibility nearly always assumes the existence of a recognizable, knowable “I” or “subject” that can assume responsibility, be held responsible, and accept or reject responsibilities. For Kant, this “I” is the rational autonomous agent whose increasing self-awareness is grounded in the

⁴ Edmund Pincoffs, "Quandary Ethics," *Mind* 80, no. 320 (1971), 552-517; quote on 552.

⁵ *Ibid.*, 561.

self's rational capacity. In Hauerwas' work, the self is a social creature, finding meaning and value in her life through participation in a particular social world that is guided by its own value-giving narrative. A person comes to see herself as an agent or a subject by accepting, rejecting, or altering the values of the community in which she lives. Yet, prior to those acts there is still some entity that accepts, rejects, participates, or eschews. That prior entity is not a self-created being but is seen as a gift from God, according to Hauerwas. In that sense, though the agent is not the efficient cause (in an Aristotelian sense) of her life, she can nonetheless account for her existence by pointing to God. Niebuhr seemingly presents an alternative view with his claim that all human life has the characteristic of responsiveness; the subject develops in relation to others. Yet, he does not provide an account of how the "self" acquires the capacity to initially respond and freely interpret. In other words, interpretation is a constitutive element of the self's responsiveness, yet there must be some prior "self" or "subject" that is able to raise the questions of interpretation: What is going on? What is happening to me?

Though Niebuhr's explication of the self is a definite challenge to the modern view of the subject, certain traces of that modern visage remain: freedom and self-knowledge are its hallmarks. For the other modes of responsibility—especially those that are far more common in bioethics discourse—the assumed subject is indeed a decidedly modern subject. This modern subject arose in part as a response to David Hume's challenge that the self was "nothing but a bundle or collection of different perceptions."⁶ Through his empiricist methodology, Hume was unable to identify an observable entity

⁶ David Hume, *A Treatise of Human Nature*, eds. David Fate Norton and Mary J. Norton, Oxford Philosophical Texts (Oxford: Oxford University Press, 2000), Book I, Part IV, section vi.

that unified those different perceptions and thus he rejected the notion of a substantive subject.⁷ Following the Humean critique, one of Kant's most significant tasks became locating the grounds for the possibility of the subject, which as noted in the previous chapter, he locates in our rational capacity.

A thumbnail sketch of the modern subject may be helpful at this point. He (because the modern subject is nearly always a "he") is rational, free, exerting control, and constantly growing in self-awareness. The progress of "civilized" or "cultured" (in other words, Western and European) societies was understood as reflective of the modern subject's reason. As the subject grew in reason and self-knowledge, so too did society progress. Here, Hegel's *Phenomenology of Spirit* is a powerful representative of this view, as history is understood as the site in which the Spirit grows in greater self-knowledge and the subject is an instance of that movement.⁸ Further, views of this modern subject are typically articulated in light of certain dualisms: mind/body, male/female, freedom/oppression, control/chaos, reason/madness, cultured/savage, science/superstition, universal/contingent, one/many, and so forth. Those divisions were seen as ontologically real, independent of agential input. To be a subject was to have a

⁷ In the mid-20th century, A.J. Ayer took up Hume's empiricist cause in *Language, Truth, and Logic* (1946), but modified the Humean position on selfhood by arguing that *bodily* identity provides the basis for an observable entity that can be called a "self." He defends this modification by arguing that while we can speak of someone losing their memory or changing their character, it would be self-contradictory to speak of someone losing their body. See pp. 120 ff. in A. J. Ayer, *Language, Truth, and Logic* (London: V. Gollancz Ltd., 1946). I do not endorse Ayer's position as I think it is possible to speak meaningfully about a person losing control of her body or becoming alienated from her body in some ways. I simply want to note that Hume's cause (at least *this* cause) has been taken up in more modern times.

⁸ Georg Wilhelm Friedrich Hegel, *Phenomenology of Spirit* trans., Arnold V. Miller and J. N. Findlay (Oxford Clarendon Press 1977).

mind, to be rational, autonomous, controlling, cultured, an individual, scientific, and a fervent supporter of scientific investigation as the means to discovering truths about the world.

Butler on Subjectivity and Responsibility

This view of the subject continues to hold sway in contemporary popular discourse, although continental philosophy's recent history is scattered with attacks on the modern image of the autonomous, free, self-grounding subject. Nietzsche, Kierkegaard, Heidegger, Rorty, Foucault, and numerous others have ushered us into the world of *posts*: post-modernism, post-structuralism, post-foundationalism, post-humanism, post-Christianity, etc. Judith Butler is a contemporary contributor to that interrogative work, especially in her book *Gender Trouble* in which she challenges the perceived coherence and static nature of sex, gender, and sexuality in modern discourses.⁹ Though Kant recognized that self-grounding knowledge never complete (but always expanding), many attacks on the modern subject have emphasized this unknown (and perhaps unknowable) dimension to selfhood as evidence of the "death of the subject." Heidegger, for example, challenged the modern view of the subject by arguing that autonomy and the capacity for knowledge (including self-knowledge) do not exist independently of that subject's interactions with the world around it. Thus, *Dasein* ("being-there") can only be understood within the complex social web of history and

⁹ Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (New York: Routledge, 1990).

value into which Being has been thrown.¹⁰ For this reason, the subject cannot be fully autonomous, nor can she ever expect to achieve exhaustive self-knowledge. Similarly, Foucault's projects (particularly his archaeological works) critique the idea of the modern subject by emphasizing the historically and socially contingent conditions that limit and shape the possibilities for what constitutes subjectivity.¹¹ In other words, the self is never fully free to make autonomous decisions about who she can be—many aspects of her subjectivity are beyond her control.

In her more recent *Giving an Account of Oneself*, Butler's work follows the insights of Heidegger and Foucault and takes a decidedly meta-ethical turn. Here, her driving concern is with the possibility of responsibility in light of the opacity of the human subject. In other words, how can moral agents be held responsible—or how can they be responsible for themselves—if the very notion of a free, autonomous, rational moral agent is no longer self-evident? Butler poses the question: “Does the postulation of a subject who is not self-grounding, that is, whose conditions of emergence can never fully be accounted for, undermine the possibility of responsibility and, in particular, of giving an account of oneself?”¹² As the previous chapter showed, responsibility's primary concern is with the relationship between the moral agent (the self or subject) and her actions. How can she call her actions her own, particularly when she can never fully give an account of her selfhood? If she is not free and autonomous, in what sense can she call actions her own?

¹⁰ Martin Heidegger, *Being and Time* (New York: Harper, 1962).

¹¹ See especially Michel Foucault, *The Archaeology of Knowledge* (New York: Harper & Row, 1972).

¹² Judith Butler, *Giving an Account of Oneself*, 19.

To respond to such enquiries, Butler combines rhetorical analysis with insights from Adorno, Levinas, Foucault, Laplanche, and Adrian Cavarero in order to affirm the possibility of responsibility, even despite the subject's inability to give an exhaustive account of herself. She argues that while the subject can never give such an account, this does not necessarily spell the death of the subject altogether. In fact, Butler follows Adorno in asserting that morality *requires* the existence of a moral subject: there can be no morality without an "I."¹³ It is thus necessary to explore what constitutes the "I." To support this claim, Butler turns to the structure of address to postulate the possibility of the subject: "...the fact that we cannot exist without addressing the other and without being addressed by the other, and that there is no wishing away our fundamental sociality."¹⁴ Thus, the address becomes the starting point for subjectivity.

Implicit here is an idea of relationality: Being addressed by the other is a form of relationship with the other. Though "I" am addressed by the other (the "you")—you call me to give an account of myself—I can do so only through linguistic tools and structures that "are not of [my own] making."¹⁵ To borrow Hauerwas' terms, I am called upon by another to give a narrative of myself, but because I must use tools that I did not create to articulate an account of a "self" that I did not bring into being, there are sure to be parts of my "self" and my "story" that remain hidden from me. In addressing my narrative to you, that story "assumes a rhetorical dimension that is not reducible to narrative function....Something is being done with language when the account I give begins: it is

¹³ Ibid., 7.

¹⁴ Ibid., 33.

¹⁵ Ibid., 21.

invariably interlocutory, ghosted, laden, persuasive, and tactical.”¹⁶ Thus, the “I” of the subject comes into being by addressing her story to the other, but because that story is told as an address (and thus “interlocutory, ghosted, laden, persuasive, and tactical”), the telling of that story is dependent upon the presence of the other and is always incomplete. Butler states, “The ‘I’ cannot give a final or adequate account of itself because it cannot return to the scene of address by which it is inaugurated and it cannot narrate all of the rhetorical dimensions of the structure of address in which the account itself takes place.”¹⁷

So where does this postulation of the subject leave us in relation to responsibility? If the subject can never fully account for herself, how can she be responsible? On these questions, Butler returns to the works of Levinas, Adorno, and Foucault to assert that responsibility arises not out of autonomous control but out of the very vulnerability that constitutes one’s subjectivity. Following Levinas, she notes that “we are vulnerable to the address of others in ways that we cannot control....Responsibility emerges as a consequence of being subject to the unwilled address of the other.”¹⁸ Here, it is worth quoting Butler at length:

“I want to suggest that the very meaning of responsibility must be rethought on the basis of this limitation [the self’s limited ability to provide an account of itself]; it cannot be tied to the conceit of a self fully transparent to itself. Indeed, to take responsibility for oneself is to avow the limits of any self-understanding, and to establish these limits not only as a condition for the subject but as a predicament of the human community....I speak as an ‘I,’ but do not make the mistake that I know precisely all that I am doing when I speak in that way. I find that my very

¹⁶ Ibid., 63.

¹⁷ Ibid., 67.

¹⁸ Ibid., 85.

formation implicates the other in me, that my own foreignness to myself is, paradoxically, the source of my ethical connection with others....I cannot think the question of responsibility alone, in isolation from the other. If I do, I have taken myself out of the mode of address (being addressed as well as addressing the other) in which the problem of responsibility first emerges.”¹⁹

Butler also suggests that because we only come into being through the call of the other, we “affirm the unfreedom at the heart of our relations” by taking responsibility for that which we do not choose or control.²⁰ Being responsible in this way is a recognition that “none of us is fully bounded, utterly separate, but, rather, we are in our skins, given over, in each other’s hands, at each other’s mercy.”²¹ It also means that, following Adorno and Foucault, acting “ethically” means that “we must avow error as constitutive of who we are.”²² From this perspective, attitudes of humility, mutual dependence, and care for others become the hallmarks of responsibility. Ethical judgment should be withheld when that judgment hinders recognition of the other and suppresses the life of oneself and the other. This humility in our ethical judgment arises out of deference to the limits of both self-understanding and the social conditions that normalize certain modes of being to the exclusion of others. While we make strides toward recognition of the self and the other, we should do so with an awareness of our own limits. Further, we are called to care for the other precisely because of our mutual dependence on one another: Without “you” there can be no “I” and vice versa.

¹⁹ Ibid., 83-84.

²⁰ Ibid., 91.

²¹ Ibid., 101.

²² Ibid., 111.

As I will show in the following chapter, these insights directly impinge on how we might think of responsibility in light of genetics and genetic technologies. Butler offers a view of the subject that appreciates the bounded, inexhaustible nature of subjectivity. Her subject never fully knows herself, nor does she achieve certainty and total control over her existence. Yet, Butler argues, responsibility remains in spite of that lack of certainty and self-control. In fact, the “error” that is “constitutive of who we are” and the “unfreedom at the heart of our relations” becomes the very locus of responsibility. In other words, autonomy, freedom, and rational decision-making are not *necessary* preconditions of responsibility. Responsibility actually requires humility in light of our limited capacities for self-understanding, self-control, and the mutual dependence that render possible any human subjectivity.

John Silber’s Status Responsibility

Implicit in Butler’s account of subjectivity and responsibility is the notion that responsibility obtains to a moral agent not only for what she does (or fails to do) but also because of who she is: a subject called into being by others, incapable of ever giving a full account of her existence or fully understanding who she is. In other words, responsibility arises out of both action *and* being. This view is obviously contrary to many of the dominant accounts of responsibility in ethics and bioethics discourse. Further, it is contrary to the ideal driving the American legal system in which justice is meted on the basis of one’s actions—which one can presumably control—rather than on the basis of status-based traits like sex, religion, skin color, or sexual orientation. Recall Jonsen’s pattern of the attribution of responsibility, which relied exclusively on this

legalistic framework. Voluntariness and intentionality are crucial elements in the pattern of attribution and they continue to shape legal discussions of responsibility (with its concern for *mens rea*), as exemplified in the work of H.L.A. Hart. Consider the following statement from Hart:

“If a person whose action, judged *ab extra*, has offended against moral rules or principles, succeeds in establishing that he did this unintentionally and in spite of every precaution that it was possible for him to take, he is excused from moral responsibility, and to blame him in these circumstances would itself be considered morally objectionable. Moral blame is therefore excluded because he has done all that he could do....In morals ‘I could not help it’ is always an excuse and moral obligation would be altogether different from what it is if the moral ‘ought’ did not in this sense imply ‘can.’”²³

Even in this brief passage, we are presented with the attribution pattern’s elements of voluntariness, intentionality, and excuse. We also see that Hart “restricts himself to a pejorative context, to a context of moral failure.”²⁴ From this perspective, morality is essentially a rule-oriented activity and that failing to follow those rules leads to negative judgment.

John Silber is a prominent legal scholar who recognized the importance of voluntary action-oriented visions of responsibility for the legal context. However, he also suggests that *in some cases* it may be logical to think of responsibility in relation to a person’s status, hence the term “status responsibility.” Silber did not claim that status responsibility to be an original idea, as he considered it to be rooted in Western Christianity’s mythology of “original sin.”²⁵ Like both Kant and Butler, Silber grounds

²³ H. L. A. Hart, *The Concept of Law*, Clarendon Law Series (Oxford: Clarendon Press, 1961), quoted in Silber, 49.

²⁴ Silber, 57.

²⁵ *Ibid.*, 47.

the possibility for responsibility in the very nature of the human subject. His concern, however, is with expanding the scope for which responsibility is a relevant concept for making moral judgments; he is not interested in articulating a vision of what constitutes responsible agents and actions.

For Silber, responsibility is situated on a broad continuum in which actions are assessed according to the degree of the agent's voluntariness present in those actions. On one end of the continuum are actions over which moral agents have no control ("I couldn't help it!") while on the other end one finds autonomous, freely chosen actions. To illustrate his argument, Silber offers a series of events, ranging from a man walking aimlessly in his garden to that same man offering poisoned eggs to his brother. "At what point," Silber asks, "shall we speak of action rather than mere event? At what point does the personality of X express itself in what happens or what is done?"²⁶ In this series of events/actions that Silber provides, one sees a gradual increase of personal involvement and a resulting increase in personal responsibility for those events/actions and their outcomes. But, as Silber is quick to note, it is often difficult if not downright impossible to distinguish between what constitutes a mere event and an action, between an action and its consequences, between voluntary and involuntary action, or even between a person and a thing.²⁷ At what point are we to distinguish between actions for which a person can be held responsible and events for which responsibility is not an issue?

²⁶ Ibid., 69.

²⁷ Ibid., 68.

Silber suggests that even at the furthest end of that continuum of events and actions—the place at which moral agents have no control over the event in question—a limited degree of responsibility remains. He calls this *status responsibility*. This type of responsibility remains, he suggests, because “human choice is not something isolated from the choosing person.”²⁸ Choice is a process of self-creation and self-discovery, but in those very processes the moral agent may soon discover the *limits* of thinking about responsibility solely in terms of one’s voluntary, intentional choices. As Silber notes, “moral obligation may obtain whether or not it is chosen. Moral obligation obtains according to the nature and the situations of persons.”²⁹

An example may be helpful for illustrating precisely what Silber means by status responsibility. I was diagnosed with type-1 diabetes when I was 15 months old. I did not choose this condition, nor did any of my actions as a toddler cause me to become diabetic. I just happened to be born with a genetic predisposition that, when coupled with certain environmental factors, made me more likely to develop that condition. Though I did not choose to be diabetic nor did I intentionally cause my diabetes, I am nonetheless responsible for attending to my unchosen status. It places certain obligations on me—to check my blood sugar levels, to be thoughtful about what I eat, to exercise, to take daily insulin injections—if I am to continue to live. Such responsibilities are what Silber seems to have in mind when he speaks of status responsibility—those responsibilities that arise out of the unique circumstances that shape a person’s very existence.

²⁸ Ibid., 90.

²⁹ Ibid., 88.

The appeal to status responsibility reaffirms Butler's interrogation of the autonomous self and her subsequent views of responsibility. As Butler and others suggest, there is always some dimension of what I call my "self" for which I can never give a full account. I cannot always point to specific choices that gave rise to particular dimensions of my being, nor can I ever give an exhaustive account of how "I" came to be as my very origins lay outside the realm of my control and decision-making capacity. Yet, the address of the other compels me to give an always-inadequate account of myself, that is, to respond and be responsible. Though argued in decidedly more legalistic language, Silber's advocacy of status responsibility echoes Butler's sentiment that responsibilities are not always chosen. Both scholars agree that responsibility oftentimes obtains by virtue of the unique conditions of the agent's existence, whether one speaks it in terms of status or the unwilled address of the other. In either case, moral agents are responsible by virtue of their unique states of being, regardless of any elements of intention or control on the part of those agents.

The idea of status responsibility may be criticized for seemingly justifying certain entrenched racist, sexist, heterosexist, abelist, and other discriminatory attitudes. By claiming that certain responsibilities obtain by virtue of who someone *is*, are we not leaving the door open for a range of exclusivist perspectives and practices? Consider the numerous appeals to "objective" science that have been deployed to justify attitudes of racial, sexual, and heterosexual superiority. Phrenology, for example, was thought prove the intellectual superiority of Europeans in comparison to Africans throughout the nineteenth century. In early 2005, former President of Harvard University, Lawrence Summers, came under serious scrutiny for stating in a speech that more men than women

might occupy high-level positions in science and engineering professions because men naturally had a potential for greater aptitude than women in those fields of study.³⁰ Such judgments are made based on a person's status—as a European or African, as male or female—but we likely bristle at these examples because they seem so negatively prejudiced. Do such examples mean that status responsibility may be little more than a euphemism for discrimination?

While there is a clear danger to potentially using the idea of status responsibility to justify discriminatory attitudes and practices, I do not find status responsibility to be inherently discriminatory or oppressive. Butler, following Foucault, is quick to point out the ways in which linguistic and social structures create oft-unrecognized boundaries that limit possibilities for how a subject can live her life. Based on her understanding of responsibility in light of those boundaries and the self's opacity, she advocates an attitude of humility and withholding ethical judgment when such judgment fails to promote life. Consider someone who, for any number of reasons, must use a wheelchair. On one hand, that person is indeed saddled with responsibilities that able-bodied individuals do not have. The built environment makes moving in a wheelchair difficult at times. It may seem that such burdens make that particular mode of being-in-the-world less desirable than that of a person who can walk.

³⁰ Specifically, Summers claimed that “in the special case of science and engineering, there are issues of intrinsic aptitude, and particularly of the variability of aptitude, and that those considerations are reinforced by what are in fact lesser factors involving socialization and continuing discrimination.” See his “Remarks at the NBER Conference on Diversifying the Science & Engineering Workforce,” 14 January 2005. Available online: <<http://web.archive.org/web/20080130023006/http://www.president.harvard.edu/speeches/2005/nber.html>>.

However, it is important to ask: What responsibilities obtain to being (temporarily) able-bodied that the wheelchair-bound individual does not possess?³¹ What implicit structures shape our society in a way that privileges able-bodiedness often to the exclusion of disabled bodies? In other words, the *evaluative* claim that being disabled in some way is worse or less desirable than being temporarily able-bodied is not necessarily and wholly rooted in these different biological states, but rather in the ways in which those states of being are accommodated—or neglected—by society at large. While I do not intend to underestimate the challenges that accompany disabled bodies, I contend that by withholding ethical judgment and being responsible for shaping society to be more conducive to the wide spectrum of states of being, we can make great strides toward eliminating discriminatory attitudes and practices aimed at disabled members of our society. In doing so, we then see that different states of being are just that—different—and not necessarily better or worse than others. In fact, from this perspective it becomes the responsibility of those who are temporarily able-bodied to render the social world more open to disabled persons.

Additionally, status responsibility resonates with much of the work in feminist ethics and Christian theology during the past half century. In her groundbreaking work

³¹ I follow Nancy Eiesland and many others in the disabled community in using the term “temporarily able-bodied” to designate so-called “normal” modes of being. Eiesland notes that the overwhelming majority of us will inevitably become physically disabled at some point in our lives, either temporarily or permanently. Thus, it is appropriate to think of able-bodiedness as a temporary status for most individuals. For more, see Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994). See also Eiesland’s “Things Not Seen: Women with Physical Disabilities” in *Liberating Faith Practices: Feminist Practical Theologies in Context*, eds. Denise Ackermann and Riet Bons-Storm (Leuven, Belgium: Peeters, 1998), 103-127.

In a Different Voice, Carol Gilligan challenges the paradigm of moral development articulated by Freud, Piaget, Erikson, and Kohlberg.³² She demonstrates ways in which their work considers maleness to be normative, excluding women's moral development from their purview. By listening to the voices of women talking about their moral experiences, Gilligan discovers that women tend to frame moral issues differently than men. She notes that where men typically think about morality in terms of rights, rational discernment, rules, and justice (distributing rewards and punishment), women typically construe moral issues in the language of responsibility for others, relationships, and caring. In other words, men and women often have different moral voices—not better or worse, just different. The difference that Gilligan highlights has given rise to an “ethics of care” that feminist scholars have drawn upon for decades in order to articulate how an agent's female status shapes how she views a moral issue and gives rise to certain responsibilities in a given situation because of that status.

In theological circles, various “identity theologies” have risen to prominence in response to abstract theologizing of post-Enlightenment Western Christianity, with its racist, sexist, heterosexist, and ableist language that contributes to the oppression of non-white, non-male, non-heterosexual, or disabled people and communities. To paraphrase the work of theologian James Cone, the theology of Karl Barth had little to say to African-Americans of the mid-20th century who spent their lives tenant farming in the rural south.³³ In another example, Marcella Althaus-Reid recalled a group of Argentine Catholic women discussing the veneration of the Virgin Mary. When asked if they

³² Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Cambridge, MA: Harvard University Press, 1982).

³³ James H. Cone, *God of the Oppressed* (New York: Seabury Press, 1975).

identified with the Virgin in their suffering, they responded, “No, because she has expensive clothes and jewels, she is white and she does not walk.”³⁴ What such statements reveal is the acknowledgement by astute theologians that theology—if it is to address the specific challenges that individuals and communities face—must consider the unique lived experiences of those people if it is to have any resonance with their lives. In other words, one’s status informs the ways in which one thinks and lives in the world; thus it is not far fetched to think that certain responsibilities may obtain from one’s unique status, as well.

As the next chapter will demonstrate, status responsibility can be a helpful concept for thinking about moral challenges associated with genetics and genetic technologies. It provides a way to identify specific responsibilities that arise as a result of one’s genetic constitution. Status responsibility also provides a means for articulating the responsibilities that may arise by virtue of one’s status as a potential parent, a patient/client, a member of a religious community, or a medical professional. Certainly many of these states or roles are freely chosen, but it is rarely the known dimensions of one’s status that an agent finds so morally troubling. Further, while agents oftentimes freely choose many of their roles, we cannot typically choose which responsibilities associated with that role are relevant to our specific instantiations of those roles. Further, agents are challenged by the unknown, by the unexpected question a patient poses or by the diagnosis that is far from definitive. What does it mean to be responsible in these

³⁴ Quoted in Marcella Althaus-Reid, *From Feminist Theology to Indecent Theology: Readings on Poverty, Sexual Identity and God* (London: SCM Press, 2004), 30.

situations where our own status places us in these difficult circumstances with little guidance? How do we exhibit responsibility for a self that cannot be fully known?

William Schweiker: Responsibility as a Matter of Integrity

William Schweiker's constructive turn in *Responsibility and Christian Ethics* provides guidance for addressing those very questions. His integrated theory of responsibility is deeply indebted to the work of the theorists described in chapter three, but none more so than to H. Richard Niebuhr. Schweiker, much like Niebuhr, contends that the basic problem of the moral life is that of *faith*, that is, in discerning what "identity-conferring commitments" should guide our lives by expressing what is to be valued.³⁵ By turning to responsibility, Schweiker addresses the contemporary outlook that typically obfuscates value in relation to power. He seeks to counter the notion that what is "valuable" is that which is powerful, or that which allows humans to merely fulfill their own interests. His emphasis on the relations between responsibility, faith, and value theory also show Schweiker's indebtedness to Niebuhr. Also following Niebuhr, Schweiker begins his analysis of the moral life with lived human experience rather than with reified first principles by which life or actions are to be judged. Though decidedly informed by Christian ideals, Schweiker's insistence that responsibility is a matter for all moral agents puts him in line with Niebuhr, who saw his own work as an example of Christian moral philosophy. To further support the task of Christian moral philosophy, Schweiker commits himself to a perspective of "hermeneutical realism" in which, to

³⁵ Schweiker, 2.

paraphrase Paul Ricoeur, “we invent in order to discover the truth of our moral condition.”³⁶

Schweiker’s overall project is a defense of what he calls the imperative of responsibility: “In all actions and relations we are to respect and enhance the integrity of life before God.”³⁷ Responsibility is defined in terms of the integrity of life. It may be appropriate to think of the integrity of life as Schweiker’s primary concern rather than to see his work as a reformulation of the concept of responsibility; responsibility is the means to the end of integrity. He states, “Moral integrity is the substantive moral good and hence the focus in theological ethics; the idea of responsibility provides the means for thinking about the meaning of that good for how we ought to live.”³⁸ This substantive moral good of integrity “designates the integration of the goods of life with respect to attitudes and commitments to a moral project which defines what an agent’s life is about...[Moral integrity] concerns consideration of the well-being of others as well as self.”³⁹ That is, a life of integrity is one in which the goods of that life are ordered in accordance with the values and commitments that a person holds dear. Following the trajectories of relational thinkers like Niebuhr and Butler, Schweiker’s vision of integrity

³⁶ Ibid., 114. Hermeneutical realism holds that moral values exist prior to the traditions and cultural artifacts that moral agents deploy in order to articulate those values. However, it also admits that our understanding of those values requires some conceptual scheme and linguistic structures. Hence, we “invent” moral frameworks with notions like “truth” or “beauty” or “good” or “God” in order to “discover” those moral goods to which those names are applied. The task of ethics becomes validating the claims of a community and its conceptual scheme “by articulating the basic character of moral experience” (110).

³⁷ Ibid., 2.

³⁸ Ibid., 44.

³⁹ Ibid., 130.

also takes the well-being of the other into account; perhaps this his recognition that there can be no “I” without a “you.”

With this understanding of integrity, it is important to consider what the “goods of life” signify. Schweiker notes, “The moral domain of life is constituted by interlocking goods endemic to human existence and the choices we make about them. Taken together these diverse goods constitute the values which the responsible person or community is committed to respect and enhance.”⁴⁰ He identifies four levels of such goods: pre-moral, social, reflective, and the ethical good of integrity. Pre-moral goods include those goods necessary for material well-being (food, shelter, bodily integrity), but also goods that “situate us in the world as feeling, aspiring, social, acting agents” (sexual fulfillment, music, etc.); these goods are pre-moral because it is sometimes necessary to diminish or sacrifice these goods in order to uphold other goods (Schweiker uses an example of sacrificing a limb in order to save a life).⁴¹ Social goods promote communal and environmental well-being and include goods like family, friendship, political participation, and interaction with the environment. These goods are “those forms of human excellence and well-being associated with fidelity to the consideration of others in a way of life and in specific choices.”⁴² Reflective goods promote personal well-being by supporting the quest for a life of truth, self-interpretation, and self-understanding. Such goods include “the goods of culture or civilization, that is, the whole domain of symbolic,

⁴⁰ Ibid., 117.

⁴¹ Ibid., 117-118.

⁴² Ibid., 118.

linguistic, and practical meaning-systems.”⁴³ The final good that Schweiker discusses, the ethical good, is described as moral integrity. This ethical good “designates a commitment through which an agent helps create her or his life with respect to goods at the root of personal and social existence” and as noted above, it “specifies the wholeness of life.”⁴⁴

The moral life, however, is an ambiguous endeavor. At times these various goods conflict; natural law advocates speak of such instances in terms of the principle of double effect. Another difficulty of the moral life is that the goods and values to which one agent is committed will come into conflict with another moral agent’s striving for her own goods. In other words, one person’s constant striving for integrity will inevitably bump up against the struggles of another person. Yet, the imperative of responsibility calls on moral agents to respect and enhance the integrity of life in themselves and others. Resolution of this conflict requires the act of *radical interpretation*, the “reflective, critical inquiry aimed at the question of what has constituted our lives in terms of what we care about and what ought to guide our lives under the demand of respect for others.”⁴⁵ Through radical interpretation moral agents do not “merely evaluate the moral worth of others in terms of our interests or inchoate feelings; we also understand the moral life and what we care about in terms of the experience of the recognition of others.”⁴⁶ It provides “moral depth and inwardness of life” through “critical assessment

⁴³ Ibid., 119.

⁴⁴ Ibid.

⁴⁵ Ibid., 176.

⁴⁶ Ibid., 176-177.

of the ground project(s) to which the meaning and value of life is bound.”⁴⁷ It is the practice that transforms the moral agent’s commitments out of respect for the moral agency of others. As an example of radical interpretation, Schweiker points to the Hebrew people’s repentance and remembrance of their covenant with God—those acts of repentance and remembrance were the basis of their very identity.⁴⁸

“We all live,” Schweiker states, “by faith. The hard question to answer is the faith by which we ought to live.”⁴⁹ One must remember that his project is a work of Christian ethics. For Schweiker, it is the conceptual framework of Christianity through which he interprets the moral life, value, power, responsibility, and integrity. He claims that “For Christian faith ‘God’ is the name for the radical interpretation of ultimate reality in which power is transformed in recognition of and care for finite existence. ‘Who’ God is...is interpreted with respect to specific values and norms: God is creator, sustainer, and redeemer.”⁵⁰ From this perspective, power is no longer self-interested power: it is the ability to promote life and care for that for which God is creator, sustainer, and redeemer. God is the root of all value, and for Christians this God is a God that promotes life and places great value on *being*. Responsibility affirms that being is valuable and moral integrity comes about when one lives a life of reverence for being and not merely one of self-interest. Schweiker concludes:

⁴⁷ Ibid., 176.

⁴⁸ Ibid., 177.

⁴⁹ Ibid., 120.

⁵⁰ Ibid. 179.

“The paradox of morality from a Christian point of view is, again, that we cannot directly aim at the final good of human life for ourselves. Genuine moral integrity is an indirect consequence of first seeking to respect and enhance the integrity of all life before God. It is in this sense that persons must lose themselves in order to find themselves. The true integrity of existence is only received when a person’s or community’s life has a purpose other than its own quest for authentic fulfillment.”⁵¹

At first glance this understanding of integrity may seem to run counter to my assertion that integrity is a matter of self-understanding. However, what Schweiker notes here—and what Butler previously asserted—is that the “self” or the “subject” that strives for self-understanding is never fully one’s own. Schweiker uses the language of losing oneself in order to find oneself. Butler speaks of the inherent relationality that undergirds moral existence—the address of the other that calls me into being. Both Schweiker and Butler recognize that self-understanding is crucial to the moral life, but it is not the *telos* of that endeavor. In fact, both suggest that the more someone comes to understand about herself, the more she realizes that she is not fully her own being; she does not have full control over her life. And yet for Schweiker, like Butler, this point does not negate the call of responsibility—it amplifies responsibility. In some sense, integrity may be a heuristic device for the moral life. Moral agents constantly strive to achieve a life of integrity, but as someone reaches closer to that goal, she comes to see the boundedness and giftedness of her own existence. A fully integrated existence may be unattainable, but through the process of striving for integrity the moral agent begins to acknowledge the significant un-accountability and unknowability that rests at the heart of her very being.

⁵¹ Ibid., p. 225.

Summary: Responsibility as a Matter of Status and Integrity

By analyzing the works of Judith Butler, John Silber, and William Schweiker relating to matters of responsibility, I have laid out a vision of responsibility that provides a necessary alternative to the dominant understanding rooted in notions of autonomy, voluntariness, and decision-making contexts. While that dominant view is helpful for thinking about certain moral challenges—particularly when those challenges take the form of a quandary—the voices of the moral agents described earlier in this chapter and in chapter two suggest that moral challenges do not always take the form of agony over making hard choices. Rather, sometimes the moral agent’s struggles are interpreted as a matter of integrity or self-understanding: Who am I and how can I live out my values in these otherwise bleak circumstances. Or, to paraphrase the minister quoted earlier, “How do I prepare myself?” Sometimes, the moral agent’s distress is not related to decision-making—perhaps the choice is all too clear or there are no choices to make—but with wrestling with issues of identity in the midst of tragedy.

If responsibility is to remain a viable concept for moral discourse in these instances—and its frequent use by professional organizations and focus group participants attests to its importance—then it must be able to address these matters of self-understanding and integrity. Hence, I advocate a vision of responsibility that emphasizes two salient features that are too often ignored by dominant understandings of that concept: 1) Responsibility entails the acceptance of obligations borne from one’s status, regardless of one’s acceptance of the status itself—whether one is a medical professional, a potential carrier of a genetic anomaly, a parent, or a member of a religious community; and 2) While responsibility promotes the movement toward greater integrity

in one's life, that movement paradoxically involves recognizing and incorporating uncertainty and loss of control into that life.

In the vein of Foucault, Derrida, and Levinas, Judith Butler's critique of the modern subject emphasizes the mutual dependency at the heart of subjectivity. She asserts that the subject is first called into being by the address of the other. The subject must first *be subject* of the other's call. She cannot control that address, nor can she give a full account of its origin. She does not enter into subjectivity voluntarily. Further, because the subject must rely on linguistic and social artifacts that she did not create in order to give an account of herself to the other, her account can never be exhaustive. Thus, the subject is always, to various degrees, opaque and perhaps ultimately unknowable to herself. Exhaustive self-knowledge and complete self-control are unattainable. Though the free, voluntary, autonomous subject is an illusion, Butler nonetheless maintains that responsibility is both possible and necessary for the moral life, not only in spite of the subject's limitations but *because* of the subject's boundedness.

Along similar lines, John Silber's argument on behalf of status responsibility supports the claim that an agent may be responsible for matters she does not necessarily choose. In this case, he notes that certain obligations may be borne from one's status. Responsibility, Silber argues, rests along a continuum in which actions are judged according to the degree of agential voluntariness present in those actions. Even those actions that are not chosen carry some limited degree of responsibility because it is impossible to fully separate the moral agent and her actions. Some range of responsibilities often exist independent of the agent's voluntary, autonomous choice; these responsibilities can develop as a result of who a person is rather than from what she

does. For example, while someone may choose to be a parent, she does not choose her uniquely different children, nor does she choose the different responsibilities that arise out of being a parent to those specific children with their own unique traits. Or, while someone may choose to be a physician, she does not choose the challenges that she and her patients will face. By virtue of being a parent or physician, however, the agent acquires certain responsibilities that she does not necessarily choose. Silber's status responsibility provides a theoretical foundation for making this claim.

Finally, William Schweiker's imperative of responsibility provides an articulation of the importance of integrity for thinking about responsibility and moral agency. He convincingly argues that thinking about responsibility in terms of integrity is especially important in our contemporary context in which value and power are often conflated. He asserts that the concern of the moral life is faith, that is, which identity-conferring commitments should guide our lives. Integrity becomes crucial because of the tragic and inevitable conflict of goods that accompany human existence. Without integrity to help us acknowledge and order those goods, power and value are conflated and human beings become nothing more than self-interested creatures. The imperative of responsibility, grounded in the notion that God is the source of value and responsibility, then calls us to respect and enhance the integrity of life in ourselves and in others. The nuances of Schweiker's argument are of little consequence to my own, though his insistence on the centrality of integrity for responsibility provides a way for thinking about responsibility in terms beyond those of isolated choice. Responsibility is more than making a "right" or "responsible" decision; it is the product of constant striving for self-understanding and

living in accordance with one's values and commitments, especially when one recognizes the limits of one's own self-understanding and self-control.

The following chapter further explicates the vision of responsibility that I advocate. I do so by returning to the challenges of genetics and genetic biotechnologies of predictive genetic testing and preimplantation genetic diagnosis (PGD). I do not offer normative guidelines about how someone ought or ought not deploy these technologies; I make no claims about what the responsible use of these tools might be. Rather, I intend to show how this new understanding of responsibility can be beneficial for patients/clients and clinicians as they reconsider the challenges they confront in dealing with these tools in the clinic. Thinking about responsibility as a matter of status and integrity enables us to think of those challenges in a different light. It calls attention to helpful ways of thinking about what responsibility entails in difficult circumstances. Further, I show how the genetics science supports the assertion that responsibilities sometimes arise out of one's status and show why responsibility requires accepting limitations to self-knowledge and self-control. I conclude the dissertation by outlining the implications of this work for the practice of medicine in general, particularly with reference to the popular notion of "evidence-based medicine."

CHAPTER V

PREDICTIVE GENETIC TESTING AND PGD IN LIGHT OF RESPONSIBILITY

This project began with an analysis of the role of genetic information in the contemporary clinic, with particular emphasis on new biotechnologies like predictive genetic testing and preimplantation genetic diagnosis (PGD). To contextualize discussions on those issues, I examined three themes that permeate public discourse on genetics: genetics as novel, genetic exceptionalism, and genetic determinism. Given what researchers have discovered about the relationship between genes, behavior, and environmental factors, I argued that those notions are often misguided. This misunderstanding about what genetic knowledge can provide leads to equally misleading promises about genetic technologies enabling people to “take charge” of their health. I also examined predictive genetic testing and PGD in detail, identifying prominent ethical challenges that these new technologies pose to patients/clients, clinicians, and counselors. In this final chapter, I conclude by returning to those challenges equipped with a vision of responsibility rooted in notions of status and integrity. I aim to show how this understanding of responsibility offers helpful ways to consider genetics-related issues in a manner that addresses the underlying moral anxieties these issues evoke. Those anxieties, I maintain, go well beyond matters of autonomous, voluntary decision-making.

I do not intend to establish strict normative guidelines for what constitutes “responsible use” of predictive genetic testing and PGD, nor do I seek to draw a normative line between acceptable and unacceptable uses of these technologies. Instead,

I want to demonstrate how thinking about responsibility in this way changes the terms of the debate, so to speak. Considering responsibility as a matter of status and integrity clarifies many of the ethical challenges that arise from genetic technologies and their increasing presence in the clinic. It equips us with tools to understand those challenges as matters of discerning who we are as moral agents and who we strive to be. Through this understanding of responsibility, I also demonstrate the importance of attitudes of humility and openness to unique states of being, noting how these attitudes are reflective of responsible moral agency in this context. Additionally, considering responsibility as a matter of status and integrity enables agents to reflect on responsibilities that they do not necessarily choose but for which they will nonetheless be held accountability. These responsibilities arise out of an agent's embodied, socially located, and role-informed status.

Further, I argue that technologies like predictive genetic testing and PGD reinforce many of the insights I have put forth about responsibility in the face of uncertainty and un-control in difficult circumstances. The information these technologies provide—and the inherent limitations of what they can offer—attest to the inexhaustible character of selfhood. In other words, the limited information and limited ability to control a progeny's future offered by these technologies is indicative of our inability to attain full self-knowledge and full self-control. Yet, predictive genetic testing and PGD may be still be helpful for individuals who want more information about their possible future health outcomes or the future health status of their offspring, provided those individuals are aware of the inherent limitations of these technologies.

Because many of these ideas are broad departures from how ethics is typically construed (particularly in bioethics discourse), I conclude this dissertation by briefly turning to bioethics and medical practice, drawing out possible implications for these fields that this vision of responsibility brings to light. Thinking about responsibility as a matter of status and integrity provides a beneficial way to consider the tasks of bioethics and the ways in which medicine is currently practiced, particularly with the emphasis on evidence-based medicine.

Responsibility and Genetics: Predictive Genetic Testing

The challenges of predictive genetic testing that I outlined in chapter one may be broadly classified under three headings: challenges of uncertainty, challenges of information, and challenges of interpretation. I see these three sets of challenges as related and I contend that the vision of responsibility that I advocate provides a beneficial lens through which those challenges may be examined. The first set of challenges—challenges of uncertainty—stem from the nature of the information that predictive genetic testing provides. These tests, as I noted earlier, are different than most other medical tests, such as any number of blood assays or a CAT scan of a patient's head; most medical testing that a clinician provides reveals something about the patient's *present* condition (the presence of absence of a specific pathogen, for example). While predictive genetic testing draws on a person's current genetic constitution, they use that information to provide forecasts about a person's *future* well-being. Further, the vast majority of conditions for which predictive genetic testing is commercially available, are subject to a variety of contingent factors: environmental, behavioral, dietary, and more.

Certainly there are conditions like Huntington disease, in which the presence of certain genetic markers guarantees that an individual will eventually develop that condition; these conditions tend to be the exception rather the rule. Thus, predictive genetic testing typically treads in probability rather than certainty. These tests offer a person risk percentages, along with the caveat that genetic constitution is only one factor (albeit an important factor) in shaping a person's future health. Additionally, predictive genetic tests do not indicate with any degree of certainty *when* a person might develop the condition for which she has been tested. Because of these limitations, I call the challenges that they pose to patients/clients and clinicians "challenges of uncertainty."

The second set of ethical challenges I identified may be classified as challenges of information. Specifically, these challenges arise when discerning how the information derived from predictive genetic tests will be shared. As noted earlier, 2008's Genetic Information Nondiscrimination Act (GINA) is a direct political response to concerns that employers and insurance companies might gain access to the results of a person's genetic testing results. Concerns have also been raised because the results of one person's genetic testing may indicate something about the health status of members of his or her family.¹ While I argued that genetic information is not often exceptional in this regard—blood tests may also reveal information relevant to a family member's health—I also noted that there are instances in which the information revealed by predictive genetic testing is directly relevant to the health of a person's family members, as the case of Katherine Moser highlighted in chapter one. Should the results of predictive genetic

¹ James P. Evans, Cécile Skrzynia, and Wylie Burke, "The Complexities of Predictive Genetic Testing," *BMJ* 322, no. 7293 (2001), 1052-1056.

testing be shared? With whom? In what instances? How should someone deal with information that may be relevant to one's family members?

The final set of ethical challenges that I noted earlier may be understood as challenges of interpretation. These challenges are closely related to the challenges of uncertainty and information because how someone deals with those challenges will be heavily influenced by how she understands predictive genetic testing and its results. The crux of the challenges of interpretation may be understood as this: How do individuals understand the information provided by predictive genetic testing? Given the pervasive public perception that what is "written in the genes" is determinative of one's well-being, how does someone interpret a test that typically provides that person with probabilities and risk percentages? This concern is especially important given the increased availability of direct-to-consumer predictive genetic tests, which give the patient/client the opportunity to bypass the genetic counselor altogether.

These challenges of interpretation, I suspect, are rooted in the very way in which the supporting data for these tests are created. Predictive genetic tests, while purportedly offering patients/clients the information necessary to "take charge of your health" and to "make the promise of personalized medicine a reality," actually provide very little "personal" information for the patient/client who uses them.² Instead, they offer statistics about populations who possess the genetic marker in question. For example, a study of 120 Ashkenazi Jewish women who possessed the BRCA1 or BRCA2 gene mutation

² These statements can be found on the websites of two commercial genetic testing companies, 23andMe and Navigenics, respectively. See 23andMe, "Genetic Testing for Health, Disease & Ancestry; DNA Test - 23andme" <<https://www.23andme.com/>> (accessed February 5, 2010); Navigenics, "Navigenics - About Us" <http://www.navigenics.com/visitor/about_us/> (accessed February 5, 2010).

indicated that those women carry a 56% chance of developing breast cancer and a 16% chance of developing ovarian cancer by the age of 70.³ What such studies indicate is that genetics is an epidemiological, population-based science; as long as one is dealing in the realm of probability rather than certainty, no predictive genetic testing can tell a person if she will be part of the 78.5% who develop the condition in question or part of the 21.5% who have the mutation in question but for whom the condition never manifests. Nor can these tests indicate how a person faced with such results *understands* her own situation. Does she see herself as part of the 56% or the 44%? Surely moral distress can result from less-than-definitive testing results like these.

As noted below, it is not clear that providing patients with information in the form of statistics, percentages, and probabilities is the best way to provide them with health information. One study indicates that depicting risk in the language of “gambling odds” (1 chance in X) leads to more accurate understanding of risk for women at high risk of developing breast cancer.⁴ Others have argued that using absolute numbers, numbers for positive and negative outcomes, common denominators, and visual aids help patients better understand risks.⁵ Another study suggests that genetic counseling contributes to

³ Jeffery P. Struewing, Patricia Hartge, Sholom Wacholder, Sonya M. Baker, Martha Berlin, Mary McAdams, Michelle M. Timmerman, Lawrence C. Brody, and Margaret A. Tucker. "The Risk of Cancer Associated with Specific Mutations of Brca1 and Brca2 among Ashkenazi Jews." *New England Journal of Medicine* 336, no. 20 (1997), 1401-1408.

⁴ Penelope Hopwood and others, "Do Women Understand the Odds? Risk Perceptions and Recall of Risk Information in Women with a Family History of Breast Cancer," *Community Genetics* 6, no. 4 (2003), 214-223.

⁵ John Paling, "Strategies to Help Patients Understand Risks," *BMJ* 327, no. 7417 (2003), 745-748.

patients' risk perception accuracy,⁶ though I would argue that being able to recall specific statistics indicates little about the patient's actual *understanding* of what those numbers mean for her own health. In other words, it is not clear that the language of probability and statistics is best for communicating risk information to patients, nor is it evident that a patient's ability to recall such statistics is indicative of her understanding of what those numbers mean for her personal health. Yet, these statistics are the most sound data clinicians have at their disposal, so clarifying patient understanding about those statistics becomes all the more crucial.

So how can thinking about responsibility help those who are faced with these challenges? First and foremost, the vision of responsibility that I developed earlier promotes an attitude of humility. Through the lens of responsibility, we see that predictive genetic testing is an attempt to gain greater knowledge, certainty, and control over one's life. If I can know what will happen to me, so this line of thinking goes, I can prepare myself for the specific future that awaits me. As the challenges of uncertainty and interpretation indicate, however, the claims that predictive genetic testing will enable someone to "take charge" of their health are often overstated. The degree of certainty offered by these tests is much less significant than patients/clients may be led to believe, particularly if they listen to the claims about genetics that permeate popular discourse.

Thus, one significant step toward using predictive genetic tests in a responsible fashion would be to do so with recognition of the limits of those tests. The information they provide, while oftentimes very valuable, is rarely determinative of one's future well-

⁶ Chris Smerecnik and others, "A Systematic Review of the Impact of Genetic Counseling on Risk Perception Accuracy," *Journal of Genetic Counseling* 18, no. 3 (2009), 217-228.

being, health-related or otherwise. If individuals are to use predictive genetic testing, they should do so with a humble acknowledgement of the limits of such attempts to better understand their health status. To take matters a step further, an agent might be well served to follow Foucault and Butler in recognizing the impossibility of complete self-knowledge and self-control. After all, one's life is never fully one's own, nor are humans wholly self-creating beings. Again, this is not to say that predictive genetic testing is a futile activity; some people may very well find those tests to provide valuable information. However, it is imperative that we do not mistake test results for fate.

We should also remember that there is inherent variability in the information provided by predictive genetic tests; similar test results can lead to different outcomes for different people. That variability should be kept in mind when someone is faced with information that can potentially be relevant to someone else's health. Given that variability, it may not be prudent to share such information with others in one's family unless it can be demonstrated that one person's test is directly indicative of another person's future health outcomes. Even in those cases, we should respect the (always limited) self-determining capacity of others by speaking with those individuals prior to testing to determine if they want to know any relevant results. Here, the importance of genetic counselors cannot be overstated. If a person is open to having such conversations with her family prior to testing, a genetics counselor can be of assistance. If she wants to keep her testing a private matter, a counselor can provide strategies for handling that information in a private fashion. Unfortunately, direct-to-consumer predictive genetic testing does not come with readily available genetics counseling services. Individuals must seek out those services. However, out of respect for the selfhood of oneself and

others, responsibility calls one to seek the help of qualified professionals in cases where information may be relevant to one's family. Though our self-legislating and self-determining capacities are limited, they are nonetheless to be respected.

Finally, an understanding of responsibility that acknowledges the centrality of integrity demands that a person considering predictive genetic testing ask herself certain questions prior to testing: What do I hope to learn about myself through this activity? How do I foresee these test results shaping my understanding about who I am? Is the pursuit of this knowledge about myself commensurate with the commitments I hold as fundamental to that self-understanding? Can I draw on those commitments for support if I am faced with moral distress because of these tests? *How* can I draw on those commitments? How might these test results challenge the commitments that I have made? If a person is committed to the position that God is able to intervene in the affairs of the world, for example, how might difficult test results impact her view of God? These questions of integrity are deeply important, and based on the vision of responsibility that I have endorsed, any responsible use of predictive genetic testing must address these questions, or at least acknowledge their relevance in the context of using predictive testing.

Responsibility and Genetics: Preimplantation Genetic Diagnosis (PGD)

As noted in the first chapter, preimplantation genetic diagnosis (PGD) is frequently portrayed as a quintessential example of biotechnology run amok. PGD brings to light serious and fundamental questions about the nature of humanity and our relationship to technology. It is the latest in a line of biotechnologies that elicits charges

of “playing God” and overextending human intentionality into a realm where it should not be. In this line of thought, genetic technologies’ casual encroachment have led to children being valued as the products of a market-driven, capitalist endeavor in which potential parents become consumers and physicians/clinicians offer their services to the consumer in exchange for appropriate compensation. For example, in his discussions of “genetic engineering” and the specter of human cloning, Leon Kass appeals to the “wisdom of repugnance” as that “emotional expression of deep wisdom, beyond reason’s power to fully articulate” the dis-ease that accompanies these technologies and the new capacities that they provide.⁷ Despite the increased level of intentionality at work in PGD, Kass argues that such technologies are ultimately *dehumanizing* because they remove sex, love, and intimacy from procreation.⁸

PGD also has profound implications for our understanding of what constitutes “desirable” or “undesirable” states of existence. We must keep in mind that genetics are only one factor—albeit an important factor—that contributes to the development of many so-called disabilities.⁹ Some disabled persons view interventions like PGD as worthy endeavors that will reduce the incidence of passing on particular disabled states to subsequent generations; others are much more ambivalent or downright opposed to using PGD to “eliminate” certain modes of being that may be classified as disabilities.¹⁰ There

⁷ Leon R. Kass, “The Wisdom of Repugnance. (Cover Story),” *New Republic* 216, no. 22 (1997), 17-26; quote on 20.

⁸ *Ibid.*

⁹ See chapter 4, footnote 31 for my statement on the usage of the label of “disability.”

¹⁰ Jackie Leach Scully, “Disability and Genetics in the Era of Genomic Medicine,” *Nature Reviews Genetics* 9, no. 10 (2008), 797-802; Jackie Leach Scully, Christine

are even documented instances of people seeking out PGD in order to select *for* disabled states.¹¹ While most people who can hear would prefer hearing to deafness, we can also understand how a deaf couple would perceive that “a deaf baby would be a special blessing,” even if we may disagree with their reasons for doing so.¹² Parents want to be able to communicate with their children and hope that those children “fit” in a community of people with shared experiences and aspirations. We can sympathize with the parents who want their children to be deaf like them, and those of us who can hear and speak frequently take those communicative traits for granted. Family members typically bond through spoken language, as evidenced by American households in which English is *not* the primary language; communication creates *community*. American Sign Language (ASL) is another example of language’s power to shape community and give people a sense of belonging. Is it any wonder that parents would use an available medical technology to make that community formation possible within their own homes? This is especially true when traits like deafness are understood as being fundamental to a person’s identity.

The move to select *for* a “disability” can also be seen as an attempt to de-stigmatize a condition like deafness, hopefully rendering deafness a more socially

Rippberger, and Christoph Rehmann-Sutter, "Non-Professionals' Evaluations of Gene Therapy Ethics," *Social Science & Medicine* 58, no. 7 (2004), 1415-1425.

¹¹ Darshak Sanghavi, “Wanting Babies Like Themselves, Some Parents Choose Genetic Defects,” *New York Times*, December 5, 2006; Susannah Baruch, David Kaufman, and Kathy L. Hudson, "Genetic Testing of Embryos: Practices and Perspectives of Us in Vitro Fertilization Clinics," *Fertility and Sterility* 89, no. 5 (2008), 1053-1058.

¹² Lisa Mundy, “A World of Their Own; In the eyes of his parents, if Gauvin Hughes McCullough turns out to be deaf, that will be just fine,” *Washington Post Magazine*, March 31, 2002, W22.

acceptable mode of being. On the other hand, there may also be considerable pressure to use PGD in order to eliminate such disabilities or to deploy PGD to promote other more “desirable” traits like height or intelligence. Further, it must be remembered that, at present, PGD is an expensive technology that is not covered under health insurance plans. It is thus open only to those who can afford its hefty price tag. To consider the social implications of PGD in light of responsibility, we must reflect on the values and commitments that a given society professes; it is only in light of those values that we can begin to think about social integrity. We should ask: Is offering unregulated PGD to those who can afford it reflective of what we as a society envision ourselves to be? On a national level, if our identity as Americans is defined by unregulated choice to consume what we choose, then perhaps leaving PGD to be regulated by the “free market” is appropriate. If, however, we are committed to notions of equality of opportunity, the inherent worth of unique individuals, and the participation of those individuals in democratic structures, then perhaps stronger regulatory frameworks are in order so that certain so-called “disabled” modes of being are not further stigmatized as a result of PGD’s availability.

As noted at the outset of this chapter, I do not aim to provide strict normative guidelines for what ought to be considered “responsible” uses of PGD, though such guidance is valuable in the realm of public policy. Because I advocate a view of responsibility grounded in notions of status and integrity, I am committed to the position that what is “responsible” cannot be predetermined—specific, unique contexts and individuals shape what responsibility entails in a given circumstance. If we are to insist on the language of line-drawing for public policy discourse on this topic, I maintain that

we must first and foremost listen to the voices of those people who are most directly affected by PGD's use: clinicians, potential parents considering PGD, and individuals and communities whose identities are partially constituted by the conditions for which PGD might be used. These are the people whose states of being will inform what responsibility or responsible uses of this technology will entail; they are the ones whose movements toward integrity are shaped by those conditions. Thus, their voices should guide—or at the very least inform—any responsible public policy discussions.

Finally, it is important to consider what the use of PGD reveals about who we are and who we see ourselves as being. Michael Sandel forcefully argues that enhancement technologies like PGD and “genetic engineering” are an affront to the *giftedness* of our lives. “To acknowledge the giftedness of life,” he asserts, “is to recognize that our talents and powers are not wholly our own doing, nor even fully ours, despite the efforts we expend to develop and to exercise them. It is also to recognize that not everything in the world is open to any use we may desire or devise.”¹³ Sandel notes that the giftedness of human life is highlighted in the realm of parenthood: “To appreciate children as gifts is to accept them as they come, not as objects of our design, or products of our will, or instruments of our ambition.”¹⁴ Parents celebrate the unique talents that their children cultivate. They are continually surprised by the gifts those children have—gifts that a parent could never anticipate. People may oftentimes *choose* to be parents, but they cannot choose the unique gifts and talents of their children (even with the use of PGD).

¹³ Michael J. Sandel, *The Case against Perfection: Ethics in the Age of Genetic Engineering* (Cambridge, MA: Belknap Press of Harvard University Press, 2007).

¹⁴ *Ibid.*, 45.

Using the language of giftedness in relation to PGD is not without its critics. John Robertson forcefully argues that PGD (and other reproductive technologies) can be valid means for exercising a person's procreative liberty.¹⁵ Broadly, procreative liberty is "a liberty or claim-right to decide whether or not to reproduce" comprised of the positive right to reproduce and the negative right to avoid reproduction if one chooses.¹⁶ Thus for Robertson, PGD and other reproductive technologies are to be legally protected (and largely unregulated) provided that they "aid in the task of successful reproduction."¹⁷ Further, utilizing PGD to ensure "healthy offspring to nurture and rear" is "usually ethically acceptable" and should be legally protected because its "use fits neatly into traditional understandings of why reproduction is valued."¹⁸ In this line of thought, PGD should be widely available when it serves as a necessary tool for the exercise of a person's procreative liberty.

Robertson finds the value of reproduction to be in the creation healthy offspring for those people who find reproduction to be a deeply meaningful, identity-shaping experience that contributes to their sense of human flourishing.¹⁹ PGD contributes to the realization of that value when it provides the necessary means for a person to procreate.

¹⁵ John A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton, NJ: Princeton University Press, 1994); "Procreative Liberty in the Era of Genomics," *American Journal of Law & Medicine* 29, no. 4 (2003), 439-487; "Procreative Liberty and Harm to Offspring in Assisted Reproduction," *American Journal of Law & Medicine* 30, no. 1 (2004), 7-40.

¹⁶ Robertson, "Procreative Liberty in the Era of Genomics," 447.

¹⁷ *Ibid.*, 446.

¹⁸ *Ibid.*, 484.

¹⁹ See also *Ibid.*, 450-452.

In many cases, PGD is used when there are strong medical indications of its necessity (i.e., when the life of the mother or fetus is likely at risk in a potential pregnancy). These uses of PGD are generally acceptable, but Robertson's notion of "necessary" goes well beyond medical necessity. Citing examples of potential parents who might use PGD to screen for "perfect pitch" or against homosexual offspring, Robertson argues that such uses of PGD are permissible if those potential parents would otherwise not reproduce. He notes that the legal system already allows for such "private prejudices" and that parents are free to train their children in music and to teach them that homosexuality should be avoided. To refuse PGD for those individuals who would use it for reasons that we might see as an affront to the giftedness of life would be to infringe upon their procreative liberties.

Admittedly, from a public policy perspective, Robertson's vision of procreative liberty has its appeal, though he fails to adequately address some of its more serious social defects and the ethical implications of largely unregulated use of PGD. On the positive side, by allowing PGD to remain largely unregulated, assessments of the moral nature of this technology are left in the hands of individual moral agents. It would allow, for example, a deaf family to pursue PGD in order to have deaf offspring with whom they could communicate. Robertson also acknowledges some of the larger social implications of PGD's widespread use, though remedies for these defects are lacking in his analysis. In one of Robertson's example cases, he casts aside questions about the amplification of social stigma associated with homosexuality, instead noting that "permitting parents to use genetic technology to avoid having a child with a homosexual orientation is distinct from the separate question of whether homosexual individuals or couples have the right

to reproduce.’²⁰ Here, he altogether neglects the large-scale social implications and the ethical dimensions of such selection, focusing exclusively on PGD’s legality.

Further, by framing discussions of PGD in the language of rights, an additional challenge arises for Robertson. If PGD is indeed a necessary tool for the exercise of a person’s procreative liberty, then it must be available to those individuals who require it in order to exercise those rights. At present, PGD is a boutique technology, available only to those who can afford it. As a result, only those who are already advantaged enough to pay out-of-pocket are currently able to enjoy the additional advantages that PGD supposedly provides. Robertson recognizes this practical problem but fails to show how it can be rectified.

Related to the issue of conceptual frameworks, Robertson’s vision of procreative liberty construes procreation almost exclusively in the language of freedom, control, and choice. Further, it is the freedom and choice of *parents* that are to be considered. Freedom and choice are undoubtedly values to be upheld in the realm of public policy, but when it comes specific individuals and families who consider using PGD, their understandings of procreation will certainly be laden with other ethical values: love, mutuality, responsibility, respect for life, and hope (to name a few). In neglecting the presence and importance of those other values, Robertson’s vision of procreation further commodifies that process and renders future children as products of their parents’ consumerist choices. In his attempt to address this concern, Robertson simply suggests that there is no good reason for thinking that such commodification is a likely outcome of PGD’s widespread use. Again, while his minimalist approach may be beneficial for

²⁰ Ibid., 468.

constructing public policy, it offers little guidance for persons struggling with whether or not to use PGD in their own circumstances. As a result, Robertson's work has little to say to those parents who are worried about how their future children will respond to being the product of PGD, nor to how those individuals may be welcomed or shunned by society at large.

Finally, Robertson directly critiques the language of giftedness because he understands such appeals to have “roots in a religiously based or metaphysical view of how reproduction should occur and a breadth that would apparently condemn nearly all forms of technological assistance in reproduction.”²¹ Yet, his appeal to “traditional understandings” of reproduction as the basis for PGD's nearly limitless usage seemingly renders the permissibility of PGD to the court of public opinion. Further, the “traditional” view that reproduction can be meaningful and identity-conferring can be articulated theologically, just as ideas about the giftedness of life can be stated without explicit theological references. In his critique, he also fails to appreciate that thinking of children, or life itself, as a form of *gift* is indeed a widely held view and also rooted in “traditional understandings” of procreation and parenthood.

To a significant degree, Sandel's analysis resonates with my own because the use of PGD and other enhancement technologies—particularly in the largely unregulated manner endorsed by Robertson—is expressive of an attitude reminiscent of modern views of the autonomous, masterful moral agent. It “expresses and entrenches a certain stance toward the world—the stance of mastery and dominion that fails to appreciate the gifted character of human powers and achievements, and misses the part of freedom that

²¹ Ibid., 444.

consists in a persisting negotiation with the given.”²² For Sandel, losing that sense of giftedness by exerting dominion through enhancement technologies would also erode our ideas of humility, responsibility, and solidarity. We would lose the humility that accompanies the recognition that we are not fully our own creations. Responsibility, in Sandel’s view, would “explode” as choice replaces chance at nearly every turn. Solidarity erodes as we lose our sense of shared fatedness and as those who can afford PGD become increasingly separated from those who cannot. As noted above, Robertson offers little guidance for addressing these issues through the lens of procreative liberty.

Sandel’s view of responsibility is largely in line with the dominant view that holds choice as a necessary component of that concept. I agree with his point that substituting choice for chance will expand the type of responsibility of which we typically speak, but I would argue that PGD’s prevalence would also expand the type of responsibility that I have presented in this dissertation. Consider the children who are created through the use of PGD. Those children may be burdened by additional responsibility precisely *because* their parents sought control over some aspect of their future states of being. Also, consider a child born to serve as a “savior sibling” for her ill brother or sister. Or, consider a child whose parents used PGD to seemingly ensure a physically gifted son or daughter. Though not subject to the “blind fate” that ushered many of us into existence, those children are like us inasmuch as they also did not choose the specific elements of their own states of being. What responsibilities hold for those children as a result of their “chosen” status? Have they been burdened with additional responsibilities as a result of the choices of their parents? These are pertinent questions

²² Sandel, 83.

that we must ask. Sandel's understanding of giftedness provides a way for considering those questions, but Robertson's vision of procreative liberty is of little help for working through these issues.

It is important to remember that even if potential parents find a clinician willing to use PGD to intentionally select for traits like height, perfect pitch, or physical performance, that intentional selection does not necessarily guarantee tall, musically inclined, physically gifted offspring. Despite any attempts to inject control and intentionality into the procreative process, an irreducible level of uncertainty and uncontrol always remain. Quite simply, we cannot control our futures—or the futures of our children—despite our best attempts. If clinicians and potential parents continue to use PGD, and I believe there are instances in which PGD may be warranted, they should do so with a recognition that those efforts to be fully self-creating, masterful agents will inevitably be thwarted. Likewise, a person can use PGD to protect future offspring from truly devastating conditions (β -thalassemia, for example), but no one can totally protect her children from danger and tragedy altogether. A parent may be able to ensure that a child is born with the trait of “perfect pitch” but this by no means ensures that her child will take an interest in music. There is inherent risk and uncertainty, not just in parenthood, but in the very heart of human existence. This inherent risk and uncertainty must be acknowledged before we delude ourselves into thinking we are willful masters of human being. To act with blindness toward that uncertainty would be irresponsible.

Implications of Status and Integrity-Informed Responsibility for Medical Practice

“A new paradigm for medical practice is emerging,” the Evidence-Based Medicine Working Group announced in a 1992 issue of the *Journal of the American Medical Association*.²³ Indeed, “evidence-based medicine” (EBM) has become quite a buzzword and has shaped medical education and practice in the past two decades. EBM represents an epistemological shift for medical practice, a movement from the “former paradigm” that relied on “unsystematic observations and clinical experience...the study and understanding of basic mechanisms of disease and pathophysiological principles...a combination of thorough medical training and common sense...[and] content expertise and clinical experience.”²⁴ The “new paradigm” of EBM makes medical claims based on “systematic attempts to record observations in a reproducible and unbiased fashion” and “certain rules of evidence” that are necessary “to correctly interpret literature on causation, prognosis, diagnostic tests, and treatment strategy.”²⁵ EBM values data derived from clinical epidemiology, research, and trials. Under this regime, the clinical experience and judgment of the expert physician still carry authority, that authority is subordinate to clear and relevant research data. I called EBM an epistemological shift for

²³ Evidence-Based Medicine Working Group and others, "Evidence-Based Medicine: A New Approach to Teaching the Practice of Medicine," *JAMA* 268, no. 17 (1992), 2420-2425; quote on 2420.

²⁴ *Ibid.*, 2421.

²⁵ *Ibid.*

medical practice because, as Tonelli notes, EBM is concerned with the “defining optimal ways to develop knowledge and describing hierarchies of medical evidence.”²⁶

Tonelli also highlights the practical dimension of EBM in which this new hierarchy of knowledge is integrated into the clinical setting.²⁷ According to the EBM Working Group, EBM involves a specific set of skills, including “precisely defining a patient problem, and what information is required to resolve the problem; conducting an efficient search of the literature; selecting the best of the relevant studies and applying rules of evidence to determine their validity...and extracting the clinical message and applying it to the patient problem.”²⁸ One task of EBM advocates is to precisely determine how to integrate the medical knowledge endorsed by EBM in the clinical context. As Tonelli indicates, however, there always remains a significant gap between research and clinical practice.²⁹ The research upon which EBM relies is, by its very nature, population-based. Clinical practice, on the other hand, is concerned overwhelmingly with *individual* patients (or sometimes, families). While EBM can quantifiably account for many differences among individuals, those that cannot be quantified are minimized through the process of “randomization.”³⁰ Yet, when it comes to providing care to *individual* patients, the possibility remains that those randomized

²⁶ Mark R. Tonelli, "The Philosophical Limits of Evidence-Based Medicine," *Academic Medicine* 73, no. 12 (1998), 1234-1240; quote on 1235.

²⁷ Ibid.

²⁸ Evidence-Based Medicine Working Group, 2421.

²⁹ Tonelli, 1236.

³⁰ Alvan R. Feinstein, "*Clinical Judgment Revisited: The Distraction of Quantitative Models*," *Annals of Internal Medicine* 120, no. 9 (1994). Cited in Tonelli, 1236.

differences can influence how an individual could best be treated. In such cases, the importance of clinical judgment on the part of the clinician cannot be overstated.

There is a related issue here that is strikingly similar to a point that I raised regarding the information provided by predictive genetic testing. Because the evidence overwhelmingly favored within EBM is population-based, the information that a clinician provides to her patients is typically conveyed in terms of probabilities and percentages. The Evidence-Based Medicine Working Group provides a case study that highlights this very point, illustrating the differences between EBM's "way of the future" and the "way of the past." In this scenario, a 43-year-old man arrives at a teaching hospital after experiencing a grand mal seizure. A junior medical resident gives the man a physical exam and orders a computed tomographic head scan and electroencephalogram (EEG). The exam and head scan are normal and the EEG shows "nonspecific findings." The patient is concerned about experiencing another seizure, but the medical resident is unsure about how to respond to his concerns. Following the "way of the past," the resident consulted a senior resident (whose views were supported by the attending physician) who stated that the risk of recurring seizures was high. The resident urges the patient not to drive, to continue his medications, and to regularly visit his family physician. We are told that the patient leaves "in a state of vague trepidation about his risk of subsequent seizure."³¹

Following EBM's "way of the future," however, the resident first visits the library in order to conduct a literature search using the key terms *epilepsy*, *prognosis*, and *recurrence*. The search yields 25 relevant articles, with one article being particularly

³¹ Evidence-Based Medicine Working Group, 2420.

relevant to her case at hand. From her trip to the library, the resident learns that “the patient risk of recurrence at 1 year is between 43% and 51%, and that at 3 years the risk is between 51% and 60%. After a seizure-free period of 18 months his risk of recurrence would likely be less than 20%.”³² The resident returns to the patient, encourages him to continue his medications and to regularly visit his family physician. She also relays her findings from the literature search. The Working Group then concludes, “The patient leaves with a clear idea of his likely prognosis.”³³

In their illustration, the Working Group assumes that providing the patient with risk percentages gives him a “clear idea” of his prognosis. Yet, it is not evident that using probabilities and statistics to inform a patient of his or her prognosis is meaningful in any way. The difficulties herein are twofold. First, as Epstein et al note, “Quantitative estimates of probability of given outcomes can be difficult to establish prospectively.”³⁴ Beyond the difficulty of establishing the best quantitative risk assessments in a given situation, there is a further difficulty that can only be addressed by the patient herself. In their example, the Working Group assumes that providing the patient with risk percentages provides him with a “clear idea” of his prognosis. However, we must ask: Does the patient view himself as part of the 43-51% who *will* have another seizure within one year, or does he see himself as part of the 49-57% who will remain seizure-free in the next year? To a degree, this is a question of how patients understand probabilities and

³² Ibid.

³³ Ibid.

³⁴ Ronald M. Epstein, Brian S. Alper, and Timothy E. Quill, "Communicating Evidence for Participatory Decision Making," *JAMA* 291, no. 19 (2004), 2359-2366; quote on 2360.

percentages and what is the most appropriate way to communicate risks to those patients. Much work has been conducted on that issue, but with little consensus.³⁵ However, it is also a question of the patient's own attitudes. He may very well understand what a 43-51% risk generally means, but when it comes what those numbers mean *for him*, that is a question that can only be addressed on an individual basis.

It is almost always the case that when one deals with statistics, percentages, and probabilities, there is an inherent degree of uncertainty that lingers at every turn. Even if a physician tells her patient that he is 99.9% likely to develop a specific outcome, that 0.1% still remains, and depending on the values and attitude of the patient, that 0.1% could be seen as a reason for despair *or* hope. Clinicians routinely face instances in which patients must grapple with making sense of their health, their well-being, and their sense of *self* in light of circumstances that inherently contain relevant degrees of uncertainty. While I laud EBM's insistence that clinical work be guided by sound epidemiological data, I also want to make sure we pay attention to the limitations of the data on which it relies.

It is at the limits of that knowledge where the vision of responsibility I have proposed can be most helpful. This view of responsibility acknowledges that specific responsibilities may obtain by virtue of one's status—including one's status as a carrier

³⁵ Andrew J. Lloyd and others, "Patients' Ability to Recall Risk Associated with Treatment Options," *The Lancet* 353, no. 9153 (1999), 645; Ashish Mahajan, "Do Patients Understand Risk?," *The Lancet* 369, no. 9569 (2007), 1243; Marilyn M. Schapira, Ann B. Nattinger, and Colleen A. McHorney, "Frequency or Probability? A Qualitative Study of Risk Communication Formats Used in Health Care," *Medical Decision Making* 21, no. 6 (2001), 459-467; Steven Woloshin, Lisa M. Schwartz, and H. Gilbert Welsh, "The Effectiveness of a Primer to Help People Understand Risk," *Annals of Internal Medicine* 146, no. 4 (2007), 10.

of a certain gene, as a clinician, as a family member, or as a patient whose physician presents her with uncertain prognoses. It also recognizes the inherent unknowability and un-control that rests in the heart of selfhood while affirming that moral agents are nonetheless responsible in the face of such uncertainty. This account of responsibility does not prescribe “the responsible thing to do” to a moral agent who is called upon to act in a difficult context; her specific responsibilities are always shaped by the context in which she acts. Rather, it affirms that responsibility is not necessarily displaced when an agent lacks control over certain circumstances, nor does responsibility dissolve in the face of uncertainty. On these points, the vision of responsibility I endorse can help clinicians and patients reflect on how they are called to be responsible even when the future remains uncertain, and even when they can do little to change the future course of events. If nothing else, thinking about responsibility in this way can help clinicians and patients become more accepting of the inherent uncertainty that is always present in the clinic, particularly when many of its norms are rooted in EBM.

Implications of Status and Integrity-Informed Responsibility for Bioethics

To conclude this project, I want to highlight how the understanding of responsibility that I have endorsed provides a way to reconsider some fundamental assumptions of bioethics. Doing so, I maintain, provides necessary tools for engaging in bioethical analysis in a way that is meaningful to persons whose lives are actually touched by these very issues. Reflecting on the centrality of uncertainty, status, and integrity for responsibility draws our analysis to the concrete reality of those individuals who struggle to uphold responsibility in difficult circumstances. Unfortunately, this

“bottom-up” approach to bioethics analysis has not been fully appreciated in the field, which is understandable given the origins of “bioethics.”³⁶ Historically, the focus of bioethics scholars has long been on provocative life-or-death scenarios, issues like organ transplantation, abortion, the allocation of scarce medical resources, and experimentation with human subjects. This should come as little surprise given bioethics’ origins in response to events of the early-to-mid-20th century, such as the Nazi war crimes trials at Nuremburg and the development of life-prolonging technologies that make organ transplants possible.³⁷ As interest in bioethics has grown in the past decades, scholars from a variety of disciplines have entered these discussions, bringing with them the methods of their “home” disciplines.³⁸ Yet, despite the multitude of method and

³⁶ I use the term “bioethics” knowing that its meaning and the appropriateness of its use is not a settled matter. I prefer “bioethics” rather than “medical ethics” because the former demonstrates a recognition that many of the topics that are addressed in this field are not *solely* medical in nature. Discussions about the ethical implications of genetic engineering, for example, may raise questions about plant and animal biology that have little or no relation to questions about medical issues. Further, while graduate programs in bioethics are in their infant stages at this time, the defining features of a field called “bioethics” have not yet been fully articulated. It may be more appropriate to consider bioethics as an evolving set of ethical issues that scholars from a variety of other disciplines examine. For example, it may be more truthful to speak of a philosopher, a pediatrician, a sociologist, a nurse, or a religious studies scholar who deals with bioethics issues rather than to call someone a “bioethicist.” Still, I use the term “bioethics” to follow its common usage in scholarship and as a short-hand reference to the ethical challenges posed by scientific and medical research advances, as well as the challenges that arise when using scientific and medical technologies.

³⁷ For more on the history of the development of “bioethics” as a field, see Nancy Ann Silbergeld Jecker, Albert R. Jonsen, and Robert A. Pearlman, *Bioethics: An Introduction to the History, Methods, and Practice*, 2nd ed. (Sudbury, MA: Jones and Bartlett Publishers, 2007).

³⁸ Sugarman and Sulmasy’s *Methods in Medical Ethics* contains chapters written by leaders in their respective fields, detailing the relevance for their particular methodologies for work in medical ethics. The collection contains chapters on the following fields: philosophy, religion and theology, law, casuistry, history, economics, ethnography, as

perspective that coheres in this not-well-defined field of bioethics, bioethics is all too often portrayed as an endeavor of applied ethics: “Is abortion permissible? How should donated organs be distributed?”³⁹ When a new medical technology arises, such as predictive genetic testing or PGD, bioethics then becomes a process of articulating and applying the right principles to the matter, thereby supplying an answer for any questions that might arise. In other words, bioethics is typically case-oriented and overwhelmingly concerned with discrete moments of decision.

Admittedly, this dissertation follows this approach to a degree in its examination of predictive genetic testing and PGD and its advocacy of a particular understanding of responsibility. I agree that scholars of bioethics must be able to critically assess morally distressing situations that arise in relation to science, medicine, and health; these scholars must be able to make judgments and express those judgments when necessary. However, by endorsing a vision of responsibility that transcends issues of isolated decision-making related to “tough cases,” I intend to highlight a much more fundamental dimension of the many tasks of bioethics. Bioethics, I maintain, must not be solely in the business of providing tidy answers to difficult challenges. It must also critically probe those challenges in order to facilitate greater clarification on precisely what makes certain

well as qualitative and quantitative sociological methods. See Jeremy Sugarman and Daniel P. Sulmasy, *Methods in Medical Ethics* (Washington, D.C.: Georgetown University Press, 2001).

³⁹ In a recently published introductory bioethics textbook, Lewis Vaughn describes bioethics as “applied ethics focused on health care, medical science, and medical technology.” His definition is one of many examples of thinking about bioethics as a form of applied ethics, but I use Vaughn as an example because his work is so recent. See Lewis Vaughn, *Bioethics: Principles, Issues, and Cases* (Oxford: Oxford University Press, 2010), quote on 4.

issues so distressing. Bioethicists must recognize that moral distress does not *always* arise out of decision-making difficulty, but rather from the ways in which medicine and medical technologies interrogate our moral concepts and self-understanding. To do this work, however, requires a different orientation than the stereotypical principlist approach to bioethics, one that does not seek to apply already-given principles to a given situation. It also requires openness to the possibility that our very assumptions—including the assumption that ethical problems are always problems of choice—are not always correct in a given set of circumstances.

If responsibility is to remain a valuable concept for bioethics discussions, we must reconsider responsibility in light of those tasks I just mentioned. As noted in the previous chapter, the vision of responsibility that I have advocated is one that recognizes the ethical import of status, integrity, uncertainty, and the challenges confronting moral agents that do not always fit squarely within decision-making frameworks. It calls us away from abstract generalizations about what the generic moral agent should or should not do when confronted with a given set of challenges. To consider the place of status and integrity is to acknowledge that ethical analysis must begin with the lived experiences of *real* moral agents, living in specific historical and cultural contexts. As the previous chapter hinted, feminist scholars have been voicing these very concerns for decades; bioethics scholars, on the other hand, have seemingly been slow to heed their calls.⁴⁰ Similarly, phenomenological voices in bioethics are rare in contemporary

⁴⁰ For a substantive overview of the contributions of feminist scholarship to bioethics discourses, see Hilde Lindemann Nelson, "Feminist Bioethics: Where We've Been, Where We're Going," *Metaphilosophy* 31, no. 5 (2000), 492-508. Key texts that deal directly with feminist contributions to bioethics include: Anne Donchin, Laura Martha Purdy, and International Association of Bioethics, *Embodying Bioethics: Recent Feminist*

bioethics, though their contributions to the field have been significant.⁴¹ Following the work of feminist and phenomenological scholars, a vision of responsibility rooted in status and integrity demands that ethics work its way from the ground up rather than starting at the top with abstract principles and applying them to concrete situations. It recognizes that the challenges of bioethics are sometimes challenges associated with striving toward greater self-understanding or integrity in the face of insurmountable uncertainty. It also recognizes the anxiety that accompanies the approach to the limits of one's self-knowledge. It can be downright frightening to see that one is not in full control of herself. It can be a real struggle—or a blessing—to deal with responsibilities that one does not choose for oneself. If scholars of bioethics are to use the language of responsibility to critically probe such challenges, they must do so in a way that is meaningful to the moral experiences of those for whom their work is directed.

Advances New Feminist Perspectives Series (Lanham, Md.: Rowman & Littlefield, 1999); Laura Martha Purdy, *Reproducing Persons: Issues in Feminist Bioethics* (Ithaca, NY: Cornell University Press, 1996); Susan Sherwin, "Whither Bioethics? How Feminism Can Help Reorient Bioethics," *International Journal of Feminist Approaches to Bioethics* 1, no. 1 (2008), 7-27; Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press, 1992); Rosemarie Tong, *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications* (Boulder, Colo.: Westview Press, 1997); Susan M. Wolf, *Feminism & Bioethics: Beyond Reproduction* (New York: Oxford University Press, 1996).

⁴¹ See, for example Howard Brody, *Stories of Sickness*, 2nd ed. (Oxford: Oxford University Press, 2003); Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine* (New York: Oxford University Press, 1991); S. Kay Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient* Philosophy and Medicine series (Boston: Kluwer Academic Publishers, 1992); Richard M. Zaner, *Ethics and the Clinical Encounter* (Englewood Cliff, NJ: Prentice Hall, 1988); Richard M. Zaner, *Troubled Voices: Stories of Ethics and Illness* (Cleveland, OH: Pilgrim Press, 1993).

Another implication of this understanding of responsibility for bioethics scholarship is its interrogation of the principle of respect for autonomy. Respect for autonomy is one of the cornerstones of the principled approach to bioethics, as exemplified in the classic *Principles of Biomedical Ethics*.⁴² For example, a search for “autonomy” in the PubMed database produces over 27,000 results.⁴³ Despite its prevalence, what “respect for autonomy” entails is not a settled affair even among its advocates, though as its Greek roots indicate, autonomy is broadly a matter of a moral agent’s self-legislating capacity, that is, the ability of the agent to make decisions for herself. As Beauchamp and Childress state, “To respect an autonomous agent is, at a minimum, to acknowledge that person’s right to hold views, to make choices, and to take actions based upon personal values and beliefs.”⁴⁴ Advocates of autonomy’s central place in bioethics rightly argue that critics wrongly attack an “oversimplified, overextended, overweighted principle of respect for autonomy” rather than acknowledge that autonomy is both limited and limiting.⁴⁵

Childress and company are no doubt correct in their assessment that autonomy is a cornerstone of bioethics analysis; many ethical challenges *are* a matter decision

⁴² Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (Oxford: Oxford University Press, 2001).

⁴³ PubMed.gov database, U.S. National Library of Medicine, National Institutes of Health. 2 March 2010. Keyword: Autonomy. Available online: <<http://www.ncbi.nlm.nih.gov/sites/entrez>>.

⁴⁴ Beauchamp and Childress, 63.

⁴⁵ James F. Childress, "The Place of Autonomy in Bioethics," *The Hastings Center Report* 20, no. 1 (1990), 12-17; quote on 12. For another defense of the principle of respect for autonomy, see James F. Childress and John C. Fletcher, "Respect for Autonomy," *Hastings Center Report* 24, no. 3 (1994), 34-35.

making. Moral agents must make choices and typically seek to make those choices in light of their own values and commitments. Being able to have some form of control over the circumstances of one's life is a profoundly important endeavor, and by no means should critiques of autonomy ignore the value of being able to exert this self-control. However, as I have indicated throughout this dissertation, autonomy and self-control have their limitations. No one individual is the sole author of her life—her story is indelibly intertwined with and shaped by the stories of others. Because we are never the sole authors of our lives, we are not always in control of some of the twists and turns that occur. No one willingly and autonomously *chooses* to have Huntington's disease—such events are beyond our control. In treating autonomy as the end-all, be-all principle of bioethics analysis, one runs the risk of reducing that analysis to the discovery of empirically verifiable facts that contribute to the moral agent's decision-making in a given context. But the moral life, particularly when dealing with issues of medicine and health, is more than decision-making and fact gathering. Again, this does not mean that respect for autonomy should be discarded, but rather that the individual moral agent who makes decisions should not always set the standard for bioethics analysis.⁴⁶

Margaret Farley echoes similar statements in her book, *Compassionate Respect*.

She states, "It begins to be clear that the requirements for right and true caring are

⁴⁶ In an edited collection of essays, MacKenzie and Stoljar develop the notion of "relational autonomy" in order to reassess autonomy in light of some of these very concerns. From this perspective, to think of autonomy as a relational matter is to consider the numerous and dynamic influences that condition the possibilities of someone's ability to make choices. In other words, relational autonomy directs one to analyze the contextual factors that render some choices possible while limiting other possibilities. See Catriona MacKenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: Oxford University Press 2000).

determined by the concrete reality of those for whom we care” as well as the relationship between the care-giver and the other.⁴⁷ Farley’s work gives voice to a theme of this dissertation, namely, that the language of autonomy is insufficient by itself for addressing many of the challenges of bioethics. She views bioethics as torn between two polarizing values and approaches: an ethic of care (following the work of Carol Gilligan) and a strident emphasis on patient autonomy. She argues that a strict focus on autonomy leads to what Pincoffs described as “quandary ethics”; structural issues fall by the wayside with this approach. This focus on autonomy, particularly as I have described it throughout this dissertation, also has negative consequences on an individual level. Farley asserts, “When autonomy is narrowly construed in terms of total self-reliance, personal preference and self-assertion, it can compound the burdens of frailty and sickness that are experienced in varying and often increasing degrees.”⁴⁸ At the same time, an ethic of care (as exemplified in the work of Carol Gilligan), if unchecked, runs the risk of developing into strong paternalism within the context of the clinic.⁴⁹ Her position of “compassionate respect” seeks to integrate an ethic of care, with its emphasis on relationality as fundamental to being, with respect for autonomy, which must also be upheld so that people can exercise their capacities for self-creation. Neither relationship-oriented care nor individual autonomy is sufficient grounds for grappling with challenges in bioethics. Both are necessary and must be integrated: “We are who we are not only

⁴⁷ Margaret A. Farley, *Compassionate Respect: A Feminist Approach to Medical Ethics and Other Questions*, Madeleva Lecture in Spirituality (New York: Paulist Press, 2002), 34.

⁴⁸ *Ibid.*, 29.

⁴⁹ *Ibid.*, 29-32.

because we can to some degree make ourselves to be so by our freedom but because we are transcendent of ourselves through our capacities to know and to love.”⁵⁰

The vision of responsibility I advocate has strong implications for bioethics analysis. By construing responsibility as a matter of status and integrity, we are called to recognize that the moral life is a constant but never-fully-achieved movement toward greater self-understanding. We also acknowledge a significant degree of *uncertainty* and *un-control* at the heart of our very being and must appreciate the struggles that attend to seeking to live a life consistent with that always-limited self-understanding. With this basic framework in mind, the challenges of bioethics may sometimes be construed in language other than the language of free, autonomous decision-making. Medical abilities and technologies—organ transplantation, extended life support, abortion, predictive genetic testing, and PGD to name a few—present moral agents with the reality of uncertainty and un-control in one’s very being. They challenge us to reflect on who we are and who we hope to be, not merely on what decisions are best. And yet amid those challenges, the uncertainty, and un-control that are present, we see that responsibility remains. Moral agents must live their lives in the midst of circumstances and events that they did not choose and over which they have no control. Despite that lack of choice and control, they still strive to live a life of self-discovery and meaning; identifying and claiming responsibilities is a significant part of that on-going process.

If my assessment is correct, if the struggles of the moral life are frequently understood as struggles of dealing with unchosen responsibilities and the always-unfulfilled movement toward greater integrity and self-understanding, then bioethics

⁵⁰ Ibid., 37.

analysis will require a basic reorientation if it is to address those challenges. Bioethicists should certainly continue to collect empirically verifiable data related to matters like predictive genetic testing and PGD, but they must also recognize that there are limits to how that data relates to individual cases. Bioethicists can analyze a given set of issues with all the data they can muster, but if bioethics analysis is to benefit the people who actually *face* the challenges of predictive genetic testing and PGD (or any other bioethics issue), they must approach those moments with an attitude of humility. Bioethics should recognize the limits of fact gathering and acknowledge the influence of unique values, commitments, and attitudes of each moral agent involved. Thus, it must humbly listen to their stories, how they describe their struggles, how they speak about their responsibilities, and how they find meaning amid moral distress. Bioethicists cannot assume that our ready-made principles like autonomy are applicable in a specific context, nor can we assume that they understand what *autonomy* or *responsibility* means for a unique individual. Above all, bioethicists should acknowledge that the moral life is more than just a movement from one decision-point to the next—it is also a constant movement toward greater self-understanding and integrity. Bioethics has done a remarkable job in helping people make decisions, but it should recognize that decision-making and rendering judgments are only part of bioethics' tasks.

On this point, I would point to the importance of scholars of religion for the emerging field of bioethics. In a significant way, this would be a return to the roots of bioethics, as many of its pioneers were scholars of religion—Paul Ramsey, John C. and Joseph Fletcher, and Albert Jonsen, to name a few. It is the theological ethicist William Schweiker's work on responsibility that most forcefully brings forth matters of integrity,

and Margaret Farley has likewise provided a significant contribution to the work of bioethics in her work on compassionate respect. Though bioethics fervently needs physicians, nurses, counselors, legal scholars, sociologists, philosophers, and members of other disciplines in its field, those of us who study in religion have great resources at our disposal to analyze those instances of moral distress that arise in the clinic. In the study of religion, we regularly deal with questions of uncertainty, identity, integrity, commitment, and that which cannot be named or exhausted. As I have tried to demonstrate in this project, those questions are not left at the door when a person enters the clinic. In fact, they often bubble up in this very context. It is imperative that we acknowledge their presence and continue to draw on those resources available in the study of religion so that we can assist those individuals who struggle with those questions of integrity and identity in the context of the clinic.

Summary

In this chapter I spelled out some implications of the vision of responsibility that I endorsed in the previous chapter, particularly in reference to predictive genetic testing and preimplantation genetic diagnosis (PGD). I also demonstrated how an understanding of responsibility grounded in notions of status and integrity provides constructive critiques to medical practice and to the burgeoning field of bioethics. A key theme running throughout this analysis is the necessity of acknowledging the limits of human self-control, self-knowledge, and the very limits of selfhood. I argued that predictive genetic testing and PGD represent attempts to exert dominion in areas previously resigned to the language of “fate.” I also argued that while fact-gathering is paramount

for both medical practice and bioethics, the collection of data cannot always provide a full picture of what causes moral distress for agents who find themselves wrestling with medical or health-related issues.

I broadly classified the ethical challenges posed by predictive genetic testing as challenges of uncertainty, interpretation, and information. I argued that predictive genetic testing rarely affords the degree of certainty that it is portrayed as providing in much of popular discourse. Because predictive genetic testing is based on population-based data, it typically provides patients/clients with percentages, probabilities, or other statistics that tell the patient/client about the population of people who share the genetic markers in question. If, for example, a test indicates that a specific patient has a 65% chance of developing a certain form of breast cancer, the test *cannot* reveal if the patient is part of the 65% of people who develop the cancer or part of the 35% who do not. Given the degree of inherent uncertainty involved in predictive genetic testing, I advocate an attitude of humility on the part of those who would use those tests, recognizing the limits of the information they can actually provide.

With respect to PGD, I again pointed out that genetics are only one factor among many that shape an individual's future status. Drawing on Michael Sandel's notion of giftedness, I argued that PGD represents an attempt by the modern, autonomous moral agent to exert her dominion over yet another realm of human existence. In doing so, we devalue the giftedness of our very being, as well as the gifts that our children provide. Reiterating a point made in the discussion of predictive genetic testing, I also noted that PGD cannot provide the level of certainty and control that people who use it may seek; there is an inherent variability and unpredictability to human existence that cannot be

quashed by technological innovation. Moving to public policy discussions, I then noted that PGD's use has large and serious implications for what we considered to be "disabled" states of being. Using PGD to select against certain disabled states (like deafness) further stigmatizes an already ostracized community. Admittedly, the vision of responsibility I endorse provides little guidance for public policy discussions on what constitutes "responsible" or acceptable uses of PGD. With that understanding of responsibility in mind, however, I maintain that any large-scale discussions must include the voices of those whose lives are most directly impacted by PGD's use.

By emphasizing that level of uncertainty and unknowability that remains at the heart of human existence, I suggested that my understanding of responsibility has implications for the way medicine is practiced, specifically in relation to the "new paradigm" of evidence-based medicine (EBM). I argued that because EBM's data is based on sound epidemiological research, it too has its limits for what it can reveal about specific patients. Echoing the problems of predictive genetic testing, I showed that although EBM can provide wonderful information for patients, there again remains an underappreciated degree of uncertainty that must be acknowledged on the clinician-patient level. Yet despite that uncertainty, I maintain, responsibility remains for clinician and patient alike. Clinicians have a responsibility to inform their patients about those limits and to help patients better understand the often-complicated statistics with which they are presented. Likewise, patients ought not give up on their futures when presented with uncertain outcomes. We must continue to live our lives in the face of uncertainty.

Finally, I drew out some large-scale implications of my work for the field of bioethics. By focusing on status and integrity as crucial components of responsibility, I

claim that bioethics should incorporate a “bottom-up” approach to its work rather than relying on the “top-down” principlism that dominates much of bioethics discourse. To understand how one’s status and one’s drive to live a life of integrity inform their moral life, we must speak to those moral agents. We cannot assume that moral distress is the result of conflicting principles or struggles with decision-making. Bioethicists must listen to moral agents describing their hopes and fears if our work is to have any real impact on their lives. Along these lines, I claim that autonomy should continue to be a foundational principle of bioethics analysis, but we should be cognizant of the limits of that self-legislating capacity. Here, my work resonates with phenomenological and feminist scholars in bioethics, scholars whose contributions are underappreciated in this relatively new field. When we as bioethicists open ourselves to these voices and to the voices of the people who struggle with the challenges posed by technologies like predictive genetic testing and PGD, we will begin to make great strides toward responsible scholarship that can have a real impact on the lives of moral agents struggling to find their way in the midst of uncertainty.

APPENDIX A

CASE STUDY SAMPLES¹

Prenatal Diagnosis

A 40-year old woman, Debbie, mother of two teenagers, is 16-weeks pregnant, her first time without the use of fertility treatments and a surprise. She has been referred for a high resolution ultrasound and a test for abnormalities in the fetus. Before undergoing ultrasound or other tests, she receives genetic counseling. The genetic counselor finds no factors that would increase existing risk assessments. She tells Debbie that every pregnancy has a 3-4% risk for birth defects, that Debbie has an age-related risk of 1/106 for giving birth to a child with Down Syndrome and 1/66 risk for giving birth to child with medical problems caused by abnormal chromosomes. The genetic counselor tells the patient that Down syndrome and a number of other conditions can be detected within a couple of weeks using a technique called amniocentesis. The genetic counselor explains the process of amniocentesis including that it carries a 1/200 risk for miscarriage.

The patient expresses concern over putting the baby at risk and her willingness to consider abortion if the baby has Down syndrome. She does not want to leave her other children the responsibility of care giving when she dies. The genetic counselor helps Debbie identify her options and possible outcomes. The patient asks what is the chance of getting pregnant at 40 and then says this baby is a miraculous gift. She indicates that God's will would be involved in any outcome adding that it would be God's will if she gave birth to child with Down syndrome and it would be God's will if she underwent amniocentesis and a miscarriage resulted. She decides not to make a decision about the amniocentesis until she has the ultrasound results.

Predictive Testing

Jeff, a 35-year-old father of two young children, watched his mother go through Huntington disease, a disorder that usually starts in middle age and progressively gets worse affecting moods, judgment, memory and movement. He saw his mother decline through the years as her disease progressed from occasional falls to incidents where his mother, a once even-tempered woman, cursed at the grocery clerk. He grew up being frightened and embarrassed and living with the frustration of not being able to help his mother whose eyes seemed trapped in a body not her own as her movements and

¹ Originally developed by multiple members of the Religion and Genetics study group, Vanderbilt University. Used for focus group discussions, Spring 2007.

personality grew foreign. Jeff recently buried his mother who spent years in a nursing home that he eventually stopped visiting.

As the child of a parent affected by Huntington disease, Jeff has a 50% chance of being affected with the same condition. He has only recently understood this risk and has begun thinking about undergoing genetic testing. He knows that symptoms could begin in the next several years, a time that he imagines being able to enjoy sports and the outdoors with his wife and two kids. Genetic testing, a process which includes psychological as well as genetic counseling, would allow him to answer a question he has repeatedly asked and avoided, "Will this happen to me?"

Jeff has always been a planner and has promised himself that he would not take loved ones down the same path as he went with his mother. As he imagines being diagnosed with the disease, he confronts suicide as a viable option and yet the thought of forgoing the remaining years with his family is unbearable. Although he had attended church regularly, his attendance has dropped as he struggles to worship a God who would allow this cycle of suffering to continue.

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