

A HISTORY OF GENETIC COUNSELING IN THE UNITED STATES

INTERPRETING THE GENETIC REVOLUTION: A HISTORY OF GENETIC
COUNSELING IN THE UNITED STATES, 1930-2000.

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Abstract

This dissertation explores the social history of genetic counseling in the United States between 1930 and 2000. I situate genetic counselors at the interstices of medicine, science, and an increasingly “geneticized” American society. My study emphasizes two central themes in the history of genetic counseling. First, genetic counselors have played a crucial role in bridging the “old eugenics” and the “new genetics” (both temporally and ideologically) as mediators of genetic reproductive technologies. Genetic counselors have negotiated the rights and responsibilities of genetic citizens in their personal patient encounters. Discourses of privilege and duty were also extrapolated outward to public debates about the new genetics, demonstrating the highly-politicized contexts in which counselors practice and women make reproductive choices.

Second, I interrogate the professionalization process of genetic counseling from a field led by male physician-geneticists in the 1940s and 50s, to a profession dominated by women with Masters degrees by the 1980s and 90s. This transformation is best understood through the framework of a “system of professions,” and counselors’ professional position between “sympathy and science.” These frameworks similarly structured the client-counselor relationship, which also centered on concepts of risk, the promotion of patient autonomy, and the ethics of non-directiveness and client-centeredness. These principles distanced

counselors from their field's eugenic origins and the traditional doctor-patient relationship.

I emphasize the voices of genetic counselors based on 25 oral history interviews, and hierarchies of gender, race, and educational status at work in the profession's history. A study of genetic counseling elucidates the social impact of genetics and reproductive technologies in the twentieth-century United States. In so doing, it is an important contribution to the histories of health and medicine, medical sociology, bioethics, disability studies, and gender and women's studies.

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List of Abbreviations

ABGC – American Board of Genetic Counseling

ABMG – American Board of Medical Genetics

ABMS – American Board of Medical Specialties

AES – American Eugenics Society

AFP – alpha-fetoprotein

AIFR – American Institute of Family Relations

AMA – advanced maternal age

ASHG – American Society of Human Genetics

BAC – Bioethics Advisory Committee

CF – cystic fibrosis

CGC – Certified Genetic Counselor

CVS – chorionic villus sampling

DI – The Dight Institute for Human Genetics

DNA – deoxyribonucleic acid

ERO – Eugenics Record Office

FINRRAGE – Feminist International Network of Resistance to Reproductive and Genetic Engineering.

HBF – Human Betterment Foundation

HBL – Human Betterment League

HC – The Hastings Center

IVF – *in vitro* fertilization.

MHS – Minnesota Historical Society

MOD – March of Dimes

NARAL – NARAL Pro-Choice America, formerly National Association for the Repeal of Abortion Laws, The National Abortion Rights Action League, and the National Abortion Rights and Reproductive Rights Action League.

NARC – National Association for Retarded Citizens (later, The Arc)

NDSC – National Down Syndrome Congress

NSGC – National Society of Genetic Counselors

NWHN – National Women’s Health Network

NYT – New York Times

PKU – phenylketonuria

PPFA – Planned Parenthood Federation of America

PSS – Professional Status Survey

Introduction: On the Genetic Frontier: Genetic Counseling in the Twentieth-Century United States.

American President Bill Clinton, British Prime Minister Tony Blair, and geneticists Francis Collins and Craig Venter announced the completion of the first draft of the Human Genome Project on June 26, 2000. Clinton proclaimed, “Today, we are learning the language in which God created life.” He insisted that, “With this profound new knowledge, humankind is on the verge of gaining immense, new power to heal. Genomic science will have a real impact on all our lives – and even more, on the lives of our children. It will revolutionize the diagnosis, prevention and treatment of most, if not all, human diseases.”¹ James Watson, co-discoverer of the double-helix structure of DNA, joked that, “Had anyone suggested in 1953 that the entire human genome would be sequenced within fifty years, [Francis] Crick and I would have laughed and bought them another drink.” Nevertheless, he lauded Clinton’s celebration as,

perfectly justified in hailing the possibilities of a marvelous new weapon in our fight against disease and, even more, a whole new era in our understanding of how organisms are put together and how they operate, and what it is that separates us from other species - what, in other words, makes us human.²

The awesome power and potential of genetic science has indeed been manipulated to address almost all aspects of the human experience. By 2013, the sixtieth anniversary of Watson and Crick’s momentous discovery, scientists could genetically engineer tomatoes

¹ *Remarks by the President, Prime Minister Tony Blair of England (Via Satellite), Dr. Francis Collins, Director of the National Human Genome Research Institute, and Dr. Craig Venter, President and Chief Scientific Officer, Celera Genomics Corporation, On the Completion of the First Survey of the Entire Human Genome Project*, 26 June, 2000, accessed 10 February, 2013, http://www.ornl.gov/sci/techresources/Human_Genome/project/clinton2.shtml

² James D. Watson, *DNA: The Secret of Life* (New York: Alfred A. Knopf, 2003), 191-193.

protected against frost by inserting “antifreeze” protein genes. They had created pigs that act as pharmaceutical manufacturers by generating human hemoglobin. Perhaps the most startling genetic achievement to date was the cloning of Dolly the Sheep in 1997.³ Exciting advances in human genetics include a shift away from traditional organ transplantation towards a new field of organ fabrication and tissue engineering; the development of pharmacogenomics or personalized medicine; and advances in gene therapy (the correction of a genetic defect by inserting exogenous genes).⁴

Perhaps nowhere has the genetic revolution been manipulated to more astounding results than in the realm of genetic reproductive technologies and prenatal diagnosis.⁵ The late-twentieth century was marked by the birth of test-tube babies, *in vitro* fertilization, surrogate motherhood, artificial wombs, and embryo cloning. As of April 2013, genetic tests exist for 2,975 genetic disorders, and comprehensive screening programs can detect Down syndrome, cancer, Tay-Sachs, sickle cell anemia, cystic fibrosis, and Huntington’s disease, amongst other conditions.⁶ These tests give people a glimpse into their genetic future and that of their children. In short, modern genetics has transformed concepts of

³ Jeremy Rifkin, *The Biotech Century: Harnessing the Gene and Remaking the World* (New York: Putnam, 1998), 20, 81.

⁴ *Ibid.*, 24.

⁵ The term genetic revolution emerged in popular discourse in the mid-1970s with Daniel Stephen Halacy’s *Genetic Revolution: Shaping Life for Tomorrow* (New York: Harper and Row, 1974). Use of the term increased significantly with the Human Genome Project. See, for example, Bernard D. Davis, ed., *The Genetic Revolution: Scientific Prospects and Public Perceptions* (Baltimore: Johns Hopkins University Press, 1991). I suggest that the genetic revolution predates the Human Genome Project. Since the rediscovery of Mendel’s laws in 1900, the twentieth century has witnessed an ongoing revolution in genetic science. In this schema, the Human Genome Project is the most recent event or stage in a continual, albeit intensifying, genetic revolution. I use the term genetic reproductive technologies to describe the array of procedures affecting women’s fertility, pregnancy, childbearing, and subsequent reproductive options that developed as a result of advances in contemporary genetic science.

⁶ “National Institutes of Health Genetic Testing Registry,” National Center for Biotechnology Information, accessed 9 April, 2013, <http://www.ncbi.nlm.nih.gov/sites/GeneTests/?db=GeneTests>

disease treatment and prevention; the experiences of conception, birth, aging, and dying; and, as James Watson suggested, the very meanings of human life.

Genetic counselors are situated at a crossroads between medicine, science, and an American society increasingly affected by the new genetics. In a prenatal setting (historically, the most common counseling context), counselors help their clients navigate genetic technologies that have dramatically altered traditional understandings of pregnancy, motherhood, and reproductive choice. In this way, they act as interpreters of complex medico-scientific information. The field's modern origins are traced to geneticist Sheldon Reed, for whom "the desire for a happy family of normal children is one of the strongest human motivations" and "the highest of life's goals."⁷ He believed counseling could help couples understand their hereditary risks for cancer, albinism, hemophilia, "mental deficiency," and harelip. Counseling might help mitigate the reappearance of spina bifida in a given family, and could provide information to an individual concerned about inheriting Huntington's chorea.⁸

The field initially relied on family histories, clinical observation, and mathematical risk calculations but transformed with the proliferation of reproductive technologies like amniocentesis and chorionic villus sampling to become an integral part of prenatal care by the 1980s and 90s. Today, genetic counseling - defined by the National Society of Genetic Counselors (NSGC) as the "process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease"-

⁷ Sheldon Reed, *Counseling in Medical Genetics* (Philadelphia: W.B. Saunders, 1955), 225.

⁸ *Ibid.*, 7-8.

is a burgeoning healthcare profession on the frontlines of the new genetics.⁹ An historical appreciation of this relatively-new field of clinical genetics is crucial to understanding how we have been swept up in a genetic revolution that demands the re-imagination of our sense of self and family; our concepts of parenthood, health, and illness; the ethical uses of genetic knowledge; and the very politics of life and death.

A History of Genetic Counseling: The Multifactorial Meanings of Genetics in the Twentieth-Century U.S.

There are many ways to tell the story of genetic counseling in the United States. My study is a social history of the field's evolution focused in the predominantly prenatal context. I explore the period between 1930 and 2000, and draw extensively on oral history interviews with genetic counselors. By interweaving topics in the history of health and medicine, medical sociology, gender history, bioethics, and disability studies, I emphasize two central themes in the history of genetic counseling. The first is the relationship between the “old eugenics” and the “new genetics.” The term new genetics emerged in the 1970s to develop a public consciousness about “the possibility of mapping and defining the structure of genes on a scale that had not previously been possible.”¹⁰ According to Alan Petersen and Robin Bunton, champions of genetic technologies employed the term “new” as a “boundary marker delineating that which promotes individual ‘freedom of choice’ (and is therefore assumed to be necessarily ‘good’) from

⁹ Resta et al., “A New Definition of Genetic Counseling: National Society of Genetic Counselors’ Task Force Report,” *Journal of Genetic Counseling* 15, no. 2 (April 2006), 79.

¹⁰ Peter W. Rose and Anneke Lucassen, *Practical Genetics for Primary Care* (Oxford: Oxford University Press, 1999), 1. See also Alan Petersen and Robin Bunton, *The New Genetics and the Public’s Health* (New York: Routledge, 2002), 38. Petersen and Bunton suggested that there is some disagreement as to whether the term was coined in 1972 or 1979.

that which denotes coercive control...(and is therefore deemed ‘bad’).”¹¹ Genetic counseling provides the ideal lens through which to explore how and why this dichotomous barrier was established; it also allows for an analysis of the blurred and fluid nature of this divide. The spectre of old/bad eugenics has loomed large in the profession’s evolution. Indeed, (anti-) eugenic discourses have structured both genetic counselors’ professional experiences and public discussions about the promises and perils of genetics, reproductive technologies, and prenatal testing.¹²

Genetic counselors offer significant insight into the social impact of the new genetics. They are frontline genetics healthcare professionals and mediators of reproductive technologies in an increasingly “geneticized” American society. The term “geneticization,” first coined by Canadian sociologist Abby Lippman in 1991, reflects “an ongoing process by which differences between individuals are reduced to their DNA codes, with more disorders, behaviors, and physiological variations defined, at least in part, as genetic in origin.” Lippman also used the term to refer to “the process by which interventions employing genetic technologies are adopted to manage problems of health,” such that, “human biology is incorrectly equated with human genetics, implying that the latter alone makes us each the organism she or he is.”¹³ This theory resembles the concept

¹¹Petersen and Bunton, *The New Genetics and the Public’s Health*, 40.

¹² Discussions about “promises and perils” are particularly evident in early twenty-first century literature on genetics. See, for example, Audrey R. Chapman and Mark K. Frankel, eds., *Designing our Descendants: The Promises and Perils of Genetic Modifications* (Baltimore: Johns Hopkins University Press, 2003), and Linda L. McCabe and Edward R.B. McCabe, eds., *DNA: Promise and Peril* (Berkeley: University of California Press, 2008).

¹³ Abby Lippman, “Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities,” *American Journal of Law & Medicine* 17, no. 1 and 2 (1991), 19. Other scholars have noted Lippman’s concept of “geneticization” including Alexandra Minna Stern in *Telling Genes: The Story of Genetic Counseling in America* (Baltimore: Johns Hopkins, 2012), 11, and Ruth Hubbard in *Exploding the Gene Myth: How Genetic Information is Manipulated by Scientists, Physicians, Employers, Insurance*

of medicalization put forward several decades earlier, which posited the application of medical definitions and frameworks to areas of life formerly beyond the “medical gaze.”¹⁴

I employ the concept of geneticization from the perspective that research in medical genetics has yielded many positive accomplishments but that the pervasive social applications of this research should be carefully considered and, at times, critiqued. Indeed, by the end of the twentieth century increasing numbers of Americans were experiencing geneticization in predictable but not unproblematic areas like prenatal diagnosis and pregnancy management. They also encountered genetics in many other areas with the discovery of the “genes for” obesity, cancer, alcoholism, criminality, and intelligence. Into the twenty-first century, genetics infiltrated aspects of everyday life previously outside a medical purview, so much so that we have been asked to “think genetically” as we navigate the new rights and responsibilities of genetic citizens.¹⁵ Genetic counselors have played a crucial role in bridging the old eugenics and the new genetics, both temporally and ideologically, as gatekeepers between complex genetic reproductive technologies and the American public.¹⁶

Companies, Educators, and Law Enforcers (Boston: Beacon Press, 1999), 65-68. These scholars do not, however, employ this idea as a conceptual framework.

¹⁴ The first reference to “medicalization” appeared in sociologist Irving Kenneth Zola’s “Medicine as an Institution of Social Control: The Medicalizing of Society,” *Sociological Review* 20, no. 4 (1972), 487-504. See also Ivan Illich, *Medical Nemesis: The Expropriation of Health* (Toronto: McClelland and Stewart, 1975).

¹⁵ Deborah Heath, Rayna Rapp, and Karen-Sue Taussig, “Genetic Citizenship,” in *A Companion to the Anthropology of Politics*, eds. Joan Vincent and David Nugent (Malden: Blackwell Publishing, 2004), 159.

¹⁶ Rayna Rapp described genetic counselors as “gatekeepers” between “science and social work” and “epidemiology and empathy” in her work focused predominantly on amniocentesis, *Testing Women, Testing the Fetus* (New York: Routledge, 1999), 51. See also Charles Bosk, *All God’s Mistakes: Genetic Counseling in a Pediatric Hospital* (Chicago: University of Chicago Press, 1992), 72. Bosk described genetic counselors as “gatekeepers without turf.”

A diverse literature on the new genetics informs my analysis of the history of genetic counseling. The two most significant histories of twentieth-century genetics and hereditarianism in the United States are Daniel Kevles' *In the Name of Eugenics* (1995) and Kenneth Ludmerer's *Genetics and American Society* (1972). Both explored the intricate nuances and overlap inherent in the categories of eugenics and genetics.¹⁷ More recently, Nathaniel Comfort analyzed the “medical dimension of human heredity” in *The Science of Human Perfection* (2012), and continuities between eugenics and medical genetics in the twentieth-century United States.¹⁸ In her article “A Kind of Genetic Social Work” (2003), historian Molly Ladd-Taylor also explored the overlap between eugenics and genetics through the contradictory character of Sheldon Reed, who simultaneously rejected and reinforced genetic counseling's eugenic legacy.¹⁹ Some of the most interesting scholarship on the new genetics has come from political scientists like Diane B. Paul, but also from sociologists and anthropologists.²⁰ Work on the new genetics and public health by Alan Petersen and Robin Bunton, as well as Deborah Heath, Rayna Rapp, and Karen-Sue Taussig's “Genetic Citizenship” (2004), have provided the

¹⁷Daniel Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity*, 2nd ed. (Cambridge: Harvard University Press, 1995), 253-258; Kenneth M. Ludmerer, *Genetics and American Society: A Historical Appraisal* (Baltimore: Johns Hopkins, 1972).

¹⁸Nathaniel Comfort, *The Science of Human Perfection: How Genes Became the Heart of American Medicine* (New Haven: Yale University Press, 2012).

¹⁹Molly Ladd-Taylor, “A Kind of Genetic Social Work”: Sheldon Reed and the Origins of Genetic Counseling,” in *Women, Health and Nation: Canada and the United States since 1945*, ed. Georgina Feldberg et al. (Montreal: McGill-Queens, 2003), 67-83.

²⁰Diane B. Paul, *Controlling Human Heredity: 1865 to Present* (Atlantic Highlands: Humanities Press, 1995); Diane B. Paul, *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature-Nurture Debate* (Albany: State University of New York Press, 1998).

conceptual frameworks through which to analyze the experience of living in an increasingly geneticized society.²¹

Interdisciplinary collections such as Alexander M. Capron's *Genetic Counseling* (1979) and Dianne M. Bartel's *Prescribing our Future* (1993) explored the ethical questions arising from the new genetics and genetic counseling with the intent of reducing the potential for coercion and discrimination in social applications of genetic science.²² Feminist works like Ruth Schwartz Cowan's *Heredity and Hope* (2008), and scholarship in bioethics and disability studies like Erik Parens and Adrienne Asch's *Prenatal Testing and Disability Rights* (2000), have also been central to framing the contemporary perspectives of specific interest groups on the eugenic potential (or lack thereof) of the new genetics.²³ This scholarship supports my analysis of the eugenics-genetics correlation as analyzed through genetic counseling. I analyze this under-studied health profession from an interest in the interaction between historical and contemporary encounters with the new genetics from 1930 to 2000.

The second major theme in my history of genetic counseling (and one that is central to the history of medicine) is the professional experiences of genetic counselors including their professionalization and patient-practitioner relationships. I re-examine the most well-known, traditional narrative of medical professionalization, which posits the

²¹ Petersen and Bunton, *The New Genetics and the Public's Health*; Heath, Rapp, and Taussig, "Genetic Citizenship," 152-167.

²² Alexander M. Capron et al., eds., *Genetic Counseling: Facts, Values, and Norms* (New York: Liss, 1979); Dianne M. Bartels et al., eds., *Prescribing our Future: Ethical Challenges in Genetic Counseling* (New York: Aldine De Gruyter, 1993).

²³ Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening* (Cambridge: Harvard University Press, 2008); Erik Parens and Adrienne Asch, eds., *Prenatal Testing and Disability Rights* (Washington: Georgetown University Press, 2000).

exclusion of female practitioners at the hands of male biomedicine, by exploring the apparent counter-trend in genetic counseling. Between the 1940s and 1990s, genetic counseling transformed from a field led by male scientists and physicians with MDs and/or PhDs, to one dominated by women with Masters degrees.²⁴ I argue that the professionalization experiences of genetic counselors are best understood through the framework of a “system of professions.” Proposed by sociologist Andrew Abbott, the system of professions counters insular studies of single professions that understand their evolution through a strict sequence of progressive steps cumulatively titled “professionalization.” Instead, Abbott positioned interprofessional competition as the crux of professional life, arguing that “Professions are never seen alone...They exist in a system.”²⁵ This interprofessional competition is characterized by shifting axes of power and authority in which jurisdictional boundaries are constantly in flux. Professionals must rely on the power of their abstract knowledge and concrete skills to claim jurisdiction and request social endorsement of their hegemonic position. Jurisdiction is then granted through rights such as monopoly of practice, public payment, self-regulation, and control over recruitment, education, and licensing.²⁶ Abbott argued that examining professions within a larger system allows for a more nuanced, comprehensive analysis of professionalization experiences, and enables us to better answer “How do professions

²⁴ Diane B. Paul mentions the shift in the educational training and gender of counselors in *The Politics of Heredity*, 108.

²⁵ Andrew Abbott, *The System of Professions: An Essay on the Division of Expert Labor* (Chicago: University of Chicago Press, 1988), 1, 33.

²⁶ *Ibid.*, 59.

develop? How do they relate to one another? What determines the kind of work they do?”²⁷

Genetic counseling evolved from within a “system of *genetics* professions” specifically, in which counselors’ educational credentials and gender structured their interactions with physician-geneticists, social workers, nurses, and others. The establishment of Masters-level training programs, the National Society of Genetic Counselors, and the American Board of Genetic Counseling (ABGC) were profoundly affected by the profession’s position between “sympathy and science.” Regina Markell Morantz-Sanchez used this binary to describe the status of women physicians in nineteenth- and twentieth-century American medical practice. Their professionalization was impeded by the apparent incongruity “between prevailing concepts of femininity and the evolving professional ethos of scientific medicine.” At the same time, their entry into medicine was encouraged by claims that women alone “could combine sympathy and science – the hard and soft sides of medical practice.”²⁸ Morantz-Sanchez suggested that “a central theme in the story of women in medicine has been the tension between ‘femininity,’ ‘feminism’ and ‘morality’ on the one hand; and ‘masculinity,’ ‘professionalism’ and ‘science,’ on the other.”²⁹

Similarly, counselors’ interactions with patients were also conditioned by counselors’ place within the system of genetics professions and their highly gendered positioning between sympathy and science. The formal inculcation of “non-directiveness” and

²⁷ Ibid., 2.

²⁸ Regina Markell Morantz-Sanchez, *Sympathy and Science: Women Physicians in American Medicine: Women Physicians in American Medicine*, 2nd ed. (Chapel Hill: University of North Carolina Press, 2000), xvii, 5.

²⁹ Ibid., 200.

“client-centeredness” as the profession’s ethical cornerstones distanced genetic counseling from the directive and often paternalistic ethos of counselors’ physician-geneticist counterparts, and endowed the field with an anti-eugenic philosophy. Within this framework, counselors’ relationship with their clients or patients (counselors used both terms, and sometimes also “counselee”) has continually revolved around ideals of patient autonomy in making reproductive choices, and negotiating the complex risks, rights, and responsibilities of modern genetic citizens. These concerns were extrapolated outward to the public sphere where discourses of rights, responsibilities, and autonomy have been considered by reproductive rights activists, disability rights advocates, bioethicists, and the American print media. I argue that genetic counselors have acted as intermediaries between private and public negotiations of the genetic revolution. As such, their history highlights how biomedical matters become highly-contested public terrain, and how the politicization of science has conditioned the contexts in which women exercise personal reproductive choice.

An historical analysis of the professionalization experiences of genetic counselors necessarily draws on key works in the sociology and history of medical professions.³⁰ For almost two decades, both sociologists and historians relied on Carr-Saunders and Wilsons’ *The Professions* (1933), which described the features of various professional groups and catalogued the steps subsequently known as “professionalization.” Talcott Parsons’ *The Social System* (1951) renewed interest in the professions, and medical

³⁰ John C. Burnham wrote an excellent essay on the concept of professionalization in the history of medicine. See “How the Concept of Profession Evolved in the Work of Historians of Medicine,” *Bulletin of the History of Medicine* 70, no. 1 (1996), 1-24.

professionals in particular, by exploring medicine as a mechanism within the social system for dealing with illness.³¹ In the late-1960s, David Mechanic explored various perspectives in the emerging field of medical sociology on the topics of medical organization and the doctor's role in "the activity surrounding illness."³² In the early-1970s, sociologists like Eliot Freidson and Ivan Illich analyzed medical dominance and power relations within healthcare, and situated medical professions as sites of negotiation for professional prestige and autonomy. Illich also thoroughly critiqued physicians' medical monopoly and the pervasiveness of "scientism" in healthcare.³³ At the same time, historians of medicine like Richard Harrison Shryock began writing histories of professionalization focused primarily on the training, licensing, professional societies, and practice of physicians.³⁴

In the past three decades, sociologists took the lead in exploring the professionalization and patient experiences of genetic counselors. Barbara Katz Rothman's *The Tentative Pregnancy* (1993) and Rayna Rapp's *Testing Women, Testing the Fetus* (1999) studied the counselor-patient relationship in relation to amniocentesis, while Regina H. Kenen scrutinized counselors' professional development, as well as the opportunities and challenges facing the contemporary field.³⁵ Charles Bosk's *All God's*

³¹ A.M. Carr-Saunders and P.A. Wilson, *The Professions* (Oxford: Clarendon Press, 1933); Talcott Parsons, *The Social System* (Glencoe: Free Press, 1951).

³² David Mechanic, *Medical Sociology: A Selective View* (New York: Free Press, 1968), 2.

³³ Illich, *Medical Nemesis*, 4; Eliot Freidson, *Profession of Medicine: A Study of the Sociology of Applied Knowledge* (New York: Dodd and Mead, 1970); Eliot Freidson, *Professional Dominance: The Social Structure of Medical Care* (New York: Atherton Press, 1970).

³⁴ Richard Harrison Shryock, *Medical Licensing in America 1650-1965* (Baltimore: Johns Hopkins, 1967); Richard Harrison Shryock, *The Development of Modern Medicine: An Interpretation of the Social and Scientific Factors Involved* (Madison: University of Wisconsin, 1979).

³⁵ Barbara Katz Rothman, *The Tentative Pregnancy: How Amniocentesis is Changing the Experience of Motherhood* (New York: W.W. Norton & Co., 1993); Rapp, *Testing Women, Testing the Fetus*; Regina H.

Mistakes (1992) examined genetic counseling as performed by physicians in a pediatric hospital in the late-1970s and early 1980s. Bosk paid particular attention to the dynamics of the counseling session, the public and private dimensions of ethical issues, and the theory versus practice of patient autonomy.³⁶ Genetic counselors have been some of their profession's most conscientious historians. Work by Audrey Heimler, Robert Resta, and others have been crucial to documenting the profession's origins, the development of the National Society of Genetic Counselors, and other significant landmarks.³⁷ I add depth to this scholarship by closely analyzing the professional and patient experiences of genetic counselors in relation to other genetics healthcare workers, and against the greater geneticization of everyday life.

Oral history interviews with genetic counselors are essential to understanding the professionalization experiences, patient relationships, and social impact of genetic science; they also elucidate the pervasive influence of gender, race, and professional or educational status at work in the field's history. The story and practice of genetic counseling is inherently gendered, particularly in a prenatal setting where counselors deal in pregnancy, motherhood, reproductive rights, and abortion politics. Additionally, since

Kenen, "Genetic Counseling: The Development of a New Interdisciplinary Occupational Field," *Social Science and Medicine* 18, no. 7 (1984), 542-549; Regina H. Kenen, "Opportunities and Impediments for a Consolidating and Expanding Profession: Genetic Counseling in the United States," *Social Science and Medicine* (1997), 1377-1386.

³⁶ Bosk, *All God's Mistakes*.

³⁷ Audrey Heimler, "An Oral History of the National Society of Genetic Counselors," *Journal of Genetic Counseling* 6, no. 3 (1997), 315-336; Robert Resta, "The Historical Perspective: Sheldon Reed and 50 Years of Genetic Counseling," *Journal of Genetic Counseling* 6, no. 4 (1997), 375-377. See also J.A. Scott et al., "Genetic Counselor Training: A Review and Considerations for the Future," *American Journal of Human Genetics* 42, no.1 (1988), 191-199; Beverly R. Rollnick, "The National Society of Genetic Counselors: An Historical Perspective," in *Strategies in Genetic Counseling: Clinical Investigation Studies*, eds. Beth A. Fine and Natalie W. Paul, Birth Defects Original Article Series 20, no. 6 (White Plains: March of Dimes Birth Defects Foundation, 1984), 3-7.

the introduction of Masters-level training programs, the profession itself has become increasingly female-dominated and is currently 95 percent women.³⁸ The majority of counselors are also Caucasian, claiming a variety of Northern European ancestries, and are well-educated as professionals with advanced university degrees.³⁹

My oral history project, which received approval from the McMaster University Research Ethics Board in March 2010, was a three phase process. The first step was the recruitment phase, which was facilitated by the National Society of Genetic Counselors. NSGC Executive Director Meghan Carey sent my call for participants over the Society's listserv, along with a twenty-question survey designed to obtain demographic data and make contact with potential interviewees. Survey participants were asked basic questions about their personal, educational, and work backgrounds, as well as whether they were willing to participate in an oral history interview. Sixty of the 110 genetic counselors who completed the survey indicated an interest in being interviewed. This survey was made available online through SurveyMonkey.com and is reproduced in Appendix A.

The second phase of the oral history project was identifying and contacting participants for one-on-one interviews. Prospective interviewees were identified according to my priority of obtaining a broad range of experience. I selected interviewees based on counselors' age, gender, time and place of educational training, varieties of counseling jobs performed, and the institutions and regions of the country in which they worked, amongst other factors. I sent an email to thirty genetic counselors that reminded

³⁸ My survey of genetic counselors found that 94.8 percent of participants were female and 5.2 percent male.

³⁹ My survey reported that 96.5 percent of genetic counselors self-identified as "Caucasian," while 3.5 percent self-identified as "Asian."

them of their interest in the project and included a letter of information, interview guide, and consent form (although consent was also confirmed verbally at the time of the interview). Of the sample obtained during the initial recruitment phase, I interviewed eighteen individuals whom I have grouped into three categories: second-generation counselors who were educated and began working in the 1980s (seven participants); contemporary counselors whose careers began in the 1990s or 2000s (ten participants); and administrators (one participant). This group included three men and fifteen women whose ages range from twenty-five to fifty-two years old, all of whom self-identified as Caucasian. These counselors graduated from genetic counseling programs at such institutions as the universities of Minnesota, Michigan, Colorado, and California, as well as Sarah Lawrence College between 1983 and 2000. Most second-generation and contemporary counselors have worked in prenatal counseling at a large university or regional medical center. In many cases, counselors also worked in research or laboratory settings, in educational capacities as faculty in genetic counseling programs, and for state or federal health initiatives. The questions that formed the basis of these interviews are listed in Appendix B.

The third phase of the oral history project entailed interviews with counselors who claim membership in their profession's pioneering generation. I enlisted participants from this group at the NSGC's 2010 Annual Education Meeting and through email correspondence, but was most successful in accessing pioneering counselors through a snowball sample; a second-generation counselor passed along a recruitment email, letter of information, and consent form to some of his more senior cohorts. Seven of my study

participants (six female, one male) were of this pioneering generation who attended the earliest Masters-level genetic counseling programs in the late-1960s and 1970s. This demographic graduated from Sarah Lawrence College, Rutgers University, or the University of California Irvine between 1971 and 1978, with the exception of one counselor who came to genetic counseling through nursing. In their more than thirty years as genetic counselors, most of the field's pioneers worked in prenatal counseling. They have also exhibited similar (and perhaps even greater) employment diversity to their second-generation and contemporary counterparts. All together, my multi-phase oral history project resulted in twenty-five interviews conducted between July 2010 and October 2011 with genetic counselors who have lived and worked throughout the United States.⁴⁰

All interview participants were asked about and shared their experiences with counseling sessions, education and professionalization, and broader socio-political and ethical issues related to genetic counseling. Interviews were conducted over the phone, and lasted between sixty and 105 minutes. I confined my study to twenty-five interviews first, because I reached saturation (a comprehensive sample of experience), and second, because I wanted to thoroughly excavate the experiences conveyed within these interviews. The primary goal of my oral history project was to infuse my analysis of the secondary literature and archival sources on genetic counseling with the perspectives of those who perform this challenging work, and who encounter and mediate the new genetics every day. It was also my intention to carve out a space in which both myself and

⁴⁰ All interviews with genetic counselors are presented as confidential. Interview participants are referenced using their unique survey and interview numbers, as well as the date of interview.

genetic counselors could complicate a humanities literature that has often been quite critical of, and skeptical about, the new genetics and genetic counseling by providing a more nuanced assessment of the field's history and contemporary status.

A significant feature of all my interviewees is their high level of involvement in the profession. Those counselors willing to be interviewed about their professional lives are, in general, those who tend to be active in the profession by publishing in the *Journal of Genetic Counseling*, serving on the board or committees of the NSGC and ABGC, and attending the NSGC's yearly education meeting. In most cases, these counselors were still actively practicing; their ongoing participation in the field means that when describing their own experiences, they often spoke in the present tense even when describing a philosophy or practice with a much longer history. These interviews were an invaluable resource for my project. Counselors' insight into what it means to be a genetic counselor provided me with an understanding of the profession's history far beyond that available in printed primary and even archival sources.

The relative privilege and overall "whiteness" of genetic counselors and the practice of genetic counseling is central to the field's history and contemporary work.⁴¹ Importantly, a small proportion of genetic counselors claim Asian or other non-Caucasian backgrounds, and the NSGC has undertaken diversity initiatives to draw individuals of varied ethnicities to the profession as practitioners and clients. Since the 1980s, increasing

⁴¹ I have placed the term "whiteness" in quotation marks to demarcate my views on this category as problematic. Like any racial category, it generalizes the experiences of members of that group and ties them to a specific identity. I use the term, however, to speak about the collective, generalized racial identity and subjectivity of genetic counselors, and as a way to denote their relative privilege and accompanying social status. While I will not continue to place this term in quotation marks for the purposes of readability, it should be read as such.

numbers of Asian, African American, and Latina women have attended counseling sessions; at the same time, these patients are more likely to encounter difficulties in obtaining genetic consultations due to poor health insurance, amongst other factors.⁴² Robert Resta described that in many cases, “the demographic profile of genetic counselors broadly reflects the patient population they serve, ie., middle to upper class well-educated white women.”⁴³ Counselors’ collective whiteness, femaleness, and Masters-level education affected interactions with both colleagues and clients. An appreciation of the personal subjectivities of counselors and many of their patients is important for understanding genetic counseling for what it has been, and in many ways continues to be: a relatively elite medical service. Counselors’ status as professionals working in a well-entrenched system of Western medicine that offers an ever-greater menu of genetic healthcare services significantly affects their internalized logic and professional understanding of the social implications of living in a geneticized society. I therefore draw attention to moments of interaction between counselors’ internalized professional principles and public perceptions of the new genetics, as well as sites of obvious disconnect.

⁴² Robert Resta, “Changing Demographics of Advanced Maternal Age (AMA) and the Impact on the Predicted Incidence of Down Syndrome in the United States: Implications for Prenatal Screening and Genetic Counseling,” *American Journal of Medical Genetics* 113A (2005), 31-36; Linwood J. Lewis, “Honoring Diversity: Cultural Competence in Genetic Counseling,” in *Genetic Counseling Practice: Advanced Concepts and Skills*, eds. Bonnie S. Leroy, Patricia McCarthy Veach, and Dianne M. Bartels (Hoboken: Wiley-Blackwell, 2010), 201.

⁴³ Robert Resta, “Demographics and the Future of Genetic Counseling,” *The DNA Exchange*, 14 November 2010, accessed 10 April, 2013, <http://thednaexchange.com/2010/11/14/demographics-and-the-future-of-genetic-counseling/>. See also Ilana Suez Mittman and Katy Downs, “Diversity in Genetic Counseling: Past, Present and Future,” *Journal of Genetic Counseling* 17, no. 4 (2008), 301-313 for a discussion of diversity in the profession, and the field’s composition of between 91 and 94.2 percent non-Hispanic white counselors (302).

Oral history interviews on the history of genetic counseling are supported by research in archives at the Universities of North Carolina and Minnesota, the California Institute of Technology, the March of Dimes National Foundation, the National Library of Medicine, and the National Women’s Health Network. Published sources by genetic counselors are also crucial to understanding the profession’s evolution including manuals produced for clinical practice by Sheldon Reed and James V. Neel; the NSGC’s academic publication, the *Journal of Genetic Counseling*, and newsletter, *Perspectives in Genetic Counseling*; and contributions to scientific and medical journals like the *American Journal of Human Genetics*.

My study of genetic counseling in the U.S. is the second monograph-length history of genetic counseling with the publication of Alexandra Minna Stern’s *Telling Genes* in October 2012. I draw on Stern’s narrative, which emphasized the “circuitous” nature of the profession’s history between the 1940s and the present, and demonstrated “why history matters to contemporary genetic principles” and the profession of genetic counseling.⁴⁴ Stern performed a thorough analysis of genetic risk, counseling philosophies of non-directiveness and client-centeredness, and the intersection of genetics with race, disability, and bioethics. Stern’s work is most compelling in her thorough historical excavation of the characters of physician-geneticists Sheldon Reed, James V. Neel, and C. Nash Herndon, and in her study of Melissa Richter’s role in establishing the first Masters-level genetic counseling program in 1969. My study layers upon but also extends beyond Stern’s work by first, emphasizing the voices of genetic counselors in

⁴⁴ Stern, *Telling Genes*, 2-4.

telling their own history, and second, by highlighting the intersection between historical perspectives, and a wide array of contemporary literatures and discourses on the new genetics.

Genetic counseling emerged in the post-WWII United States amidst a rapidly-changing social, political, and scientific landscape. Throughout the twentieth century, Americans witnessed the popular transition from the old eugenics to the new genetics, a wave of scientific discoveries and genetic technologies, and novel ways of thinking about sex, reproduction, and the family. These shifts conditioned a change in cultural meanings and material practices that are central to the history of genetic counseling and the development of an increasingly geneticized society.

Negotiating Eugenics, Science and Sex in the Mid-Twentieth Century United States.

Eugenics, according to “father of eugenics” Francis Galton, is the “science which deals with all influences that improve the inborn quality of a race.”⁴⁵ The phenomenon Daniel Kevles described as the “mainline” eugenics movement was most popular in the United States between 1900 and the early 1930s.⁴⁶ Charles Benedict Davenport and Harry Hamilton Laughlin led the crusade for human betterment in the United States through the Eugenics Record Office, established in 1910. American eugenicists sought the regeneration of the “American race” to counter the differential birthrate stemming from the alleged “outbreeding” of “fit” white Anglo-Saxon Protestants by poor, “unfit”

⁴⁵ Francis Galton, “Eugenics: Its Definition, Scope, and Aims,” *The American Journal of Sociology* 10, no. 1 (July 1904), accessed 2 April, 2013, <http://galton.org/essays/1900-1911/galton-1904-am-journ-soc-eugenics-scope-aims.htm>

⁴⁶ Kevles, *In the Name of Eugenics*, 88.

immigrants and other undesirables.⁴⁷ This message was quite obviously gendered as the task of reproducing good American stock rested squarely on the shoulders of women who were divided into “good” and “bad” mothers.⁴⁸ Mainline American eugenic ideology subscribed to a “hard” Mendelian genetics, and preached a reductionist understanding of heredity that claimed only inborn traits were reproduced.⁴⁹

The ERO sponsored “positive” eugenic incentives intended to encourage reproduction of the “fit” through exhibits at state fairs, and “Better Baby” and “Fitter Families for Future Firesides” contests.⁵⁰ American eugenicists are most famous, however, for their “negative” measures intended to curb the propagation of the “unfit,” particularly surgical sterilization. By the early 1930s, thirty states had passed compulsory sterilization legislation and the movement saw more than 60,000 sterilized across the U.S.⁵¹ Eugenicists also championed scientific racism, anti-miscegenation laws, and anti-immigration policies, and counted the 1924 Immigration Act (which placed a strict quota on immigration) as one of their foremost achievements. At the height of the mainline movement, many states had some kind of eugenics society, and the appeal of eugenics

⁴⁷ Mark Haller, *Eugenics: Hereditarian Attitudes in American Thought* (New Brunswick: Rutgers University Press, 1963), 65, 79-82.

⁴⁸ Molly Ladd-Taylor described a “motherhood-eugenics” and the connections between sterilization and welfare services in “Saving Babies and Sterilizing Mothers: Eugenics and Welfare Politics in the Interwar United States,” *Social Politics* 4, no. 1 (1997), 136-153.

⁴⁹ Paul, *Controlling Human Heredity*, 46-48.

⁵⁰ See Robert W. Rydell, *World of Fairs: The Century-Of-Progress Expositions* (Chicago: University of Chicago Press, 1993), Chapter 2: “Fitter Families for Future Firesides”: Eugenics Exhibitions between the Wars, 38-58. See also Devon Stillwell, “Eugenics Visualized: The Third International Congress of Eugenics, 1932,” *Bulletin of the History of Medicine* 86, no. 2 (2012), 206-236.

⁵¹ Mark A. Largent, *Breeding Contempt: The History of Coerced Sterilization in the United States* (New Brunswick: Rutgers University Press, 2008), 72, 79-80.

was broad enough to attract physicians, lawyers, politicians, businessmen, and others from across the political spectrum.⁵²

By the end of the Second World War, eugenics as a popular mainline movement had lost much of its allure. The Nazi's particularly horrific brand of eugenics associated with the Holocaust accelerated the decline of eugenics movements around the world that had already begun to wane of their own accord.⁵³ The Nuremberg Trials, particularly the Doctor's Trials held between December 1946 and August 1947, exposed the extent of the Nazi's crimes. These crimes included the sterilizing of approximately 400,000 people and the euthanizing of 275,000 others.⁵⁴ Famous Nazi doctor Josef Mengele (the "Angel of Death") and others conducted experiments with hypothermia and the physical effects of high altitude. These physicians also infected subjects with cholera, smallpox, and malaria to study these diseases' effects and create vaccines. They also performed extensive research on twins in order to better understand the heritable nature of certain diseases.⁵⁵

The Nuremberg trials resulted in the conviction and sentencing of the Nazi doctors, but also the development of the Nuremberg Code. The Code was designed to avert future medical misconduct and crimes against humanity by outlining principles for ethical research involving human subjects. The Code required that experiments have identifiable

⁵² Haller, *Eugenics*, 5-6, 144-159.

⁵³ Kevles, *In the Name of Eugenics*, 169-170. By the early 1930s, eugenics in the U.S. was under fire from geneticists, religious leaders, and anthropologists, amongst others. These individuals criticized the movement's racial, class, and political biases, and questioned its scientific legitimacy.

⁵⁴ Robert Proctor, *Racial Hygiene: Medicine Under the Nazis* (Cambridge: Harvard University Press, 1988), 108; Albert R. Jonsen, *The Birth of Bioethics* (Oxford: Oxford University Press, 1998), 133-135. See Paul Julian Weindling, *Nazi Medicine and the Nuremberg Trials: From Medical War Crimes to Informed Consent* (New York: Palgrave MacMillan, 2004) for a detailed analysis of the Nuremberg Doctors' Trials and their implications for bioethics.

⁵⁵ Jonsen, *The Birth of Bioethics*, 135. Remarkably, Mengele evaded capture by the Allies, and therefore never stood before the International Military Tribunal.

benefits that outweigh potential risks, are carried out by qualified researchers, and performed only with the voluntary consent of the participant.⁵⁶ As such, early-twentieth century eugenics (and Nazi eugenics in particular) ushered in an era of more formalized bioethical principles that disavowed the misguided tenets of the mainline movement.

A perceptual shift in the boundaries of ethical and legitimate medico-scientific research conditioned a popular backlash against the early-twentieth century eugenics movement as reprehensible and indefensibly immoral. Eugenics did not, however, disappear. Relics of the mainline movement persisted in the form of sterilization laws, which remained on the books of at least nineteen states including Minnesota, North Carolina, Montana, and Virginia well into the 1980s.⁵⁷ Eugenics was also reconfigured into what Daniel Kevles called a “reform” eugenics. Reform eugenics originated amongst dissenters of the mainline movement in the 1930s, but gained traction post-WWII as it entwined itself with the emerging fields of human and medical genetics.⁵⁸ We are reminded by Diane B. Paul that “the distinction between reform and mainline eugenicists should not be overdrawn” as reform eugenicists maintained that the goal of human biological improvement was fundamentally sound; importantly, however, they denounced the coercion and extremism (particularly the intense racism and classism) of the mainline movement.⁵⁹

⁵⁶ “Nuremberg Code,” The National Institutes of Health, Office of Human Subjects Research, accessed 5 January, 2011, <http://ohsr.od.nih.gov/guidelines/nuremberg.html>

⁵⁷ Philip Reilly, *The Surgical Solution: A History of Involuntary Sterilization in the United States* (Baltimore: Johns Hopkins, 1991), 148.

⁵⁸ Kevles, *In the Name of Eugenics*, Chapter 11: A Reform Eugenics, 164-175, 251-253.

⁵⁹ Paul, *Controlling Human Heredity*, 119. Thomas M. Shapiro also suggested that reform eugenicists maintained the underlying tenets of early-twentieth century eugenics, despite changes in “tactics and tone”

In the U.S., Frederick Osborn, president of the American Eugenics Society in the late-1940s and early-1950s, eschewed views of eugenics as a social panacea in favour of a more realistic emphasis on health education and the concrete facts of heredity. The most significant difference between reform eugenicists and their predecessors was their belief that while heredity played a significant role in determining ones characteristics and capabilities, so too did the environment. Although reform eugenicists often still favoured hereditary explanations, they paid explicit attention to how factors like poverty, poor nutrition, lack of adequate housing, and social position contributed to who and what one became.⁶⁰ This cohort of eugenicists also shifted their concerns from issues of race and the differential birthrate to the importance of “the population.”⁶¹ The mid-twentieth century therefore saw the persistence of a eugenic ideology, albeit one accompanied by the emergence of bioethics and a shift in the meaning of human betterment.

The refashioning of eugenics and development of bioethics were intimately connected to major scientific advances in the field of genetics. Indeed, eugenics and genetics were ensnared with one another in the early-twentieth century as many geneticists who performed credible work were affiliated with the mainline eugenics movement. Geneticists, for example, published in eugenics periodicals like the *Journal of*

in *Population Control Politics: Women, Sterilization and Reproductive Choice* (Philadelphia: Temple University Press, 1985), 45-47.

⁶⁰ Kevles, *In the Name of Eugenics*, 173-74. Before the installation of Mendelism as the letter of the day for mainline eugenics, a cadre of late-nineteenth century eugenicists subscribed to a softer, Lamarckian brand of eugenics that advocated the role of the environment in good or bad heredity. The importance of the environment was also recognized by twentieth century figures like sociologist Lester F. Ward and geneticist Hermann J. Muller, who advocated the role of economics and class in the manifestation of human potential (Ludmerer, *Genetics and American Society*, 12; Hermann J. Muller, “The Dominance of Economics over Eugenics,” *Scientific Monthly* 37, no. 1 (Jul. 1933), 40-47; Paul, *Controlling Human Heredity*, 42-43).

⁶¹Ibid., 175.

Heredity and accepted funding from eugenics institutions.⁶² Almost from the start, however, geneticists interested in scientific research criticized eugenicists' social applications of genetics based on studies tainted by class and racial biases, and based on sloppy scientific methods.⁶³ Geneticists seriously questioned eugenicists' studies on inherited "feeble-mindedness" and criminality as the eugenics movement acquired a strong political component aimed at acquiring stringent sterilization and anti-immigration legislation. Indeed, in 1924 geneticist Herbert S. Jennings criticized what appeared to be the great interpretive license of eugenicists in promulgating the "facts" of heredity, and attacked eugenicist Harry Hamilton Laughlin in particular as relying on "false biology."⁶⁴

The over-simplified Mendelian model championed by eugenicists became increasingly untenable in the 1930s with the publication of British physician Lionel Penrose's Colchester Survey. Concluded in 1938, Penrose's seven-year study demonstrated that "mental retardation" was caused by the complex interaction of multiple genes, as well as environmental and pathological factors.⁶⁵ Despite the importance of Penrose's findings, genetic science developed slowly during WWII. Madge T. Macklin, Laurence Snyder, and others performed genetic research, yet there existed what historian Nathaniel Comfort called "the 'no-man's-land' of medical genetics, between the heyday

⁶² Ludmerer, *Genetics and American Society*, 48-49.

⁶³ *Ibid.*, 51.

⁶⁴ Kevles, *In the Name of Eugenics*, 132; See also "H.S. Jennings' letter to Science, about H. Laughlin Work on Immigration," *Science* LIX, no. 1524 (1924), 256, DNA Learning Center, accessed 5 May, 2013, <http://www.dnalc.org/view/11148-H-S-Jennings-letter-to-Science-about-H-Laughlin-s-work-on-immigration.html>

⁶⁵ Kevles, *In the Name of Eugenics*, 149, 162.

of ‘mainline’ eugenics and the medical turn in human genetics in the 1950s.”⁶⁶ Moreover, physicians focused on curing diseases and implementing public health measures disregarded genetics as too abstract to be usefully applied at the bedside.⁶⁷

Genetics became increasingly popular in the 1950s with Cold War anxieties about the dangers of radiation and genetic mutations, and with a growing cultural faith in biomedicine and medical technologies. As Davenport and Laughlin passed away, and eugenics institutions were closed, they were replaced by geneticists with strong research backgrounds and advanced degrees including Laurence Snyder and Hermann J. Muller in the U.S., and by Lionel Penrose, J.B.S. Haldane, Lancelot Hogben, and Irving Fischer in Britain.⁶⁸ This generation of geneticists performed important work on Rhesus (Rh) maternal-fetal incompatibility, ABO blood groups, and the linking of genes for colour blindness and hemophilia to the X chromosome.⁶⁹ Human and medical genetics received further legitimation in the late-1940s with the founding of the American Society of Human Genetics in 1948, and the establishment of doctorate-level human genetics programs at the Bowman Gray School of Medicine in North Carolina, Ohio State University, and the Universities of Minnesota, Michigan, and Chicago.⁷⁰

The prestige of human and medical genetics was augmented with a wealth of scientific discoveries beginning in the 1950s with Watson and Crick’s discovery of the

⁶⁶ Nathaniel Comfort, “Polyhybrid, Heterogeneous Bastards: Promoting Medical Genetics in America in the 1930s and 1940s,” *Journal of the History of Medicine and Allied Sciences* 61, no. 4 (2006), 415. See also William Leeming, “Tracing the Shifting Sands of ‘Medical Genetics’: What’s in a Name?” *Studies in the History and Philosophy of Biological and Biomedical Sciences* 41, no.1 (2010), 50-60.

⁶⁷ Ludmerer, *Genetics and American Society*, 65-66.

⁶⁸ *Ibid.*, 166.

⁶⁹ *Ibid.*, 168.

⁷⁰ *Ibid.*, 169.

double-helix molecular structure of DNA.⁷¹ By 1956, cytogeneticist Joe Hin Tjoe discovered that human cells contained 46 chromosomes, and the chromosomal bases for diseases like Klinefelter, Triple X, and Turner syndromes were discovered later in the decade. In 1959, Jérôme Lejeune and his colleagues attributed Down syndrome to the presence of an extra twenty-first chromosome. Phenylketonuria (PKU), an inborn error of metabolism that can cause mental retardation, was first discovered in 1934. By the 1960s, this problem was manageable through attention to diet and medication. By 1969, Tay-Sachs, which causes rapid deterioration and death during childhood and affects primarily Ashkenazi Jewish populations, was understood to be caused by an heritable enzyme defect.⁷²

Rapid rates of genetic discoveries led to greater emphasis on disease prevention through genetic screening programs and prenatal technologies. Between 1963 and 1968, the Guthrie test (named after physician and bacteriologist Robert Guthrie) was legally sanctioned in forty-three states to test newborns for PKU. Screening programs also emerged for Tay-Sachs and sickle cell anemia in the 1970s.⁷³ Screening initiatives were facilitated by advances in prenatal diagnostics like amniocentesis. This procedure, which involves the extraction of a small amount of amniotic fluid by needle, was first used by Fuchs and Riis in 1956 for *in utero* detection of fetal sex. By the mid-1960s, amniocentesis was being incorporated into prenatal healthcare to detect genetic defects.

⁷¹ J.D. Watson and F.H.C. Crick, "Molecular Structure of Nucleic Acids: A Structure for Deoxyribose Nucleic Acid," *Nature* 171 (1953), 737-738.

⁷² Peter S. Harper, *A Short History of Medical Genetics* (Oxford: Oxford University Press, 2008), 118, 147-49, 153-54, 176; Cowan, *Heredity and Hope*, 138

⁷³ Philip Reilly, *Genetics, Law and Social Policy* (Cambridge: Harvard University Press, 1977), 37, 110-111. See also Marc Lappé, *Genetic Politics: The Limits of Biological Control* (New York: Simon and Schuster, 1979), 83-99.

Alpha-fetoprotein screening (AFP) and chorionic villus sampling (CVS) emerged in the 1970s and 1980s respectively as alternative methods of prenatal diagnosis. CVS, which can be performed earlier in the pregnancy than amniocentesis, involves obtaining a sample of placental tissue while AFP screens analyze maternal blood for signs of fetal developmental abnormalities, primarily neural-tube defects.⁷⁴ Genetic reproductive technologies proliferated throughout the 1980s and 90s with the development of preimplantation genetic diagnosis and *in vitro* fertilization.⁷⁵ Early-twentieth century interest in genetics research quite obviously accelerated in the post-WWII period based on a rapid succession of discoveries made by formally-trained scientists in laboratories, and growing public support for biomedicine and biotechnology.

The decades following World War II also witnessed a dramatic shift in the interrelated discourses surrounding population problems, birth control, and women's reproductive roles. In the early 1950s, many former eugenicists, birth controllers, and public health advocates including Margaret Sanger and Dr. Clarence J. Gamble revised their concerns about the differential birthrate and race suicide. They focused now on the domestic baby boom and global population explosion, and created what Linda Gordon described as a new “distinction between the moderate, restrained ‘us’ and the teeming, profligate ‘them’” on a world stage.⁷⁶ Activists like Sanger and Gamble, and organizations like the Rockefeller Population Council and the Planned Parenthood World Population division of the PPFA, sought to solve the problem posited by Thomas Malthus

⁷⁴ Harper, *A Short History of Medical Genetics*, 355-357.

⁷⁵ *Ibid.*, 358.

⁷⁶ Linda Gordon, *The Moral Property of Women: A History of Birth Control Politics in America* (Urbana: University of Illinois Press, 2002), 280.

almost two centuries ago. Malthus hypothesized that, “Population, when unchecked increases in a geometrical ratio,” while “Subsistence increases only in an arithmetical ratio.”⁷⁷ Sanger, Gamble, and allied institutions focused on the Third World, which appeared to have the highest rates of population growth. They pursued an agenda of population control which famed author of *The Population Bomb* Paul Ehrlich described as “the conscious regulation of the numbers of human beings to meet the needs not just of individual families, but of society as a whole.”⁷⁸ It was no accident that targets of population control were non-white and often historically on the “wrong” side of colonialism. Clearly, a focus on population problems simply recast racist assumptions inherent in eugenic and reproductive discourses within a global context.

According to Betsy Hartmann, Western population control philosophy rested on three premises: that population growth was responsible for Third World problems of development such as poverty, political volatility, and lack of economic growth; that the main solution lay in curbing fertility rather than improvements to living conditions; and that Third World women should take birth control and accept “Western management techniques” despite concerns over the safety of various contraceptives, and the lack of basic healthcare infrastructure.⁷⁹ Echoing these very concerns, oral contraceptive researcher John Rock commented in 1954 that, “The greatest menace to world peace and

⁷⁷ Thomas Malthus, *An Essay on the Principle of Population* (London: Printed for J. Johnson in St. Paul’s Church-Yard, 1798), Chapter 1, accessed 5 January, 2013,
<http://socserv.mcmaster.ca/econ/ugcm/3ll3/malthus/popu.txt>

⁷⁸ Paul Ehrlich, *The Population Bomb* (New York: Ballantine Books, 1971), xi.

⁷⁹ Betsy Hartmann, *Reproductive Rights and Wrongs: The Global Politics of Population Control and Contraceptive Choice* (New York: Harper and Row, 1987), xiii.

decent standards of life today is not atomic energy but sexual energy.”⁸⁰ Many campaigners therefore advocated birth control as a sure-fire method of reducing the population but also as a solution to pervasive problems of underdevelopment, underemployment, and other socio-economic issues of global significance. Western birth control programs in India or China promoted sterilization as their most effective contraceptive method and encouraged local participation by cash or material incentives. These initiatives were often met with skepticism, however, due to the failure of Western efforts to produce the large-scale modernization and social cures they promised.⁸¹

Popular discourses on domestic birth control politics also shifted in the 1950s in ways that aligned with the rhetoric and concerns of global population controllers. Historian Elaine Tyler May noted that although the concepts were often used interchangeably (and despite important linkages between the two programs), “Family planning emphasized individual choice, whereas population control focused on large-scale reduction of fertility rates.”⁸² The Cold War era saw a reinforcement of the American family as the ideal domestic unit and expectations of a conservative, proper femininity; the model of a happy, healthy, and stable nuclear family headed by a breadwinning father and a doting housewife mother pervaded the American consciousness as the familial norm. Increased public discussions about birth control emerged, however, with a shift in attitude towards sexuality within marriage and a

⁸⁰ Elaine Tyler May, *America and the Pill: A History of Promise, Peril and Liberation* (New York: Basic Books, 2010), 1.

⁸¹ Gordon, *The Moral Property of Women*, 283-285.

⁸² May, *America and the Pill*, 39.

gradual acceptance of the desirability of family planning given the global population crisis.⁸³

After the Second World War, both marriage and sex counseling centers cropped up across the U.S. to educate husbands and wives on ways of maintaining an active sex life, which was increasingly deemed integral to a happy marriage. This promotion of a healthy marital love life, however, necessitated more permissive attitudes towards contraception. Many women grew more comfortable visiting Planned Parenthood clinics and their physicians to explore birth control options. They were also increasingly willing to express dissatisfaction within their marriages, ask doctors for sexual advice, and speak more openly about sexuality. Importantly, this did not necessarily expand women's prescribed roles within marriage as such discourses carefully avoided the issue of women's rights; rather, birth control and sex counseling were meant to give women the tools and knowledge necessary to perform their traditional marital functions.⁸⁴

Women's rights were won, and access to birth control increased, with the sexual and contraceptive revolutions of the 1960s precipitated by Second Wave Feminism generally, and the Reproductive Rights and Women's Health movements in particular. For reproductive rights activists, all other rights were meaningless without the ability to control when or when not to bear children. As Thomas M. Shapiro noted, "*The women's movement*, throughout most phases, has stood for birth control and reproductive freedom as a social precondition for sexual equality, even if the meaning of birth control has

⁸³ Gordon, *The Moral Property of Women*, 256-259.

⁸⁴ *Ibid.*, 259, 261-262.

changed.”⁸⁵ Enovid, the first contraceptive pill, became available in 1960. There was apprehension about its intended uses by women of color who had long been targets of coercive and racist reproductive policies.⁸⁶ Moreover, African American and Latina women were often more concerned about what Jennifer Nelson described as “the right to bear healthy children and to raise them out of poverty.”⁸⁷ Oral contraception was also unavailable to many women as it was under physician control and only prescribed to married women. At the same time, the pill gave those who could secure access a highly effective birth control method, and successfully revolutionized the contraceptive market. By 1964, 6.5 million married women and innumerable singles were using oral contraceptives, and the pill was the most popular birth control method in the United States.⁸⁸

The Women’s Liberation movement made significant gains with the repeal of the remaining Comstock laws, which had banned the dissemination of birth control or contraceptive information since 1873, in the 1964 decision of *Griswold v. Connecticut*.⁸⁹ Feminists’ most recognized landmark victory was *Roe v. Wade*, the 1973 Supreme Court decision that decriminalized abortion in the United States. Importantly, access to birth control and abortion remained uneven and varied considerably according to marital status,

⁸⁵ Shapiro, *Population Control Politics*, 12.

⁸⁶ Jennifer Nelson, *Women of Color and the Reproductive Rights Movement* (New York: New York University Press, 2003), Chapter 2: Black Women, Feminism, and Reproductive Rights, 55-83. The nuances of the reproductive rights movement are further explored in Chapter 4: “Abortions Under Community Control”: Feminism, Nationalism, and the Politics of Reproduction among New York City’s Young Lords, 113-132.

⁸⁷ Nelson, *Women of Color and the Reproductive Rights Movement*, 2.

⁸⁸ May, *America and the Pill*, 2. See also Elizabeth Siegel Watkins, *On the Pill: A Social History of Oral Contraceptives 1950-1970* (Baltimore: Johns Hopkins University Press, 1998).

⁸⁹ Andrea Tone, *Devices and Desires: A History of Contraceptives in America* (New York: Hill and Wang, 2001), 4-5, 24.

race, socio-economic position, and political regime; the New Right in the U.S., for example, introduced the Hyde Amendment in 1976, which was passed by Congress to restrict federal funding for abortions and significantly impeded poor women's access to the procedure.⁹⁰ Nevertheless, the gains of the women's movement had important implications for the re-conceptualization of women's traditional roles, sexuality, and reproductive choices, and their ability to fully utilize genetic services. These shifts in attitude, along with transformations in the meanings of eugenics and accelerations in genetic knowledge, worked cumulatively to create the space in which genetic counseling emerged in the twentieth-century United States.

A History of Genetics and Genetic Counseling in Six Parts.

Six thematic chapters organized chronologically comprise my social history of genetic counseling. Chapters 1, 5, and 6 explore the relationship between the old eugenics and the new genetics through the evolution and practice of genetic counseling. The first chapter analyzes the emergence of genetic counseling through Sheldon Reed and the Dight Institute in Minnesota; Paul Popenoe and marriage counseling in California; and the Human Betterment League of North Carolina between 1930 and 1980. I argue that genetic counseling arose from the identifiable shifts in cultural meanings and material practices outlined above which occurred at different times and paces, and demonstrate a

⁹⁰ Rickie Solinger, *Pregnancy and Power: A Short History of Reproductive Politics in America* (New York: New York University Press, 2005), 200-201. Not surprisingly, the Hyde Amendment passed during a resurgence in the anti-abortion movement. See also Rosalind Pollack Petchesky, *Abortion and Woman's Choice: The State, Sexuality, and Reproductive Freedom* (Boston: Northeastern University Press, 1990), Chapter 7: The Antiabortion Movement and the Rise of the New Right, 241-285.

profound blurring of eugenic and genetic ideologies and practices in mid-twentieth century America.

Chapters 5 and 6 explore the conditions of the new genetic citizenship as negotiated within the private client-counselor encounter, and in public debates surrounding genetic counseling amongst reproductive and disability rights activists between 1960 and 2000. The ethics of genomic science (or “genethics”), and the privileges and duties inherent in the new genetics, were considered at The Hastings Center from quite nuanced, sophisticated, and often woman-centered perspectives. Conversely, the American print media, a key site through which Americans have encountered the genomic enterprise, has often drastically over-simplified the social impact of genetic reproductive technologies and largely ignored the experiences of women in a geneticized society. Public perspectives on genetic counseling and reproductive technologies are integral to understanding what it means for women, as primary users of genetic reproductive technologies, to “mak[e] ‘private’ choices in public contexts.”⁹¹

The middle chapters of my dissertation focus on genetic counseling within a broader system of professions, and in relation to central themes in the history of health and medicine. Chapters 2 and 3 explore the genesis of genetic counseling and the professionalization experiences of counselors between 1947 and 2000. I argue that genetic counseling developed within a system of genetics professions and from its position between sympathy and science. Counselors’ professional interactions were profoundly shaped by the juxtaposition of their strong science backgrounds with the

⁹¹ Solinger, *Pregnancy and Power*, 14.

caring and nurturing aspects of their jobs. Chapter 4 analyzes the counselor-patient relationship and the dynamics of the genetic counseling session. The counseling appointment has consistently revolved around concepts of risk and the value of patient autonomy. Counselors also based their patient ethos on principles of non-directiveness and client-centeredness, which worked to differentiate themselves from their eugenic antecedents and other practitioners within a system of genetics professions. I modify Charles Bosk's profile of MDs engaged in the "dirty work" of genetic counseling whose lack of professional prestige led them to describe their role as a mere "mop-up" service within a pediatric hospital.⁹² In contrast, the colleague and patient experiences of Masters-level genetic counselors reveal a profession certainly shaped by a larger healthcare hierarchy, but who fulfil multiple healthcare roles and engage in a sophisticated scientific enterprise.

A historical study of genetic counseling probes the interstices between science, technology, medicine, and twentieth-century American society. Genetic counseling is a key site through which everyday Americans (particularly women) have encountered genetic reproductive technologies in profoundly personal and life-altering ways. Counselors, and certainly the women they counsel, have been positioned as intermediaries between genetic science and the American public. As counselors facilitate, and as women make, reproductive choices, they act as bodyguards of moral and ethical discourses surrounding reproductive freedoms, disability rights, genetic citizenship,

⁹² Bosk, *All God's Mistakes*, 22-27, and Chapter 3: Counseling as a Mop-Up Service, 57-82.

responsible parenthood, and the politics of pregnancy and abortion.⁹³ Entering the second decade of the twenty-first century, a history of genetic counseling is of ever-greater importance as we experience the accelerated geneticization of everyday life to a degree beyond that which early-twentieth century geneticists and Sheldon Reed could have imagined.

⁹³ Barbara Katz Rothman focused specifically on the role of women as negotiators of social anxieties about abortion, disability, and motherhood. She described that increasingly, “We are asking mothers to become the gatekeepers of life,” in *The Tentative Pregnancy*, xii.

Chapter 1: “To Guarantee That Children Will Be Well Born”: Eugenics, Genetics, and Genetic Counseling, 1930-1980.

On Monday, August 18th 1947, geneticist Sheldon Reed arrived at the Dight Institute for Human Genetics at the University of Minnesota to take up his newly-appointed post as the institution’s director. Reed recalled of that day that,

[I] beg[a]n my duties and during the morning was summoned to the Pediatrics Outpatient Department to give genetic advice to a family in which four out of five children had some type of eosinophilia. In the afternoon, there was a request made for information on first cousin marriages. The next day, I was asked to come to Pediatrics again to advise a family in which five of eight children had an heredomacular degeneration.¹

Much of Reed’s time at the Dight Institute was consumed by such case consultations. This work was integral to what he saw as the institution’s primary clinical function: genetic counseling. Reed himself coined the term “genetic counseling” in 1947. He recalled in 1974 that the term “occurred to me as an appropriate description of the process which I thought of as a kind of genetic social work without eugenic connotations.”² Defining genetic counseling in this way, he forged an explicit connection between early twentieth-century eugenics and genetics of the post-WWII period, and placed genetic counseling within a much longer history of research in heredity. Even as he connected genetic counseling to its past, Reed also believed that distancing genetic counseling from its early-twentieth century eugenic origins was essential to the development of this new field of clinical genetics. He insisted that, “genetic counseling should be concerned

¹ Sheldon C. Reed, “A Short History of Genetic Counseling,” *The Dight Institute for Human Genetics of the University of Minnesota Bulletin* 14 (1974), 4-5, Dight Institute Info File, Records of the Dight Institute for Human Genetics (hereafter DI) Elmer L. Andersen Library, University of Minnesota Twin Cities, Minneapolis, MN. Eosinophilia is an elevated white blood cell count indicating allergic reactions, parasitic infections, or underlying pathologies including certain auto-immune diseases, lymphomas or leukemias.

² Ibid.

primarily with the person and his or her family and only secondarily with society's demand or interest" and maintained that he was uncertain about "whether the net effect of genetic counseling is eugenic or dysgenic."³ Between 1947 and his death in 2003, Reed counseled thousands of parents on their reproductive options, wrote prolifically on medical genetics and genetic counseling, and performed research on a wide range of hereditary conditions. It is not surprising that at the time of his death, a contemporary genetic counselor described his legacy as one where, "More than just giving name to a nascent field, Dr. Reed helped imbue genetic counseling with an ethos that has guided the profession into the 21st century."⁴

Sheldon Reed's career provides the standard script for the early history of genetic counseling, and is a significant site through which to analyze the complex relationship between eugenics and genetics. Given his involvement in genetics education and research, and his influence on the profession's evolution, he certainly earned his reputation as one of America's foremost genetic counseling enthusiasts of the Cold War era. Nonetheless, a consistent focus on Reed as the "father" of genetic counseling has obscured other points of origin and alternate histories that are integral to a well-rounded account of the genesis of this clinical field. The work of Paul Popenoe, the Human Betterment Foundation (HBF), and the American Institute of Family Relations (AIFR) in California elucidate the linkages between marriage counseling of the 1930s to 1960s, and contemporary genetic counseling. The history of genetic counseling also has roots in the

³ Sheldon C. Reed Lecture, "Practical Genetic Counseling," Genetic Counseling, 1977 folder, Box 3, Subject and Lecture Files, DI. Underlines in original.

⁴ Robert G. Resta, "In Memoriam: Sheldon Clark Reed, PhD, 1910-2003," *Journal of Genetic Counseling* 12, no. 3 (June 2003), 283.

Human Betterment League (HBL) of North Carolina, a non-profit eugenics organization founded in 1947. These case studies demonstrate how genetic counseling emerged amidst multiple and cumulative shifts in cultural meanings and material practices that characterize the twentieth-century history of genetics and hereditarianism in the United States. In so doing, they elucidate points of convergence and divergence, and the complexities and contradictions, in the linkages between the old eugenics and the new genetics, and our transition to an increasingly geneticized society.

Scholars of eugenics, genetics, and hereditarianism have, for several decades, been interested in the relationship between eugenics and genetics, and especially in how much distance contemporary genetics can claim from its eugenic past. Recently, some have taken a hard line on whether or not the new genetics is, in fact, simply a contemporary eugenics. Merryn Ekberg argued that despite efforts to paint eugenics as coercive, discriminatory pseudo-science and genetics as voluntary, empowering, and scientifically-sound, “at the ideological level, there is essentially no difference. The old eugenics was genetics and the new genetics is eugenics.”⁵ In *Backdoor to Eugenics*, sociologist Troy Duster made a similar argument, warning that “a parallel play” to the early-twentieth century eugenics movement is being “re-enacted...but on a subtler stage set,” based on much more precise and cost-effective technologies that can achieve eugenic aims more efficiently than advocates of the old eugenics would dare have hoped.⁶ Historian Ruth Schwartz Cowan took quite the opposite perspective by arguing against such scenarios of

⁵ Merryn Ekberg, “Second Opinions: The Old Eugenics and the New Genetics Compared,” *Social History of Medicine* 20, no. 3 (2007), 581.

⁶ Troy Duster, *Backdoor to Eugenics*, 2nd ed. (New York: Routledge, 2003), xii.

eugenics-revivalism. She disputed efforts to depict recent state-sponsored genetic screening programs as eugenically-motivated. She argued, rather, that genetic technologies increase reproductive choices and enhance parents' chances of having not the perfect child, but a child free of hereditary disease.⁷ These scholars, however, represent the extremes.

More often, the trend since the 1970s has been a fairly moderate, nuanced historical perspective on the eugenics-genetics correlation. In their comprehensive twentieth century histories of genetics, historians Kenneth Ludmerer and Daniel Kevles, and political scientist Diane B. Paul, each explored the convoluted transition from an old eugenics to the new genetics. They emphasized the enduring presence of eugenics and hereditarianism after WWII despite the legacies of mainline eugenics and the Nazi program. Genetic counseling appears in these narratives as part of other post-war developments including a reform eugenics, advances in human genetics and molecular biology, genetic screening programs, and prenatal diagnosis.⁸ The emergence of genetic counseling, however, is featured but briefly and in broad terms. In such studies, Nathaniel Comfort explored the “eugenic impulse” within medical genetics, and suggested that both eugenics and medical genetics had the same goals: human improvement and the relief of

⁷ Cowan, *Heredity and Hope*, 9-10, 245.

⁸ Ludmerer, *Genetics and American Society*, 178, 186-190; Kevles, *In the Name of Eugenics*, 253-258; Paul, *Controlling Human Heredity*, Chapter 7: From Eugenics to Human Genetics, 115-135. The trend of countering an older assumption that eugenics disappeared after WWII and the Holocaust has been particularly poignant in the literature on eugenic sterilization including Reilly, *The Surgical Solution*, Chapter 9: The Quiet Years, 128-14, and Ian R. Dowbiggin, *The Sterilization Movement and Global Fertility in the Twentieth Century* (Oxford: Oxford University Press, 2008).

human suffering. Comfort explored this argument in the context of post-WWII heredity clinics, but said little of genetic counseling after the 1940s.⁹

Alexandra Minna Stern's *Telling Genes* (2012), the most comprehensive historical study of genetic counseling, focused intently on the heredity clinics of Sheldon Reed, James V. Neel, and C. Nash Herndon, often at the expense of the field's other points of origin. Her work is, however, incredibly adept at exposing the emergence of genetic counseling as a "protracted and uneven process" characterized by great scientific advances while continually marred by the "burdensome historical baggage" of the eugenics era.¹⁰ In this chapter, I build on this scholarship by expanding the origin stories for genetic counseling, and situating these origins against a larger twentieth-century history of genetics in the U.S.

More specifically, this chapter explores the process through which the old eugenics became the new genetics as genetic counseling emerged in the United States between the 1930s and 1980s. My central interest is *how* we get from eugenics to genetics specifically through the establishment and evolution of genetic counseling, rather than determining once and for all whether eugenics and genetics are the same or similar (and if so, to what degree?). I aim to broaden our perspective geographically, temporally, and institutionally on how, where, when, and why genetic counseling emerged by focusing on the case studies of Sheldon Reed at the Dight Institute; Paul Popenoe at the Human Betterment Foundation and the American Institute of Family Relations; and the Human Betterment League of North Carolina. There are, of course, other parts to this story. For example, one

⁹ Comfort, *The Science of Human Perfection*, ix-xiii, Chapter 4: The Heredity Clinics, 97-129.

¹⁰ Stern, *Telling Genes*, 2.

might consider, as Stern did, James V. Neel's heredity clinic in Michigan. I chose these particular case studies in part because they capture diverse points of origin and thus cover broad territory. The Dight Institute was linked to the University of Minnesota's genetics department, while the HBL was a non-profit organization for "human betterment," and the AIFR was a family planning and marriage counseling clinic. As such, these case studies provide insight into the range of individuals, organizations, and ideologies that contributed to the emergence of genetic counseling. Additionally, these examples were chosen for their geographic diversity so as to observe the field's emergence in the American South, Midwest, and West coast. Reed is central to the history of genetic counseling, but is not the only narrative of value to the field's history. Indeed, when analyzed together, these case studies form a more nuanced and multifaceted picture of the origins of genetic counseling in the United States.

I situate genetic counseling as emerging from, but also contributing to, larger national shifts in cultural meanings and material practices that have been typically characterized as post-WWII phenomena. These shifts include (but are not limited to) the perpetuation of a reform eugenics alongside scientific advances in genetics and molecular biology that founded new fields of medico-scientific inquiry. The fallout from Nazi medicine, the Nuremberg trials, and the development of bioethics also conditioned a mid-century shift. A further transformation came from a growing focus on family planning and population control, as well as attitudinal changes regarding family life and women's reproduction. The timing of such shifts varied by regional circumstances, and these meanings and practices could often co-exist or overlap. For example, the discovery of Nazi human

experimentation certainly influenced the emergence of bioethics but did not completely halt interest in eugenics. Similarly, while advances in the science of genetics made the greatest headway after the Second World War, many geneticists had been doing scientifically-credible work even during the era of mainline eugenics. Finally, while family planning became popular after the war, Paul Popenoe had popularized the practice through marriage counseling as early as the 1930s in California.

I suggest, then, that there are historically identifiable, hegemonic shifts in socio-cultural ideologies and practices in the twentieth-century that created the space for genetic counseling. At the same time, however, there also existed more covert meanings and practices (what Foucault might call “subjugated knowledges”) which, in a particular historical moment, were less visible and left out of dominant scientific and socio-political changes. Subjugated knowledges refer to “historical contents that have been buried and disguised in a functionalist coherence of formal systemisation.” Foucault’s concept also applies to knowledges that are “disqualified as inadequate to their task or insufficiently elaborated.”¹¹ In many ways, genetic counseling sat uncomfortably in the spaces between dominant shifts and those that were subjugated, arising from transformations typically identified with the post-WWII period but which occurred at different times and speeds, and according to local circumstance across the United States. To understand how genetic counseling arose from the contentious and oft-debated relationship between eugenics and

¹¹ I am borrowing the idea of “subjugated knowledges” from Michel Foucault, *Power/Knowledge: Selected Interviews and Other Writings 1972-1977*, ed. Colin Gordon (New York: Pantheon Books, 1980), 81-83. Foucault also notes that these particular knowledges are often local or regional in character and “incapable of unanimity” yet powerful in their difference (82). Alexandra Minna Stern also employed the concept of “subjugated knowledges.” She used it to describe the disability community’s use of genetic labels within its advocacy agenda even as it reacted against the medicalization of disability (*Telling Genes*, 77).

genetics, we must explore its emergence against specific historical shifts that acted on the field at the same time that the field's founding principles reinforced and contributed to these very changes. I therefore stress elements of both transition and continuity in the eugenics-genetics correlation and the increasing geneticization of American society.

“Insuring These Children are Normal”: Sheldon Reed, the Dight Institute, and Genetic Counseling in Minnesota.

Genetic counseling was first named in the late-1940s by Sheldon Reed, who characterized the field as a branch of clinical genetics with significant social ramifications but without the stigma of old-fashioned eugenics. Genetic counseling was to be “entirely for the benefit of the whole family without direct concern for its effects upon the state or politics.”¹² His identification of this burgeoning genetics specialty made Reed the “father” of genetic counseling, and characterized the profession in a way that influenced its evolution. Reed, like many post-WWII researchers in human genetics, sought to establish credibility for this scientific field in the shadow of early-twentieth century hereditarianism.¹³

The importance of differentiating genetic counseling from older eugenic models was underscored by Minnesota's avid participation in state-sanctioned eugenic sterilization. Reed was, in fact, employed as director of the Charles Fremont Dight Institute for the Promotion of Human Genetics which was established by a financial bequest from the state's most prominent eugenics crusader.¹⁴ Under Reed's leadership, the Dight Institute

¹² Reed, “A Short History of Genetic Counseling,” 6.

¹³ Ludmerer, *Genetics and American Society*, 165-167.

¹⁴ Minnesota ranked 8th out of 32 states in the number of sterilizations performed between 1907 and 1983 (Largent, *Breeding Contempt*, 77).

metamorphosed into one of the better-known and well-respected genetics clinics and research centers of its age in the United States. In that same post-war period, renewed interest and advances in human and medical genetics, a focus on population policy, and new currents in reproductive politics paved the way for the development of genetic counseling and a new era of genetics.

Minnesota's eugenics movement reached its apex in the 1920s under the leadership of Dr. Charles Fremont Dight, president of the Minnesota Eugenics Society and unabashed admirer of Hitler's eugenic program.¹⁵ An eccentric socialist who lived part of his life in a self-made treehouse, Dight sought to augment the average American's knowledge of eugenic principles through pamphlets, editorials in Minneapolis' daily newspapers, and a series of radio talks. He frequently addressed the importance of mate selection and eugenically-desirable marriages, preaching that, "It matters greatly who you marry" since "Your choice is a choice of a parent for your children."¹⁶ Despite the variety of eugenics initiatives to which he devoted his life, Dight is remembered primarily for his tireless campaign to sterilize Minnesota's "feeble-minded" population. He worked indefatigably for state-level sterilization legislation. Minnesota's sterilization law was enacted in 1925 and resulted in the surgical sterilization of 2,350 individuals (79 percent of whom were women) between 1925 and 1960.¹⁷ Dight saw this law, which provided for

¹⁵ Charles Fremont Dight to Adolf Hitler, 1 August, 1933, Box 8, Charles Fremont Dight Papers, Minnesota Historical Society (hereafter MHS), St. Paul, MN; Paul, *Controlling Human Heredity*, 123.

¹⁶ John Medelman, "The Incredible Dr. Dight: His Crusade to Abolish Wickedness," *Select Twin Citizen* 4, no. 11 (1962), 12, MHS .

¹⁷ Molly Ladd-Taylor, "The 'Sociological Advantages' of Sterilization: Fiscal Politics and Feebleminded Women in Interwar Minnesota," in *Mental Retardation in America: A Historical Reader*, eds. Steven Noll and James W. Trent Jr. (New York: New York University Press, 2004), 282; Largent, *Breeding Contempt*, 79.

the “voluntary” sterilization of the institutionalized feeble-minded, as inadequate. He therefore sought a law that would enable the sterilization of “morons” within the general population at five subsequent legislative sessions, always unsuccessfully.¹⁸ Dight’s proposal for sterilization legislation was significantly influenced by California’s sterilization law, and he often sought advice on his eugenics campaign from Paul Popenoe, E.S. Gosney, and the Human Betterment Foundation.¹⁹ Minnesota’s popular eugenics movement waned throughout the 1930s despite the active use of the state’s sterilization statute at Faribault State Hospital until the 1960s. The law remained on the books until the mid-1980s, but Dight’s passing in 1938 sounded the death knell for Minnesota’s mainline eugenic program.²⁰

Upon his passing, Dight left a generous portion of his estate (approximately \$75,000) to establish the Dight Institute on the express condition that it “promote biological race betterment.” Dight expected those employed by the institution to accomplish this goal by providing lectures on eugenics and heredity, collecting and preserving family histories and pedigrees, and forming eugenics societies for hereditary consultations.²¹ In addition to Dight’s own donation, the Institute also received funding from well-known California philanthropist and eugenicist Charles M. Goethe. A real estate investor supported by his wife’s family fortune, Goethe is best known for his versatile approach to eugenics which

¹⁸ Gary Phelps, “The Eugenics Crusade of Charles Fremont Dight,” *Minnesota History* (Fall 1984), 102-108, MHS.

¹⁹ Evandene Burriss Swanson, “Biographical Sketch of Charles Fremont Dight, M.D.,” *The Dight Institute of the University of Minnesota Bulletin* 1 (1943), 14, Charles Fremont Dight Info File, DI.

²⁰ Reilly, *The Surgical Solution*, 142, 148; Largent, *Breeding Contempt*, 79.

²¹ “Notice of Fund Establishment,” 5 June 1944, Dight Endowment Fund, 1944-1984, Box 2, Correspondence and Administrative Files, DI; “Last Will and Testament,” 30 July 1936, Dight Endowment Fund, 1944-1984, Box 2, Correspondence and Administrative Files, DI.

focused on better breeding and immigration regulations, but also environmental conservation.²² In 1947, he donated what amounted to approximately \$400,000 to the Institute in order to “promote the practical aspects of human genetics mostly through education with the improvement of the human gene pool as the eventual goal.”²³ Goethe was optimistic about the work of the Institute and noted in his personal correspondence to Sheldon Reed in the late-1940s that, “I feel somehow that [the] Dight Institute, along with the work we are doing here in California, in an entirely different way, is carrying on what was unfortunately ended in the old setup [of the Eugenics Record Office] at Cold Springs Harbor.”²⁴ In this way, the Dight Institute was established for purposes aligned with the visions of mainline eugenicists in the United States.

The Dight Institute opened on July 1, 1941 under the direction of Dr. Clarence P. Oliver, an American radiation and human geneticist who had worked as a graduate student under renowned geneticist Hermann J. Muller.²⁵ Under Oliver, the Dight Institute was organized to provide public education in human genetics and eugenics; distribute pamphlets on these and other related subjects; collect family histories demonstrating hereditary traits and various anomalies; and act as a clinic where people could obtain “genetic and eugenic interpretations.”²⁶ In the early 1940s, the Dight Institute demonstrated a continued affinity with mainline eugenic theories and practices. During

²² Stern, *Eugenic Nation*, 134-137.

²³ Sheldon Reed, “Report of Progress, *The Dight Institute*, for July 1, 1972 through June 30, 1974,” 16 and “Report of Progress, *The Dight Institute*, for July 1, 1970 through June 30, 1972,” 19, *The Dight Institute of the University of Minnesota Bulletin* 14 (1974), Dight Institute Info file, DI.

²⁴ C.M. Goethe to Sheldon Reed, 28 June 1947, Goethe, C.M Correspondence, 1947-1960, Box 1, Correspondence and Administrative Files, DI.

²⁵ Ludmerer, *Genetics and American Society*, 136, 167.

²⁶ Clarence P. Oliver, “Report on the Organization and Aims of *The Dight Institute*,” *The Dight Institute of the University of Minnesota Bulletin* 1 (1943), 1-2, Charles Fremont Dight Info File, DI.

WWII, the Institute focused on producing a fairly valorizing biography of Dr. Dight that chronicled his leadership of Minnesota's eugenics movement and emphasized his "humanitarianism."²⁷ The group also reviewed a proposal to initiate an annual prize for the individual who submitted the most complete family pedigree to the Dight Institute. Such a competition invoked the tradition of Fitter Families contests held at state fairs of the nineteen-teens and twenties. Dight had tried, but failed, to secure such a eugenic enterprise for Minnesota's own state fair in 1924.²⁸ Oliver directly connected the institution's eugenic heritage to the larger American eugenics movement when reporting on the growing popularity of the Dight's clinical consultations. He contended that,

the number of requests for information about heredity and eugenics received from persons outside Minnesota is increasing and probably will continue to increase. The increase is traceable to the closing of the Eugenics Records Office, Long Island. That office is now referring their communicators to the Dight Institute.²⁹

Indeed, the Dight Institute inherited 45,000 folders of pedigrees from the Eugenics Record Office, and 2 million index cards.³⁰ Reed would later make a related connection between the work of the Dight Institute and the ERO. He noted that the eugenic institution's director Charles Benedict Davenport "undoubtedly did some bona fida [sic] genetic counseling...though he didn't use that term."³¹ Moreover, the Dight Institute

²⁷ "Minutes of the meeting of the Committee of the Dight Institute, June 2, 1942," Box 2, Committee Minutes and Reports, 1941-1957, DI.

²⁸ "Minutes of the meeting of the Committee of the Dight Institute, May 27, 1943," Box 2, Committee Minutes and Reports, 1941-1957, DI.; Phelps, "The Eugenics Crusade of Charles Fremont Dight," 102.

²⁹ "Minutes of Dight Institute Committee, June 13, 1946," Box 2, Committee Minutes and Reports, 1941-1957, DI.

³⁰ Sheldon C. Reed to Dean T.C. Blegen, 21 November, 1947, see attachment "Conversational Report to the Dight Committee" and W.T. Middlebrook to Dr. Vannevar Bush, 16 April, 1948, Box 1, Correspondence B, 1947-1960, Correspondence and Administrative Files, DI.

³¹ Reed, "A Short History of Genetic Counseling," 2. Diane B. Paul also made the point that Davenport had given "marriage advice" to couples who requested the service (Paul, *Controlling Human Heredity*, 123).

established the Minnesota Human Genetics League in 1945 to support and publicize its work. Despite the explicit use of “genetics” in its name, Oliver founded the League in line with the conditions stipulated in Dr. Dight’s will that his estate be used to establish eugenics societies.³² The Dight Institute was therefore initially guided by a belief in the importance of genetics and heredity, and the possibility of human biological betterment through clinical consultations and social intervention, much like its eugenic predecessors.

Sheldon Reed became director of the Dight Institute in 1947 after Oliver left Minnesota to develop a program for human genetics at the University of Texas at Austin. Born in 1910 in Barre, Vermont, Reed completed an undergraduate degree at Dartmouth, and was awarded both a Masters (1933) and a PhD (1935) at Harvard. He came to the Dight Institute after teaching at McGill and Harvard throughout the late 1930s and early 1940s. Reed’s interest in mouse genetics, especially the role of genetic factors in cleft lip and cleft palate, led him to study under two early American geneticists, E.M. East and W.E. Castle. He abandoned his interest in mice, however, for human genetics when he was promoted to the Dight Institute, and took up the post of Director and professor of zoology at the University of Minnesota where the Institute was housed.³³ It was here that Reed developed a profound interest in genetic counseling, a central aspect of his career and his major legacy within the field of genetics. During his time at the Dight Institute, Reed counseled more than 4,000 cases. He also wrote prolifically about medical genetics,

³² Sheldon Reed, “The Local Eugenics Society,” *American Journal of Human Genetics* 9, no. 1 (March 1957), 1-8. According to Reed, none of the members of the Minnesota Human Genetics League had been involved in the Minnesota Eugenics Society.

³³ “Biography of Sheldon Clark Reed, University of Minnesota Professor of Zoology and Director Dight Institute, January 15, 1957,” and “Sheldon C. Reed,” undated Curriculum Vitae, Sheldon Reed Info File, DI.

genetic counseling, and “mental retardation” in collaboration with his wife Dr. Elizabeth Reed.³⁴

Reed wrote in 1957 that he saw no significant difference between “pure” scientific research and “applied” genetic programs such as eugenics; nevertheless, he reportedly “made a practice of divorcing eugenics from his day-to-day counseling and research activities.” Indeed, the Institute was separated according to its three main functions of research, education, and counseling.³⁵ Under Reed’s directorship, the Dight Institute pursued a number of genetics research programs between the late-1940s and late-1970s including projects on the genetic transmission of, and hereditary mechanisms for, conditions such as “mongolism” (Down syndrome), breast cancer, epilepsy, cleft palate, albinism, and “racial mixture.”³⁶ In the early years, research in these subjects was confined to studies of family pedigrees obtained from the Eugenics Record Office at Cold Spring Harbor; in the later years, however, the Institute was able to make use of more scientific laboratory methods. As part of its educational program, the Dight Institute conducted courses in elementary and advanced genetics at the University of Minnesota; Reed also offered public lectures on various topics related to human genetics. While at the Dight Institute, Reed lectured on subjects such as the discovery of chromosomes and chromosomal aberrations, differential birthrates in the U.S., evolution in human

³⁴ “Retired Genetics Prof Keeps Himself Busy,” *Minnesota Daily*, 2 February, 1982, Sheldon Reed Info File, DI.

³⁵ Reed, “The Local Eugenics Society,” 2; Lori Sturdevant, “U of M Research on Genetics Spans Three Generations,” 2, *University of Minnesota News Service*, 25 March, 1975, Dight Institute Info File, DI; Sheldon C. Reed, “Reactivation of the Dight Institute, 1947-1949,” *The Dight Institute of the University of Minnesota Bulletin* 6 (1949), 1-6, Dight Institute Info File, DI.

³⁶ Clarence P. Oliver, “Fourth Annual Report of the Dight Institute for the Academic Year 1944-45,” *The Dight Institute of the University of Minnesota Bulletin* 4 (1946), 4-11, Bulletin, 1943-1979, Box 1, Correspondence and Administration Files, DI.

intelligence, and genetics in relation to “racial diversity” and “mental deficiency.”³⁷ It was the Institute’s third function of genetic counseling, however, that was perhaps the most central for Reed. It is certainly the enterprise for which is remembered.

The heredity clinic at the Dight Institute typically saw three kinds of clients: couples who were referred from their physicians, walk-in inquiries, and individuals participating in the Institute’s clinical trials.³⁸ In an era before the development and standardization of prenatal technologies, the counselor met with couples with a known family history of hereditary disease who were either contemplating starting a family or who already had a child with a genetic condition.³⁹ In this medical encounter, the counselor provided information and mathematical risk estimates about the probability of such “defects” occurring in future offspring. Reed was steadfast in his belief that genetic counseling was not meant to recommend or advise patients about whether or not to have children; rather, it was meant to provide couples with an education in genetics on which to base informed reproductive decisions.⁴⁰ The ultimate goal of genetic counseling was to psychologically prepare prospective parents or expecting couples for the possibility of a child with a birth defect. In later years, genetic counseling could help them decide whether to continue the pregnancy.

³⁷ Reed, “Reactivation of the Dight Institute,” 2-3; Lecture folders on “The Chromosome Breakthrough,” n.d., “Differential Birthrates in the USA, text,” n.d., “The Evolution of Human Intelligence, 1964-1965,” “Genetics and Racial Diversity, 1950s,” “Genetics and Mental Deficiency, 1949,” Box 1, Subject and Lecture Files, DI.

³⁸ Stern, *Telling Genes*, 34.

³⁹ F. Clarke Fraser, “Types of Problems Presented to Genetic Counselors,” in *Heredity Counseling*, ed. Helen G. Hammons (New York: Hoeber-Harper, 1959), 78.

⁴⁰ “Heredity Explained: U Team Calls Toss on Genetic Gamble,” St. Paul *Pioneer Press*, 16 March, 1958, Sheldon Reed Info File, DI; Reed, *Counseling in Medical Genetics*, 11-16.

Many of Reed's most foundational and ardent beliefs were expressed in *Counseling in Medical Genetics* (1955). For almost a decade, this text was the only book available on the subject.⁴¹ In this work, he summarized his approach to counseling and articulated a philosophy that strongly resembled the concept of non-directiveness so central to the later profession.⁴² He explained that,

The parents often ask us directly whether they should have more children. This question is one that we do not answer because we cannot. The counselor has not experienced the emotional impact of their problem, nor is he intimately acquainted with their environment. We try to explain thoroughly what the genetic situation is, but the decision must be a personal one between the husband and wife, and theirs alone.⁴³

Reed suggested that genetic counselors required three particular qualifications: a firm background in human genetics; a “deep respect for the sensitivities, attitudes and reactions of the client”; and a commitment to teaching “the truth” about the couple’s heredity based on known genetic facts.⁴⁴

Reed held advanced degrees in biology and genetics from an esteemed academic institution, and undoubtedly realized that the Dight’s work in genetic counseling and research would never be respected if its program appeared in any way coercive. He emphasized autonomy as a central value of genetic counseling, and explained that, “We are concerned only about what is good for a particular family...We did not try to make

⁴¹ Reilly, *Genetics, Law, and Social Policy*, 154.

⁴² A non-directive approach was proposed by psychologist Carl Rogers. His counseling philosophies are discussed in the case study of Paul Popenoe and the AIFR. Reed’s adherence to Rogersian principles of non-directiveness and client-centeredness are further elaborated in Chapter 4.

⁴³ Reed, *Counseling in Medical Genetics*, 14.

⁴⁴ *Ibid.*, 11-12.

any judgement as to whether genetic counseling was good for the country as a whole.”⁴⁵ Reed repeatedly and publicly expressed commitment to individual choice in matters of heredity over social considerations about the fitness of the gene pool. He rejected Danish geneticist Tage Kemp’s term “genetic hygiene” allegedly due to associations in the United States of the word “hygiene” to deodorants and toothpastes. He also likely sought an alternative to Kemp’s suggestion because of inevitable associations to Nazi Germany’s program of “race hygiene.” Instead, Reed favoured “genetic counseling,” which he intentionally defined as lacking eugenic motivations. In the mid-1970s, Reed reflected on his choice of terminology and its impact on the growing field, saying, “It is my impression that my practice of divorcing the two concepts of eugenics and genetic counseling contributed to the rapid growth of genetic counseling. Genetic counseling would have been rejected, in all probability, if it had been presented as a technique of eugenics.”⁴⁶

Reed continually emphasized the non-eugenic aspects of his work and the potential benefits of genetic counseling for individuals and families, and could be progressive for his times. At the same time, both Reed and the Dight Institute were plagued by contradictions and could slip back into familiar eugenic territory. Reed advocated for couples’ autonomy in reproductive decision-making and stressed the importance of genetic counseling for individuals’ psychological well-being. His counseling philosophy was, however, based on the assumption that given the appropriate genetic information,

⁴⁵ George E. Jordan, “Reducing the Odds Against Genetic Disorders,” *University of Minnesota Medical Bulletin* (Spring 1981), 20, Sheldon Reed Info File, DI.

⁴⁶ Reed, “A Short History of Genetic Counseling,” 4-5.

couples would make a rational decision about their childbearing that was not only good for themselves, but which “seems correct to society as a whole.”⁴⁷ He also took for granted that an individual or couple’s personal happiness, and a woman’s self-fulfillment in particular, was intimately bound to having a “normal” family. Moreover, Reed supported the continued use of Minnesota’s “voluntary” sterilization law in the post-WWII period as he deemed it of great psychological value to women who had born several children with devastating genetic diseases. Reed and his wife Elizabeth were keenly interested in “mental retardation.” The Reeds conducted a study based on the records of the Faribault State School, one of Minnesota’s most notorious institutions for the “feeble-minded” during the eugenics era, and concluded (much like early-twentieth century eugenicists) that “mental retardation” was primarily hereditary. Reed also supported the institutionalization of people with disabilities, who put a happy “normal” family life in jeopardy through their lack of conformity to kinship ideals of the 1950s.⁴⁸ Typical eugenics discourses also slipped into his understanding of genetic counseling as a way to promote the reproduction of “the responsible” while hopefully curtailing the “production of abnormal children.”⁴⁹

His counseling advice on interracial adoptions was also problematic. Reed and other geneticists were often consulted by adoption agencies who wanted an evaluation of a

⁴⁷ Sheldon C. Reed, “Counseling in Human Genetics, Part II,” *The Dight Institute of the University of Minnesota Bulletin* 7 (1951), 6-7, Bulletin, 1943-1979, Box 1, Correspondence and Administrative Files, DI. Diane B. Paul noted that many clinicians of the period held a similar belief that their patients would make “the right choice” about their reproduction (Paul, *Controlling Human Heredity*, 127).

⁴⁸ Reed outlined many advantages of institutionalization to an individual whose child appeared to have congenital microphthalmos with mental deficiency in *Counseling in Medical Genetics* (100-101). See also Ladd-Taylor, “A Kind of Genetic Social Work,” 76-79; Stern, *Telling Genes*, 80-81; Elizabeth W. Reed and Sheldon Reed, *Mental Retardation: A Family Study* (Philadelphia: Saunders, 1965).

⁴⁹ Sheldon Reed Lecture, “A Eugenics Program for the Future,” n.d., Box 3, Subject and Lecture Files, DI.

newborn child. The societies wanted, above all, assessments for biracial children to determine their ability to blend into white American society.⁵⁰ Reed was consulted so frequently by adoption agencies attempting to place interracial children with adoptive families that “skin color” was the second most common reason for consultation between 1947 and 1949. Indeed, issues of race also entered into his publications such as *Counseling in Medical Genetics*, in which he demonstrated through three “illustrative examples” the intergenerational quandaries arising from ambiguous racial heritage.⁵¹ Reed sometimes advocated “racial matching” between parents and the adoptive child in order to prevent an awkward future situation in which the child’s traits exposed its lack of biological connection to the adoptive parents. He also often gave the advice that placing a child of a particular race with members of that group would promote social and cultural stability.⁵² As Barbara Melosh has described, “color was often destiny” for children in need of adoption as racial matching was the most common and well-entrenched determinant for adoptive placements at least into the 1960s.⁵³

At the same time, Reed suggested that it was often desirable to place a biracial child with a white family if the child could “pass.” Although the child’s adjustment period might be more difficult, in the end, the child would reap many rewards based on the presumably higher socio-economic status of a white family, as well as the white family’s

⁵⁰ Stern, *Telling Genes*, 63.

⁵¹ Sheldon C. Reed, “Counseling in Human Genetics,” *The Dight Institute of the University of Minnesota Bulletin* 6, (1949), 14; Reed, *Counseling in Medical Genetics*, 153-162.

⁵² Sheldon C. Reed Lecture, “Genetic Counseling (for children of mixed racial ancestry), 1961,” Box 3, Subject and Lecture Files, DI; Stern, *Telling Genes*, 65.

⁵³ Barbara Melosh, *Strangers and Kin: The American Way of Adoption* (Cambridge: Harvard University Press, 2002), 93.

assumed stability.⁵⁴ This advice may have been encouraged by post-WWII attitudes toward black mothers including the resurgence of racial biological theories situating them as innately hypersexual, and the concept of the “culture of poverty,” which posited black women’s fecundity and welfare dependence as a menace to the American family.⁵⁵

At the same time, Reed’s willingness to place a biracial child with a white family could be seen as moderately progressive. Transracial adoption, though virtually unheard of before the 1950s, became more common in the civil rights era. In the early 1960s, adoptions across racial divides became living proof of the new ethos of American liberals centered on greater social tolerance, and a minimization of racial differences and animosity.⁵⁶ Reed was, in fact, an outspoken critic of racism and an advocate of the “complete amalgamation of all the races now in this country.”⁵⁷ Alexandra Minna Stern demonstrated that the contradiction of Reed’s adoption philosophies “illustrates the extent to which he could escape neither the scientific theories of racial differentiation he sometimes so vocally condemned nor the expectations of phenotypic familial similarity that predominated at the time.”⁵⁸

The term “eugenics” appeared consistently in Reed’s writings and lectures in what might be interpreted as direct evidence of his subscription to throwback hereditarian ideology. Importantly, however, Reed recast his use of the term to align with a post-WWII emphasis on a reform eugenics, and a shift in understanding of what eugenics

⁵⁴ Sheldon C. Reed Lecture, “Genetic Counseling (for children of mixed racial ancestry), 1961”; Stern, *Telling Genes*, 63-72.

⁵⁵ Rickie Solinger, *Wake Up Little Susie: Single Pregnancy and Race before Roe v. Wade* (New York: Routledge, 2000), 57-59.

⁵⁶ Melosh, *Strangers and Kin*, 159, 165, 174.

⁵⁷ Stern, *Telling Genes*, 53.

⁵⁸ *Ibid.*, 65-66.

meant. As Diane B. Paul noted, Reed and other geneticists believed that eugenics had “a rational core,” that certain genes were “unreservedly bad,” and that medical genetics was good eugenics guided by the admirable intention of alleviating the burdens of genetic diseases.⁵⁹ One indication of Reed’s subscription to reform eugenics is his correspondence with Frederick Osborn of the American Eugenics Society. Osborn requested information on Reed’s research on Huntington’s chorea, and invited him to an AES meeting to discuss “the present situation and prospects of eugenics in this country.”⁶⁰ Like many reform eugenicists, Reed lamented the Nazi perversion of eugenics and was of the opinion that “eugenics under a dictator such as Hitler can only lead to disaster, as it did in Germany.” He believed, however, that the “fundamental defect was not so much in the eugenics program as in the form of government which permitted the perversion of eugenics to nothing but legalized robbery and murder.”⁶¹

For Reed, eugenics had a much older and more profound history than that which had imprinted itself on the public consciousness. He suggested that the notion that man can enhance his heredity is “older than Christianity”; he traced it specifically to Plato and Grecian practices, as well as to the arranged marriages of the Orient designed to produce genetically-superior offspring.⁶² Reed differed from an earlier eugenic ideology in his belief that “any Eugenics Program must serve the individual first, and presumably the state will also benefit from the improvement of the individual. If the program is forced on

⁵⁹ Paul, *Controlling Human Heredity*, 124-125; Paul, *The Politics of Heredity*, 142.

⁶⁰ H.G. Hammons (on behalf of Frederick Osborn) to Sheldon Reed, 19 May, 1958, and Frederick Osborn to Sheldon Reed, 10 April, 1959, Correspondence H, 1948-1988, Box 1, Correspondence and Administrative Files, DI.

⁶¹ Sheldon C. Reed, “Do We Need a Program of Eugenics?,” n.d., Work of the Dight Institute Folder, Box 4, Subject and Lecture Files, DI.

⁶² *Ibid.*

the people from above, it is bound to fail, as has always been the case in the dismal history of the formal so-called Eugenics movements.”⁶³ His eugenics, then, was based on a philosophy of human betterment that focused on the individual presumably without coercion and state involvement.

Reed’s work as a geneticist necessitated an interest in heredity and inheritance but, like other reform eugenicists, he also believed in the crucial role of the environment as a determining factor in the expression of certain characteristics or conditions. Reed began a lecture on “The Environment” by stating that, “The strongest genotype ever conceived could not develop in a vacuum. Thus the study of genetics must always attempt to evaluate the environmental variables which can easily confuse the genetic interpretations.” He suggested that while some clinical cases will be due to environmental factors and others to simple Mendelian genetics, most will result from their complex interaction.⁶⁴ In another lecture, Reed asked whether differences between socio-economic classes were related to genetics, or rather to “chance fluctuations in the environment...Did Lincoln rise from the bottom to the top of the milk bottle because of fortuitous circumstances alone, or did his ability have a genetic basis?”⁶⁵ Reed also worked to dispel the myth perpetuated by mainline eugenicists that the nation’s collective IQ was dropping by approximately four points each generation because of the differential birthrate. He argued that intelligence was a product of both genetic and environmental factors, and

⁶³ Ibid.

⁶⁴ Sheldon C. Reed Lecture, “The Environment XXVIII,” n.d., Box 3, Subject and Lecture Files, DI.

⁶⁵ Sheldon C. Reed Lecture, “Differential Birth Rates in the USA,” n.d., Box 3, Subject and Lecture Files, DI. Underline in original.

suggested that “the intelligence of the population was not decreasing but probably improved slightly with each generation.”⁶⁶

The developing field of genetic counseling was also shaped by other shifts in cultural meanings and material practices such as advances in molecular biology, cytogenetics, medical genetics, and affiliated technologies. Reed was astutely aware of how technological developments in genetic science moulded genetic counseling. In 1949, he wrote that his work “Counseling in Human Genetics” was “not a scientific paper; instead it is an exploration into a still unknown branch of science where opinion has been much too strong in view of the dearth of scientific facts. The exploration is justified by the daily necessity of providing counseling in human genetics.”⁶⁷ Indeed, as Reed recognized, the early days of genetic counseling were plagued by a lack of credible genetic studies that were untainted by the poor experimental methods of eugenicists and based on “objective” laboratory experimentation. New data was scarce due to technological obstacles but also geneticists’ reluctance to work in human genetics after WWII, and eugenicists’ perversions of hereditary principles in Germany and the United States.⁶⁸ Owing to this lack of genetics research, counselors were constantly caught off guard by the questions of couples who already had an “abnormal” child and wanted to know their risk of recurrence. Reed described this problem not as a lack of “genetic theory,” but as “one of a practical lack of appropriate data.”⁶⁹

⁶⁶ Sheldon C. Reed Lecture, “Do We Need a Program of Eugenics?,” n.d.

⁶⁷ Reed, “Counseling in Human Genetics,” 7.

⁶⁸ Ludmerer, *Genetics and American Society*, 135.

⁶⁹ *Ibid.*, 18.

The major impediments to the growth of genetic counseling were dissolved by advances in genetic research and available reproductive technologies. The field's development was also spurred by changes to the legal framework in which these technologies were employed. In particular, the field was revolutionized by Lejeune and Turpin's work on "mongolism" (Down syndrome), American and British studies in biochemistry, and the discovery of chromosomes and techniques for karyotyping.⁷⁰ Late in his career, Reed marvelled at advances in reproductive technology, specifically the development of amniocentesis, saying,

Amniocentesis is a tremendous boon for those who need it...So, suddenly, genetic counseling is transformed from a simple guessing game in which the counselor interprets the genetic or environmental risks to the couple who have had an abnormal child to a preventive medicine situation of the most critical importance for the family.⁷¹

Reed envisioned a new, better role for counselors with accelerations in prenatal diagnosis, and argued that, "genetic counseling should be involved both before and after amniocentesis is performed."⁷² He also recognized that changing legislation, coupled with advances in reproductive technology, had the potential to greatly modify the brand of genetic counseling himself and others had performed since the 1940s.

In 1973, the same year the *Roe v. Wade* Supreme Court ruling decriminalized abortion, Reed noted that amniocentesis could detect biochemical and chromosomal aberrations, and "provides the option of a therapeutic abortion for those who wish to

⁷⁰ Kevles, *In the Name of Eugenics*. Chapter 15: Blood, Big Science, and Biochemistry, 223-237; and Chapter 16: Chromosomes - The Binder's Mistakes, 238-250. See also Harper, *A Short History of Medical Genetics*, 348-354.

⁷¹ Sheldon C. Reed lecture, "Practical Genetic Counseling," 1977. Underline in original.

⁷² Reed, "A Short History of Genetic Counseling," 7.

exercise the option.”⁷³ Moreover, Reed and the Minnesota Human Genetics League fought for the repeal of Minnesota’s abortion law and for the provision of therapeutic abortions. As early as 1968, Reed called for the “modernization of our antiquated statutes” and liberalization of abortion laws, “which did not foresee the beneficial scientific advances now coming about.”⁷⁴ He argued that “abortion should be treated as any other medical condition, and that the moral aspects should be determined by the persons involved rather than by law.”⁷⁵ The possibility of detecting birth defects *in utero* and the option to legally terminate a pregnancy dramatically altered the practice of genetic counseling. Patients certainly had a greater range of reproductive choices, although the extent and meanings of these choices would come to be seriously questioned by the disability community and reproductive rights activists throughout the late-twentieth century.

Reed’s brand of genetic counseling also coalesced well with dominant shifts of the post-WWII period through a new emphasis on population policy and family planning. Like many scientists, Reed increasingly focused his attention on the “population explosion.” He argued that there were two types of population growth of interest to the geneticist: gene quality and gene quantity.⁷⁶ Reed was concerned about the growing differential birthrate between various “classes” of nations, and was part of the Office of

⁷³ Ibid.

⁷⁴ Sheldon C. Reed to “The Reader of This Pamphlet,” 16 April, 1969, Correspondence H, 1948-1961, Box 1, Correspondence and Administrative Files, DI. The pamphlet was titled “Medical and Genetic Indications for Therapeutic Abortions.” See also “Abortion Laws Repeal Urged,” St. Paul *Pioneer Press*, 22 November, 1968, Sheldon Reed Info File, DI.

⁷⁵ Sheldon C. Reed to Senator Gilbert E. Bursley, 28 July, 1969, Correspondence B, 1965-83, Box 1, Correspondence and Administrative Files, DI.

⁷⁶ Sheldon C. Reed Lecture, “Population Problems, General,” Box 4, Subject and Lecture Files, DI.

International Programs' Committee on Population Studies in the late-1960s.⁷⁷ He saw reproductive regulations of various kinds as the answer to population problems, arguing that if you send a few million tons of grain to India, you will save the lives of many people; a decade later, however, famine and hunger will once again be a problem because of unchecked reproduction.⁷⁸ Reed clearly subscribed to larger discourses of “the prolifically fertile Third World,” and concerns that the over-breeding of women of colour in particular was resulting in global hunger and poverty.⁷⁹

Nonetheless, Reed was wary of uncritically applying genetic counseling to the pursuit of population control; in particular, he worried that counseling, which was intended to help individual families, would “become the tool of [a] governmental population program,” arguing that, “Humanity cannot afford the costs of political perversion of the principles of genetics.”⁸⁰ Still, genetic counseling had some role to play in the agendas of population controllers. Reed advocated the application of birth control methods abroad, but thought genetic counseling would be crucial in providing people with the children they wanted within a smaller population. Reed suggested that, “Genetic counseling will become increasingly important if population growth is controlled, as

⁷⁷ “Committee on Population Studies of the Office of International Programs, 1968-69,” Committee on Population Studies, 1967-1969, Box 1, Correspondence and Administrative Files, DI.

⁷⁸ “Sexual Abstinence Called Answer to Food Crisis,” *Minneapolis Star*, 6 April, 1951, Publicity for the Dight Institute, Clippings and Programs, 1940s and 50s, Box 3, Correspondence and Administrative Files, DI.

⁷⁹ Laura Briggs, *Reproducing Empire Race, Sex, Science, and US Imperialism in Puerto Rico* (Berkeley: University of California Press, 2002), 115-116. Briggs focused particularly on Puerto Rican women as the subjects of U.S. social scientists interested in overpopulation, Chapter 4: Demon Mothers in the Social Laboratory: Development, Overpopulation, and “the Pill,” 1940-1960, 109-141.

⁸⁰ Reed, “A Short History of Genetic Counseling,” 9.

couples having a limited number of children will seek ways of insuring that these children are normal.”⁸¹

As a corollary to population policy, genetic counseling grew as a valuable service within domestic post-war family planning projects. Here, new practices were aided by the growing acceptance of birth control and the decriminalization of abortion. Since the early days of the Dight Institute, Clarence P. Oliver had indicated that family planning was an important part of the institution’s mission by acting as an advisor to the Marital Counselors of the Planned Parenthood League.⁸² Sheldon Reed also acted as the director of the Minnesota’s Planned Parenthood from 1948 to 1965.⁸³ He supported Planned Parenthood on the logic that people must want and use family planning measures (like oral contraceptives or douches) since most contemporary families were limited to three children. Reed applied this interest in family planning to genetic counseling specifically by suggesting the valuable role counseling could play by preventing birth defects and insuring the “normalcy” of each child within these smaller families.⁸⁴

Sheldon Reed named and developed the profession of genetic counseling within dominant socio-cultural, technological, and legislative transitions of the post-WWII era. During his time as director of the Dight Institute, Reed received countless inquiries from parents, physicians, researchers, adoption agencies, and others who wanted to know more

⁸¹ Sheldon Reed, “Human Factors in Genetic Counseling,” The Delivery of Genetic Counseling folder, Box 4, Dight Lectures, DI.

⁸² Clarence P. Oliver, “The Dight Institute Report for the Year July 1, 1942 to June 30, 1943,” Annual Report (2nd), 1942-43, Box 1, Correspondence and Administrative Files, DI.

⁸³ Short Biography of Reed upon his retirement, untitled, *College of Biological Sciences Newsletter*, June 1978, Sheldon Reed Info File, DI.

⁸⁴ Sheldon Reed Lecture, “Human Genetics and Family Planning,” Genetic Counseling and Planned Parenthood, 1966 folder, Box 5, Dight Lectures, DI.

about genetics and their particular chances of carrying or passing on a genetic disease. Reed stayed as Director of the Dight Institute until 1977 and exercised a profound impact on the profession of genetic counseling and the field of clinical genetics. In 1941 there were only 10 counseling centers in the U.S. but by 1974, nearly 400 counseling centers had cropped up across the country.⁸⁵ Most significant is his influence on contemporary genetic counselors. One counselor who started working in the 1980s remembered that he wrote to Sheldon Reed for advice when unsure about whether to pursue genetic counseling as a career. He recalled that,

I had questions for him, and he was very nice to send a handwritten response back explaining very clearly. I don't even remember what my question was, but just getting a letter back from someone like that was such an inspiration to me to keep with it. If people like him were encouraging me and writing back, then I thought, 'Yeah, this is going to work out ok for me.'⁸⁶

“Better Offspring Everywhere”: Paul Popenoe and Marriage Counseling in California.

Marriage counseling as it emerged in the 1930s was designed to promote the health and happiness of the American family. Counseling services were popularized due largely to the efforts of Dr. Paul Popenoe. His interest in marriage counseling sprouted from his enthusiasm for, and involvement in, the early-twentieth century eugenics movement. Indeed, Popenoe was a member of the Human Betterment Foundation of California and a colleague of famous American eugenicists like Harry Hamilton Laughlin. The importance of marriage counseling was underscored by the attention allocated to mate selection and eugenically-sound marriages within both positive and negative eugenics programs.

⁸⁵ Jordan, “Reducing the Odds,” 20.

⁸⁶ Interview with GCS00I20, 5 October, 2010.

Popenoe aimed to stem the reproduction of “defectives” through eugenic measures such as marriage laws, anti-immigration legislation, and surgical sterilization. At the same time, Popenoe encouraged the reproduction of desirable couples through marriage counseling, which sought to apply contemporary medico-scientific knowledge to the creation and maintenance of successful, eugenically-healthy marriages.

As they promoted happy marriages, Popenoe and his organization, the American Institute of Family Relations (AIFR), founded in 1930, engaged with larger shifts away from a strict, mainline eugenic ideology and towards family planning. Popenoe was also integral to the emergence of genetic counseling through his explicit concern with couples’ health and that of their future offspring. Marriage counseling certainly gained momentum in the post-WWII period. Its initial development, however, occurred in the 1930s and therefore before the dominant shift towards family planning. This was due to local circumstances including the particular intensity of California’s eugenic program. Marriage counseling also emerged in California during this period as a result of Popenoe’s exposure to “Hollywood’s chronic culture of divorce,” and his perceptions of a decline in family life across the early-twentieth century United States.⁸⁷ The persistence of marriage counseling after the Second World War, however, also demonstrates what historian Molly Ladd-Taylor described as “deep affinities between eugenics...and the pronatalist domestic culture of the postwar period.”⁸⁸

⁸⁷ Stern, *Eugenic Nation*, 160.

⁸⁸ Molly Ladd-Taylor, “Eugenics, Sterilisation, and Modern Marriage in the USA: The Strange Career of Paul Popenoe,” *Gender & History* 13, no. 2 (August 2001), 299.

Paul Popenoe is a particularly intriguing historical character who transitioned seamlessly from a hard-line eugenicist to the nation's foremost marriage counselor.⁸⁹ Born in Kansas in 1888 but raised in California, Popenoe was fascinated by horticulture and agriculture from an early age. During the 1910s, Popenoe worked as editor of a Pasadena newspaper. He abandoned this work by 1913 to pursue his interest in eugenics and human breeding, and to become editor of the *Journal of Heredity*. During the First World War, Popenoe acted as a lieutenant and later as a captain in the U.S. Sanitary Corps with the responsibility of implementing prohibitory laws against prostitution and drinking. After three years of service, he returned to his eugenic inclinations, serving as executive secretary to the American Social Hygiene Association in New York before returning to California.⁹⁰ In the mid-1920s, Popenoe began his work with E.S. Gosney, a lawyer, banker, and eugenics enthusiast who founded the Human Betterment Foundation (HBF) in 1928. The purpose of the non-profit organization was to work for “the advancement and betterment of human life, character and citizenship, particularly in the United States of America, in such a manner as shall make for human progress in this life.”⁹¹ For the HBF, this meant “constructive and educational efforts for the protection and betterment of the human family” rather than the provision of “relief work” or “care of the unfortunate.”⁹²

⁸⁹ Ibid., 300-301.

⁹⁰ E.S. Gosney and Paul Popenoe, *Sterilization for Human Betterment: A Summary of Results of 6,000 Operations in California, 1909-1929* (New York: MacMillan, 1929), x-xi; Paul Popenoe, ed., *Techniques of Marriage and Family Counseling* (Los Angeles: The American Institute of Family Relations, 1977), v-vii.

⁹¹ “Articles of Incorporation for the Human Betterment Foundation,” Folder 2.10, Corporate Documents, Members, Trustees, Human Betterment Foundation (hereafter HBF)-Records, Research, and Personal Correspondence, California Institute of Technology archives, Pasadena, CA.

⁹² Ibid.

The Human Betterment Foundation worked on familiar eugenic concerns such as the differential birthrate, “race suicide,” and the threat of “mental defectives.” Their main efforts, however, centered on sterilization as the cornerstone of the state’s eugenics movement. California was responsible for 20,000 of the more than 60,000 individuals sterilized across the U.S., by far the most of any state.⁹³ Many of these individuals were non-white, unskilled laborers; indeed, 15 percent of sterilized individuals were of Mexican heritage despite comprising only 4 percent of California’s population.⁹⁴ For eugenic extremists (a definition which is appropriately applied to many Californian eugenicists), sterilization was the key to halting the reproduction of “defectives” and promoting the regeneration of good American stock. In their work *Sterilization for Human Betterment* (1929), Gosney and Popenoe described the successful implementation of their state’s 1909 sterilization law, particularly its provision for the sterilization of all “feeble-minded” patients before their release from the Sonoma state home.⁹⁵ Sterilization prohibited the transference of “inherited defects” to subsequent generations, and was the practical remedy to Gosney and Popenoe’s belief that,

No one has any right to carry the gene of Huntington’s chorea or haemophilia into another family; the state might well annihilate such diseases as these just as it has yellow fever. Families that have suffered from them would probably be the first to agree to this, if they were intelligent. The growth of a eugenic conscience and knowledge of human pedigrees would help to make these carriers unmarriageable unless sterilized, hence they would probably welcome sterilization.⁹⁶

⁹³ Largent, *Breeding Contempt*, 77.

⁹⁴ Ladd-Taylor, “Saving Babies and Sterilizing Mothers,” 144. Ladd-Taylor’s study is a very useful comparison of sterilization in California and Minnesota. See also Alexandra Minna Stern, *Eugenic Nation*, 111.

⁹⁵ Gosney and Popenoe, *Sterilization for Human Betterment*, xiii.

⁹⁶ *Ibid.*, 120.

German eugenicists applauded the California program while HBF members and California eugenicists, for their part, openly approved of Germany's sterilization policies.⁹⁷ Dr. George Dock, who translated the German legislation for the group, noted in a letter to Gosney that, "It seems to me that the German law is an excellent one...I think the reference to the California work, and the work of the Foundation is a very significant thing. The matter has given me a better opinion of Mr. Hitler than I had before. He may be too impulsive in some matters, but he is sound on the theory and practice of eugenic sterilization."⁹⁸

To supplement their central focus on sterilization, Paul Popenoe and the Human Betterment Foundation encouraged other eugenic measures to curb the marriage and reproduction of the "unfit," and promote the regeneration of the gene pool. In a paper titled "Sterilization as a Social Measure," Popenoe admired a 1935 Nebraska statute requiring the registration of the state's feebleminded population. Registered individuals were barred from obtaining a marriage license unless they could provide evidence of sterilization.⁹⁹ Indeed, marriage laws were implemented throughout the United States whereby individuals deemed eugenically-undesirable were prohibited from marrying and (at least in theory) from producing similarly "unfit" offspring.¹⁰⁰ Popenoe also subscribed

⁹⁷ Paul, *Controlling Human Heredity*, 86.

⁹⁸ Dr. George Dock to E.S. Gosney, 31 January, 1934, Folder 21.7, Germany-Sterilization Law, Box 21, Sterilization-Papers, Data, Correspondence, HBF.

⁹⁹ Paul Popenoe, "Sterilization as a Social Measure," Folder 1.6, Articles by the Human Betterment Foundation Staff, Box 1, Records, Research, and Personal Correspondence, HBF; Stern, *Eugenic Nation*, 108.

¹⁰⁰ Connecticut became the first state to pass a law regulating marriage of imbeciles, epileptics, and the feebleminded in 1896. Kansas, Ohio, New Jersey, Michigan and Indiana passed similar laws into the early 1900s. Additionally, 28 states passed anti-miscegenation laws explicitly prohibiting the intermarriage of, and reproduction between, white and black Americans to prevent "racial mixture." Some laws also extended to Native American or Asian individuals (Haller, *Eugenics*, 47, 158).

to the anti-immigration sentiments expressed by mainline eugenicists like Harry Hamilton Laughlin and Madison Grant, and was a proponent of immigration quotas through the Immigration Act of 1924.¹⁰¹

The HBF sought to supplement sterilization and immigration restrictions with other measures to effect lasting change in the hereditary composition of the American people. Popenoe and Gosney in particular understood that, “Great as may be the effects of sterilization, this measure is valuable largely as a help to, as a means for clearing the way for, a positive program of eugenics.”¹⁰² As the larger American eugenics movement promoted Better Baby and Fitter Families contests, California’s key eugenicists concentrated instead on the development of marriage counseling. Throughout the late-1930s and early 1940s, the Human Betterment Foundation, and Paul Popenoe in particular, pushed for the establishment of marriage counseling as an institution. Popenoe recalled that, “I suggested [marriage counseling] to Mr. Gosney, who agreed emphatically and offered to let me give half my time, at his expense, to promoting a campaign for better offspring everywhere - some needed fewer children but many more needed more and better offspring.”¹⁰³

The development of marriage counseling was part of an identifiable post-WWII shift from eliminating the “unfit” and cataloguing racial differences, to an emphasis on sexuality, gender, and the habits of “desirable” married couples.¹⁰⁴ Popenoe captured this shift earlier through his ability to combine what Ladd-Taylor described as “eugenics

¹⁰¹ Ladd-Taylor, “Eugenics, Sterilisation and Modern Marriage,” 304.

¹⁰² Gosney and Popenoe, *Sterilization for Human Betterment*, 135.

¹⁰³ Popenoe, ed., *Techniques of Marriage and Family Counseling*, vii.

¹⁰⁴ Stern, *Eugenic Nation*, 9.

evangelising with a steadfast moralism and ringing endorsement of family values.”¹⁰⁵ Popenoe still advocated eugenic sterilization, but by the 1930s he focused his efforts primarily on marriage counseling. He pursued his new vocation at the recently-established American Institute of Family Relations (AIFR) in Pasadena, which he championed as the “first of its kind in the world” devoted to “employing the resources of modern science to strengthen marriage and family life.”¹⁰⁶

Popenoe’s interest in marriage counseling and the foundation of the AIFR surfaced from what he perceived to be a breakdown in family life. He was troubled by his estimation of 400,000 divorces a year in the U.S., and found the Los Angeles divorce rate particularly unsettling. He declared that, “the average person who marries in Los Angeles County has only half a chance to succeed” since, by his calculations, 13,000 of 25,000 marriage licenses granted ended in divorce or other family court cases.¹⁰⁷ Moreover, Popenoe saw marriage counseling as integral to the maintenance of the institution of marriage amidst a general receding of Victorian values, particularly regarding gender roles and women’s place within marriage.¹⁰⁸ He believed that the concepts of marriage and monogamy were fundamentally well-suited to basic human nature, and that marriages encountered problems or failed because young people were not adequately prepared for married life nor sufficiently educated in finding an ideal mate.¹⁰⁹ Sheldon Reed voiced a similar concern in a 1948 lecture, “Genetics and Marriage.” In this lecture, he supported

¹⁰⁵ Ladd-Taylor, “Eugenics, Sterilisation and Modern Marriage,” 305.

¹⁰⁶ Paul Popenoe and Dorothy Cameron Disney, *Can This Marriage Be Saved* (New York: MacMillan, 1960), vii. This volume is a collection of articles published in the *Ladies’ Home Journal*.

¹⁰⁷ *Ibid.*, xviii; Popenoe, *Marriage: Before and After* (New York: W. Funk, 1943), 3.

¹⁰⁸ Ladd-Taylor, “Eugenics, Sterilisation and Modern Marriage,” 308.

¹⁰⁹ Paul Popenoe, *Modern Marriage: A Handbook* (New York: The MacMillan Co., 1925), vii-viii.

“more education for marriage” considering an estimated divorce rate of two in five marriages, and strongly advocated for the utility of marriage counseling courses.¹¹⁰ Popenoe therefore provided heterosexual couples with counseling on how to find a suitable mate based on mutual age, race, socio-economic class, and religion (amongst other factors), and how to create a happy and successful marriage characterized by companionship, an active sex life, and long-term compatibility.

The American Institute of Family Relations aimed to “promote successful family life in every possible way” by helping couples deal with relationship issues including sex, marriage, heredity, and parenthood. Like the Dight Institute, the AIFR was divided into three departments devoted respectively to education, research, and “personal service,” the branch concerned with client consultations and marriage counseling.¹¹¹ In its earliest years, the Institute employed eight “medical consultants” and four psychologists, although Popenoe performed the majority of the marriage counseling himself with the assistance of a psychiatric social worker.¹¹² Popenoe recalled that initially, “To a large section of the general public...the purpose of marriage counseling was a mystery.”¹¹³ The Institute’s clientele grew, however, with the onset of the Great Depression, a crisis that revealed the lack of family services in Los Angeles. In the Institute’s first 1,000 cases, Popenoe helped couples with premarital issues and matters of child welfare, as well as with issues of “marital maladjustment.” As a supplement to counseling, the Institute also offered training courses to certify marriage counselors and by 1960, the AIFR had sixty-

¹¹⁰ Sheldon C. Reed Lecture, “Genetics and Marriage, 1948,” Box 3, Subject and Lecture Files, DI.

¹¹¹ Popenoe, *Marriage: Before and After*, vii-ix.

¹¹² Popenoe and Disney, *Can This Marriage be Saved?*, vii.

¹¹³ *Ibid.*

one counselors on staff.¹¹⁴ The organization also published *Family Life*, a monthly bulletin, as well as other educational materials for public circulation, and conducted conferences on marriage counseling across the United States.¹¹⁵

Popenoe's marriage counseling, and his publications on marital happiness, focused explicitly on the importance of planning one's marriage and family. Above all, Popenoe's counseling philosophy revolved around what Ladd-Taylor described as a "therapeutic approach to personal happiness and the elevation of family togetherness."¹¹⁶ Popenoe sought to rid mate selection of a "bogus idea of so-called romance" and notions of "love at first sight," criteria which he deemed a ridiculous basis for a lasting marriage.¹¹⁷ He suggested that when deciding on one's "choice of a wife," which he described as "the most important choice a man ever has to make," one cannot be "entirely the victim of caprice or of any 'little blind god.'"¹¹⁸

Popenoe described the decision to marry as "a scientific choice," and suggested that,

It goes without saying, that a man ought to marry a girl whom he loves. But as I have previously remarked, love is to a large extent a matter of propinquity, and is also largely governed by one's ideals. Before one reaches the stage of falling in love, it will do no harm to have clearly in mind the kind of girl with whom one should prefer to fall in love. If the girl is the right one, the husband's love for her will be likely to last much longer than if it is based on mere propinquity, sex attraction, ignorance, and curiosity.¹¹⁹

Popenoe was confident in the merits of a scientifically-orchestrated marriage and the Institute's track record; apparently not one couple who attended the AIFR for pre-marital

¹¹⁴ Ibid., vii-viii.

¹¹⁵ Ibid., ix.

¹¹⁶ Ladd-Taylor, "Eugenics, Sterilisation and Modern Marriage," 305.

¹¹⁷ Popenoe, *Marriage: Before and After*, vii.

¹¹⁸ Popenoe, *Modern Marriage*, 30.

¹¹⁹ Ibid., 42.

counseling divorced in the clinic's first eight years.¹²⁰ Once a couple had initiated the courting process, the key to a successful relationship was for the man and the woman to fulfill their proper roles. Popenoe suggested that women involve themselves in their male companion's interests, "minister to his comforts," and "take care that the young man sees her often, but sees her always at her best." Men were then expected to avoid rushing a woman into a commitment, attempting to dazzle her, and taking up a "Don Juan" attitude.¹²¹ Once married, Popenoe counseled couples to continue to attune themselves to their suitable roles, and work on companionship and "sexual adjustment" since an active and fulfilling sex-life was integral to a happy marriage. Here, he anticipated themes of the post-WWII movement towards family planning by emphasizing the importance of an active sex life in fostering a happy family life, while simultaneously reinforcing men and women's observance of appropriate gender roles within marriage.

There are several direct links between Popenoe's version of marriage counseling and early genetic counseling. As Alexandra Minna Stern noted, marriage counseling was a predecessor of genetic counseling in its emphasis on heredity and genetics, and its use of pedigrees and family histories. Both types of counseling also subscribed to Carl Rogers' psychotherapeutic philosophies.¹²² The medical aspects of a relationship and the health of future progeny were clearly integral to the work of the Institute, which was referred to as "a marriage doctor with a phenomenal rate of 'cures.'"¹²³ From the start, the importance of biology and heredity, and an interest in patients' psychological processes, underlay

¹²⁰ Popenoe, *Marriage: Before and After*, 3.

¹²¹ Popenoe, *Modern Marriage*, 92-95, 104-105.

¹²² Stern, *Eugenic Nation*, 162. Stern mentioned this correlation in her chapter otherwise focused on Popenoe and the AIFR. See Chapter 5: Centering Eugenics on the Family, 150-181.

¹²³ Popenoe, *Marriage: Before and After*, vi.

much of Popenoe's advice on marriage. In each counseling session, clients were administered at Johnson Temperament Analysis Test (JTA) that consisted of 182 questions to evaluate their temperament, personality, emotional maturity, and compatibility with their partner. The AIFR staff assessed the individual's test results in relation to a series of oppositional traits including "active-quiet," "aggressive-submissive," and "depressive-gay-hearted." Popenoe's adherence to this testing format was part of a larger post-WWII fascination with biotypology. This was a system of scientific categorization that catalogued people along continuums, rather than in rigid vertical hierarchies, in order to emphasize hereditary but also environmental, emotional, and psychological factors. One's place on the continuum was based on the results of Rorschach inkblots, dream analysis, personality testing, and blood samples.¹²⁴

Popenoe's marriage counseling overlapped significantly with genetic counseling. The crossover is evident in their mutual emphasis on individual and family health histories when advising couples on the implications of mate selection for their offspring. In an AIFR counseling session, couples seeking premarital education were interviewed separately by a counselor of the same sex. Counselors also took and assessed the client's personal and family histories, and a medical counselor performed a physical examination.¹²⁵ Popenoe stressed the importance of heredity and intergenerational factors that could affect marital happiness, and implored his clients to "Look over your past history and that of your family. Note anything that is likely to affect that happiness of

¹²⁴ Stern, *Eugenic Nation*, 152-54.

¹²⁵ Popenoe, *Marriage: Before and After*, v, 4-6.

your marriage, and prepare to offset it. It may be a question of health, or heredity, or of some unhappy personal experience.”¹²⁶

Paul Popenoe’s marriage counseling also resembled genetic counseling in his overall concern for, and appreciation of, genetic science. Popenoe was trained as a biologist and received a doctorate from Occidental College in 1929 for his work with the date palm. He was particularly fascinated by mechanisms of inheritance, transmission modes of inherited diseases, and the implications of genetics for marriage. He echoed Sheldon Reed’s philosophy on the ultimate purpose of reproduction and childbearing in his belief that “the production of children is the goal of all life.”¹²⁷ Popenoe understood that his role was to provide education about hereditary diseases so as to create informed marital unions and foster intelligent matings. His works *The Child’s Heredity* (1930) and *Problems of Human Reproduction* (1926) focused exclusively on biological issues couples could potentially face in childbearing and hereditary issues likely to affect their offspring.¹²⁸

Popenoe recognized as early as 1930 that eugenicists’ reliance on over-simplified Mendelian genetics was inadequate; he therefore turned to newer scientific understandings of genetics with the hypothesis that “most human traits, particularly the more normal and important ones, are compound.”¹²⁹ He described to his readers how chromosomes worked and how sex was determined at conception. He explained how to identify single gene traits, whether a trait was dominant or recessive, and if a gene was

¹²⁶ Ibid., 4.

¹²⁷ Popenoe, *Modern Marriage*, 175.

¹²⁸ Paul Popenoe, *The Child’s Heredity* (Baltimore: Wilkins and Williams, 1930); Paul Popenoe, *Problems of Human Reproduction* (Baltimore: Williams and Wilkins, 1926).

¹²⁹ Popenoe, *The Child’s Heredity*, 13, 260.

located on a sex-chromosome or was “sex-limited.”¹³⁰ Popenoe performed calculations using a “checkerboard” Punnett square to demonstrate the risk for inheriting dominant versus recessive conditions, and the ways in which a mother and father’s genes might interact in a given “mating.”¹³¹ He provided great detail on how the inheritance of diseases or errors of development such as deafness, defects of the eyes, and congenital dislocation of the hip were expressed through the reproduction of individuals carrying particular genes. In his work *Problems of Human Reproduction* (1926), Popenoe also counseled parents on problems related to conception, pregnancy, and childbirth. He focused on problems of sterility, impotence, and even artificial insemination, where he spent some time debating the medical ethics of the procedure.¹³²

Popenoe’s marriage counseling was also based on a patient ethos comparable to that encapsulated in Carl Rogers’ client-centered therapy. Rogers was a central figure in the humanist brand of psychotherapy that was the dominant psychological paradigm in the United States after the Second World War. Rogers was best known for his “person-centered” and “non-directive” counseling philosophies. These theories (which are further elaborated in chapter 4) emphasized the need for counselors to view patients as sources of information and generators of meaning within a session, and cautioned counselors against becoming directly involved in the therapeutic subject’s decision-making process.¹³³ As the field of genetic counseling professionalized, it drew heavily on Carl Rogers’

¹³⁰ Ibid., 254-256.

¹³¹ Ibid., 257-258.

¹³² Popenoe, *Problems of Human Reproduction*, 104, 129, 135-140.

¹³³ Carl R. Rogers, *Counseling and Psychotherapy: Newer Concepts in Practice* (Boston: Houghton Mifflin, 1942), 34; Carl R. Rogers, *Client-Centered Therapy: Its Current Practice, Implications, and Theory* (Boston: Houghton Mifflin, 1951), 29.

principles to structure counselors' relationships with their clients. Popenoe articulated a commitment to such an ethic in response to client's concerns that marriage counselors would tell them to get a divorce, or label them "crazy," saying,

No counselor ever intends to make any decision for a client. His function is to guide the client into thinking through his own problem more carefully, so that he can make his own decision on the basis of all the evidence, not on the basis of ignorance or a momentary whim.¹³⁴

Popenoe, like Sheldon Reed, envisioned counseling as a type of education, and the role of the counselor as a mediator or interpreter who "can guide and encourage, but the client must do the work."¹³⁵ This language and understanding of counseling is reflected in the experiences and ideologies of genetic counselors from the 1960s to 2000.

In the 1930s, the AIFR became an integral part of California's social services. The Institute advised thousands of clients and reached an additional 20 million people through printed articles.¹³⁶ After 1945, marriage counseling expanded as psychological therapy was incorporated into mainstream medical practice. In 1932, just three centers for marriage counseling existed in the United States but by 1968, California had more than 1,800 practicing marriage counselors.¹³⁷ Indeed, marriage counseling services are solicited by couples even today, demonstrating a continued subscription to the field's underlying principles. Despite this growth, however, Popenoe's particular brand of marriage counseling lost much of its influence by the late-1960s. With the emergence of Second Wave feminism, Popenoe's attempts to slot modern families into Victorian

¹³⁴ Popenoe and Disney, *Can This Marriage Be Saved?*, xvi.

¹³⁵ *Ibid.*, xvii.

¹³⁶ Stern, *Eugenic Nation*, 163.

¹³⁷ Ladd-Taylor, "Eugenics, Sterilisation and Modern Marriage," 312.

models of womanhood and manhood were challenged and lost much of their currency.¹³⁸ Popenoe, who was unwilling to waiver from his conservative vision of the family, found himself increasingly aligned with religious authorities and removed from current social discourses about marriage and the American family. As marriage counseling lost cultural relevance, genetic counselors took up Popenoe's interests in biology and heredity, and incorporated them into an increasingly-elaborate scientific schema that made such ideas more palatable to Americans after the war.

“Wednesday’s Child is Full of Woe”: The Human Betterment League of North Carolina.

The Human Betterment League of North Carolina (HBL) was founded by Dr. Clarence Gamble in 1947 amidst the post-WWII Nuremberg Trials. The League was established through Birthright, a New Jersey-based organization for sexual sterilization. The group wanted to furnish a Southern sterilization stronghold, an endeavour perfectly suited to North Carolina's deeply-entrenched local eugenic traditions.¹³⁹ Although it was founded at mid-century, the work of the HBL resembled that of early-twentieth century eugenics societies, particularly through its focus on enforcing North Carolina's sterilization legislation. The League participated in dominant shifts in cultural meanings and material practices, however, by focusing on population control, family planning, and genetic counseling by the 1960s. The Human Betterment League, known as the Human Genetics League of North Carolina by the early 1980s, therefore offers another pathway

¹³⁸ Ibid., 320.

¹³⁹ Reilly, *The Surgical Solution*, 133-134; Ian R. Dowbiggin, *The Sterilization Movement and Global Fertility in the Twentieth Century* (Oxford: Oxford University Press, 2008), Chapter 2: A New League, 46-134. Birthright changed its name to the Human Betterment Association of America in 1950 (Dowbiggin, 73).

to genetic counseling, and demonstrates the overlap between hegemonic and subjugated ideologies of the period.

North Carolina claims a rather complex and intriguing history of abortion, sterilization, and birth control politics, and one that is integral to an appreciation of the emergence of genetic counseling in this state. In *Choice and Coercion*, a study of twentieth-century health and welfare in North Carolina, Johanna Schoen analyzed the state's birth control program. Pushed by Clarence Gamble and Margaret Sanger, and supported by New Deal programs, birth control trials often used poor and/or African American women to test the efficacy of various birth control methods. Schoen also emphasized, however, the ways in which women could resist such exploitation and turn contraceptive initiatives to their own purposes.¹⁴⁰ The history of abortion politics in North Carolina is also complex. Although the procedure was criminalized in 1881, women could obtain illegal abortions in the early-twentieth century with relative ease. Fears about “abortion mills,” however, led to a crackdown on abortion providers and regulations in the immediate post-war period. By the 1960s, abortion reform was a prominent issue. North Carolina reformed its abortion law in 1967 (six years before *Roe v. Wade*) to allow for greater access to therapeutic abortions based on an intricate interweaving of eugenic arguments, fiscal concerns over welfare costs, anxieties about unmarried women's sexuality, and increasing support for the prevention of birth defects.¹⁴¹

¹⁴⁰ Johanna Schoen, *Choice and Coercion: Birth Control, Sterilization and Abortion in Public Health and Welfare* (Chapel Hill: University of North Carolina Press, 2005).

¹⁴¹ *Ibid.*, 147, 163, 195

North Carolina also had one of the country's longest-standing sterilization programs and one which, by the mid-1970s, had sterilized almost 6,000 people. The state, which passed its original sterilization law in 1929, was only surpassed in the number of operations performed by Virginia and California.¹⁴² The original law was amended in 1933 to standardize sterilization practices and create the State Eugenics Board, which considered petitions for the sterilization of individuals within or outside of state mental or penal institutions.¹⁴³ During the 1940s, North Carolina expanded its sterilization program as part of a larger extension of public welfare services across the state. The rationale behind such programs were reoriented towards the culture of poverty and concerns over growing welfare costs. These anxieties targeted African Americans in particular, whose representation on welfare rolls increased from 31 to 48 percent between 1950 and 1961.¹⁴⁴

The rising number of sterilizations in North Carolina after WWII is representative of a larger geographic shift in the endorsement of sexual surgery and active use of sterilization laws. Under early-twentieth century mainline eugenics, sterilization was most popular in Progressive Midwestern states and in California, while the American South performed relatively few surgeries. After 1930, however, the numbers of sterilized individuals in North Carolina (along with Georgia and Virginia) grew rapidly. While the number of sterilizations in these states made up just 24 percent of the nation's total in

¹⁴² Largent, *Breeding Contempt*, 77. Virginia sterilized 7,325 people, while California sterilized over 20,000. The numbers do, however, vary. Johanna Schoen estimated that North Carolina sterilized 8,000 people, which would put it in second place behind California (Schoen, *Choice and Coercion*, 82).

¹⁴³ Schoen, *Choice and Coercion*, 82; Katherine Castles, "Quiet Eugenics: Sterilization in North Carolina's Institutions for the Mentally Retarded, 1945-1965," *The Journal of Southern History* 68, no. 4 (Nov. 2002), 852.

¹⁴⁴ Schoen, *Choice and Coercion*, 105, 108-109.

1944, by 1958 they had carried out 76 percent of the nation's sterilization operations.¹⁴⁵ Importantly, after 1930, there was also an increase in the numbers of women sterilized.¹⁴⁶ While many surgeries may have been administered under the guise of eugenics, sterilization was also sought out by women attempting to permanently end their childbearing capabilities. In 1963, a voluntary sterilization law was passed that allowed physicians to determine an individual's suitability for the operation.¹⁴⁷

The Human Betterment League emerged into this complex matrix of reproductive, welfare, and eugenic politics in 1947, aiming to investigate the causes and treatment of the “mentally defective” and mentally ill, and educate the public so as to provide these individuals with the best possible care.¹⁴⁸ The HBL focused on implementing North Carolina's sterilization laws as its primary objective in order to prohibit to the propagation of feeble-minded children and eliminate mental deficiency from the state's population. These goals emerged from the state's eugenic history and Birthright's sterilization agenda, but also from League members' concerns with the mental fitness of North Carolina's recruits during WWII. The rejection from service of an estimated 48 percent of potential troops on account of “mental deficiencies” and illiteracy convinced this group of concerned, well-to-do individuals that the time was ripe for a “citizens’

¹⁴⁵ Largent, *Breeding Contempt*, 81; Reilly, *The Surgical Solution*, 137-38.

¹⁴⁶ Reilly, *The Surgical Solution*, 94-95, 135.

¹⁴⁷ Schoen, *Choice and Coercion*, 120. See also John S. Rhodes, “President's Message: Voluntary Sterilization,” *North Carolina Medical Journal* 25, no. 10 (October 1963), 487.

¹⁴⁸ “Certificate of Incorporation of The Human Betterment League of North Carolina,” Charters and Articles of Incorporation, Folder 25, Series 1 Files of Marian Moser, 1947-1980, Human Betterment League Records (hereafter HBL), Southern Historical Research Collection archives, University of North Carolina Chapel Hill, NC.

organization” to “improve the quality of the state’s human resources.”¹⁴⁹ The League’s fervor was also propelled by concerns about the apparently low general intelligence of North Carolina’s children as suggested by a survey conducted by Clarence Gamble and Elsie Wulkop, then head of the Massachusetts General Hospital Children’s Department. The highly unfavourable survey results compelled North Carolinians, many of whom came from legal, education, health and business backgrounds, to organize the state-wide volunteer organization of the Human Betterment League.¹⁵⁰

Between the late-1940s and the mid-1950s, the HBL focused almost exclusively on popularizing sterilization and ensuring the implementation of the state’s sterilization legislation. The group focused largely on public education about the benefits of sterilization through the dissemination of pamphlets and other educational materials. At the League’s second meeting, Mrs. Jessica Stroup, the group’s secretary, explained that 40,000 copies of a questionnaire “What do you know about Sterilization?” were prepared to be distributed to college students, welfare workers, physicians, nurses, public officials, and others.¹⁵¹ Gamble estimated that the League distributed 136,000 pamphlets and reprints about sterilization in North Carolina, and 50,000 in other American states by 1949.¹⁵² The League also worked to obtain influence with authorities of various state agencies and institutions to affect the implementation of the law. One of the League’s members, Miss Elsie Parker, was appointed Executive Secretary of the State Eugenics

¹⁴⁹ “Our Seeds Sprouted,” history of the HBL reprinted from the 25th Anniversary Program, 14 November, 1972, author unknown, Folder 45B, Series 1 Files of Marian Moser, 1947-1980, HBL.

¹⁵⁰ Ibid.

¹⁵¹ “Meeting Minutes, November 3 1947” and “Meeting Minutes, May 8, 1948,” Charter (Original) and Meeting Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁵² Clarence J. Gamble, “Eugenic Sterilization in the United States,” *Eugenical News* 34, no. 1-2 (March-June 1949), 3.

Board, while the group's first president George H. Lawrence interviewed individuals such as the Director of State Prisons and reported him to be "keenly interested in better enforcement of the sterilization law, especially among women prisoners."¹⁵³ The League also sought eugenics experts to address the organization, and arranged for its membership to receive a copy of *Eugenics Quarterly*.¹⁵⁴

A focus on sterilization was strongly reinforced by Dr. Clarence J. Gamble who, when unable to attend meetings in person, sent letters of congratulation or notes in which he suggested other organizational initiatives. At the meeting of May 12, 1954, League secretary Jessica Stroup read that,

[Gamble] congratulates our League on our accomplishments, pointing out that N.C. reported last year 6.4 sterilizations per 100,000 population, exceeded only by Georgia. Over the five year period, N.C. is by far the leading state. Dr. Gamble believes that it would be helpful if each Board member would write to the Superintendents of Mental Institutions, commending them for the sterilizations they have arranged, if any, and urging support of the procedure when it is indicated. He also re-emphasized the value of personal contact with county welfare superintendents.¹⁵⁵

Gamble was a well-known and ardent supporter of sterilization, which he championed as the medium through which "feeble-minded persons" could be "protected from parenthood."¹⁵⁶ By 1953, the League proudly reported that North Carolina had performed more surgical operations than other states with eugenic sterilization laws in the last five

¹⁵³ "Meeting Minutes, November 5, 1949," Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL. Lawrence, a social work professor at the University of North Carolina, was an advocate for abortion reform on eugenic grounds (Schoen, *Choice and Coercion*, 183).

¹⁵⁴ "Meeting Minutes, May 12, 1954," Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁵⁵ "Meeting Minutes, November 5, 1954," Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁵⁶ Clarence J. Gamble, "Preventive Sterilization in 1949," *Journal of the American Medical Association* 144, no. 9 (1950), 783.

years and by 1954, counted 2,500 sterilizations performed since the initiation of sterilization legislation in 1929.¹⁵⁷ It was likely not a coincidence that the number of African Americans sterilized in North Carolina increased dramatically from 23 to 64 percent between the 1930s and 40s and the mid-1960s, the period characterized by the HBL's most fervent pro-sterilization efforts.¹⁵⁸ The League, therefore, quite obviously focused on eugenics and sterilization in its early existence, even after many states had shied away (at least publicly) from overtly eugenic agendas.

The Human Betterment League continued to discuss the merits and uses of sterilization throughout the 1940s and 50s, and even intermittently into the early 1960s. Gradually, however, they also began to incorporate other ideological trends of the post-WWII period, specifically a concern with family planning and population policy. In 1952, the League received letters from Clarence Gamble noting his work on population policy in a global context, and in relation to other key birth and population control advocates. One correspondence read, "Dr. Gamble sends us his greetings. Last month he and Mrs. Gamble met Margaret Sanger in Japan, where they had interviews with officials concerning birth control. They are now in India to attend a World Conference of Planned Parenthood."¹⁵⁹ In a significant international corollary, Gamble was also intimately involved with clinical birth control trials in the island "laboratory" of Puerto Rico

¹⁵⁷ Joseph L. Morrison, "Illegitimacy, Sterilization and Racism: A North Carolina Case History," *The Social Service Review* 39, no. 1 (1965), 2-3.

¹⁵⁸ Schoen, *Choice and Coercion*, 108.

¹⁵⁹ "Meeting Minutes, November 13, 1952," Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL. Johanna Schoen also noted the efforts of Gamble and Sanger to take birth control to Japan, India, and Puerto Rico as part of population planning initiatives. See *Choice and Coercion*, Chapter 4: "Bringing Foam and Jelly to the Natives": Family Planning Goes Abroad, 197-240.

between the mid-1930s and 1950s.¹⁶⁰ At a 1957 meeting, the HBL discussed a *Time* magazine article titled, “The Population Explosion,” and the problems of overpopulation in “underdeveloped countries” in particular.¹⁶¹ By the early 1960s, population policy dominated many of the group’s discussions.

Members of the Human Betterment League also subscribed to the growing sentiment that the population explosion was one of the greatest problems facing the United States internationally but also at home. Historian Rickie Solinger has suggested that American fears of the population bomb centered domestically on the culture of poverty, and the fecundity and sexuality of black women. These women were increasingly seen throughout the 1960s not only as “breeders of unwanted babies,” but as “bearers of social pathology and of social breakdown.”¹⁶² The HBL participated in family planning initiatives within North Carolina and throughout the U.S. For example, the group received an invitation each year to the Planned Parenthood Association of New York’s annual conference, and decided to start sending a representative in 1965.¹⁶³ The HBL also became associated with the Family Life Council in 1959, and the League’s Marian Moser sat on North Carolina’s Family Planning Advisory Council, which argued for women’s access to birth control and abortion.¹⁶⁴ North Carolina’s voluntary sterilization law of 1963 was undoubtedly shaped by post-war shifts towards family planning and population control.

¹⁶⁰ Briggs, *Reproducing Empire*, 102-108.

¹⁶¹ “Meeting Minutes, November 12, 1957,” Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁶² Solinger, *Wake up Little Susie*, 208, 211, 213.

¹⁶³ “Meeting Minutes, May 10, 1965,” Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁶⁴ “Meeting Minutes, November 2, 1969,” Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL; “Statewide Family Planning Advisory Council, N.C. Family Planning Council Membership,” North Carolina Family Planning Advisory Council, Folder 60, Series 1, Files of Marian Moser, 1947-1980, HBL.

While the new sterilization law was still wielded for eugenic purposes, it could also be used by women looking to control their fertility and the size of their families.

The most significant divergence from the Human Betterment League's original purpose began in 1955. On May 7, Dr. C. Nash Herndon of the American Eugenics Society opened the group's meeting by remarking upon "the changing atmosphere in public opinion as to protective sterilization as gauged [sic] by hospital experiences as well as by statistics."¹⁶⁵ The HBL did not abandon their work on sterilization, but a growing awareness of the public disillusionment with eugenic measures prompted them to explore other avenues for activism. In particular, the HBL became increasingly interested in genetics through studies of radiation and the effects of nuclear fallout. On May 13, 1958, Dr. Herndon, who was also the Director of the Department of Medical Genetics at the Bowman-Gray School of Medicine, described geneticists' concerns with radiation and the incidence of mutations. He enumerated the dangers of radiation exposure and emphasized that while medical professionals were working to reduce the impact of radiation in routine medical encounters, citizens should prepare to face the larger threat of atomic energy.¹⁶⁶

By 1960, the group invited speakers to discuss the current state of the field of genetics, and the ways in which North Carolina was working towards a training program in human genetics.¹⁶⁷ The group first addressed genetic counseling specifically at a meeting on November 12, 1957, when Herndon reported that at the latest meeting of the

¹⁶⁵ "Meeting Minutes, May 7, 1955," Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁶⁶ "Meeting Minutes, May 13, 1958," Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁶⁷ "Meeting Minutes, May 18, 1960," Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

American Eugenics Society, “Emphasis is being put on eugenic counseling and the counseling of parents of defective children.”¹⁶⁸ By 1963, a clinic had been opened in Forsyth county to offer complete physical examinations, Pap smears, and counseling in an effort to apply preventive medicine to patients at low cost.¹⁶⁹ Within the next two years, the HBL studied Sheldon Reed’s seminal work *Counseling in Medical Genetics*.¹⁷⁰

In 1968, the HBL by-laws were amended to make education about, and facilitation of, genetic counseling services within a broader agenda on family planning and population control the organization’s primary focus. Although still interested in mental illness, the group carried a motion to give primacy to “the study of population trends and methods of control.”¹⁷¹ The League immediately set to channelling their efforts into a novel project for public education: a film on family planning called *Windsong*. The film was approximately fourteen minutes long and shown in a public service format, but was also available for private viewings by clubs, schools, and other organizations. Released in 1971 (four years after the reform of North Carolina’s abortion law and eight years after the sterilization law’s amendment), the film “makes the point that the availability of family

¹⁶⁸ “Meeting Minutes, November 12, 1957,” Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁶⁹ “Meeting Minutes, November 5, 1964,” Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁷⁰ “Meeting Minutes, November 2, 1959,” Charter (Original) and Minutes 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁷¹ “Meeting Minutes, April 30, 1968,” Charter (Original) and Minutes, 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL. The group discussed the film at this very first meeting focused on their new organizational purpose.

planning services has made it possible for every woman to decide her own destiny by enabling her to control the number and frequency of her pregnancies.”¹⁷²

The League focused attentively on the production of *Windsong* while at the same time reviewing its commitment to eugenic sterilization. By the early 1970s, many members felt that the state Eugenics Board needed to be modified if not completely abolished. Members also suggested that North Carolina’s sterilization law needed reconsideration given increasing access to abortion and a general acknowledgement that the broader scientific and medical community viewed sterilization “as repressing individual rights.”¹⁷³ The focus on *Windsong* was indicative of HBL member Dr. Goodman’s suggestion that “a lot of exciting things are happening now to guarantee that children will be well born. Things are moving at such a pace...that the average Obstetrician and Gynaecologist cannot keep pace with the new developments in the field [of genetics]. This is an area in which the Human Betterment League could play an important role by providing educational materials.”¹⁷⁴

By 1972, the HBL decided to once again modify its purpose to focus on “efforts to educate the public in population problems through a concentrated program on genetic counseling.” In so doing, they aspired to cultivate public awareness about the existence and value of counseling services.¹⁷⁵ One proposed course of action was to sponsor genetic

¹⁷² *Windsong* pamphlet, Brochure Development, Folder 20A, Series 1, Files of Marian Moser, 1947-1980, HBL. *Windsong* conveyed the importance of family planning through a series of songs based on familiar tunes like “Skip to My Lou.”

¹⁷³ “Meeting Minutes, May 9, 1972,” Charter (Original) and Minutes, 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁷⁴ *Ibid.*

¹⁷⁵ “The Human Betterment League of North Carolina Inc., Summary of Activities,” Committees-1977-1979, Folder 26, Series 1, Files of Marian Moser, 1947-1980, HBL.

counseling clinics throughout North Carolina. Another was to put on a series of workshops across the state on genetic counseling. The proposal that garnered the most support, however, was the production of a second film, this time on genetic counseling specifically. The film was titled *Wednesday's Child*, after the poem that reads, "Monday's child is fair of face, Tuesday's child is full of grace, Wednesday's child is full of woe." The 25-minute film demonstrated the value of genetic counseling for preventing or bettering the lives of mentally-deficient individuals, and the potential of genetic counseling within larger population control initiatives. It strove to foster constructive rather than discriminatory views of genetic disorders and "mental defects."¹⁷⁶ The League created *Wednesday's Child* with the input of geneticists from three of North Carolina's medical schools, and screened it for students, parents, teachers, local organizations, and public clinics.¹⁷⁷ The project was also submitted to film festivals, and won the top prize at the International Film and T.V. Festival in New York in 1975.¹⁷⁸

In the mid-1970s, the Human Betterment League continued its efforts to promote genetic education and ensure the availability of genetic services across North Carolina through federal funding. This funding was made available to states under the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act of 1976, sometimes referred to simply as the National Genetic Diseases Act.¹⁷⁹ The Act intended to "preserve and protect the health and welfare of all citizens" by providing national

¹⁷⁶ Ibid.

¹⁷⁷ *Wednesday's Child* pamphlet, Artwork, Folder 5, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁷⁸ "Our Seeds Sprouted," 14 November, 1972, HBL.

¹⁷⁹ *National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act*, Public Law 92-278, 22 April, 1976, National Institutes of Health, accessed 1 May, 2013, <http://history.nih.gov/research/downloads/PL94-278.pdf>

support for the development of programs in genetic research, education, testing and counseling for a range of hereditary conditions.¹⁸⁰ Of particular interest to the HBL was Title XI of the Act, which allowed for the distribution of federal monies to both public and private non-profit organizations specifically for projects on genetic screening or counseling, education, and research. Marian Moser, Executive Director of the HBL, wrote to Senator Jacob Javits in 1975 soliciting his support in passing the National Genetic Diseases Act. She even volunteered a copy of *Wednesday's Child* to show members of the Senate.¹⁸¹ The League recorded in its Board of Director meeting notes of 1979 that the state was successful in being allotted federal funding (approximately \$700,000) under the new genetics legislation.

With the passing of the Act, the Human Betterment League's efforts shifted to securing funding for more general, state-wide genetic healthcare services, particularly educational endeavours. In 1980, the organization sought to promote "the value of genetic health services in reducing infant mortality and developmental disabilities."¹⁸² Mrs. Herbert Bradshaw, then president of the League, wrote to the North Carolina General Assembly Appropriations Committee to urge support of H.B. 466, which asked for resources to support genetic healthcare programs, saying,

We believe that it is important to have genetic counseling and genetic healthcare more readily accessible across the state. Investment in such preventive programs will relieve human suffering in the short run, and pay large dividends in cost effectiveness in the long run. We hope that adequate

¹⁸⁰ "A Bill to amend the Public Health Service Act to establish a national program with respect to genetic diseases," Senate Bill 1715, Legislation, Folder 47, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁸¹ Mrs. Howard J. Moser to Senator Jacob Javits, 2 September, 1975, Legislation, Folder 47, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁸² "Board of Directors Mini-Retreat Meeting Minutes, February 2, 1980," BOD Meeting Minutes 1952-1979, Folder 15, Series 1, Files of Marian Moser, 1947-1980, HBL.

funding for the State's Genetics Program will be provided, and thus will have an impact on the improvement of our human resources and the quality of life for the people of this state.¹⁸³

The HBL also sought sponsorship through organizations such as the National Foundation March of Dimes (MOD). The MOD, for example, supported Dr. Harold O. Goodman between 1975 and 1976 in his development of a program in genetics at the Bowman-Gray School of Medicine.¹⁸⁴ The League also attempted to set up an educational campaign around genetic disease due to its belief that “the importance of basic education is understood by most citizens. How to deal with genetically related health problems is not.”¹⁸⁵ The HBL made *Wednesday's Child* a campaign cornerstone, while also elaborating on local and regional efforts around “mental retardation,” Tay-Sachs, and other genetic diseases. Most importantly, it focused on increasing the visibility of genetic counseling and securing access to counseling services. The League even invited Dr. Sheldon Reed to speak at their 1979 annual meeting.

The Human Betterment League officially changed its name in 1984 to the Human Genetics League of North Carolina in order to “reflect more accurately its emphasis on genetics issues.”¹⁸⁶ The League's new charter emphasized the importance of promoting awareness of genetic problems and birth defects, and publicizing available counseling programs and treatment options. Their ultimate goal was to “give every baby born in

¹⁸³ Mrs. Herbert Bradshaw to the Members of the Appropriations Committee, North Carolina General Assembly, 1 May 1980, Legislation, Folder 47, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁸⁴ “The National Foundation March of Dimes,” grant support list, National Foundation-March of Dimes, Folder 53, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁸⁵ Statement prepared by Mrs. J. McNeill Smith Jr., 19 December, 1979, Newsletters, Folder 54, Series 1, Files of Marian Moser, 1947-1980, HBL.

¹⁸⁶ “The Human Genetics League of North Carolina, Needs Your Support,” Brochures 1982-1988, Folder 20B, Series 1, Files of Marian Moser, 1947-1980, HBL.

North Carolina the best possible chance for a happy and productive life,” which would be accomplished through education on genetic technologies and services, and the meticulous supervision, project administration, and legislation to this end.¹⁸⁷ Despite this re-orientation in the mid-1980s, the League lost momentum; its membership began to wane as recruitment efforts were unfruitful and as funding became scarce. While dissolution of the League was discussed as early as 1985, the group rallied for three more years until they disbanded permanently in 1988. The history of the Human Betterment League between 1947 and 1988 demonstrates the ways in which one organization took part in larger shifts of the post-WWII period. A late-founded organization initially focused on sterilization, the HBL eventually concentrated on the state-wide application of genetics, a program in which genetic counseling was central. That an emphasis on family planning, population control, genetic counseling developed later in North Carolina than in other states offers another example of the tenuous link between eugenics and genetics, and speaks to the complex origins of genetic counseling as a post-war profession.

Sheldon Reed formally introduced the concept of genetic counseling in 1947 and became one of the most famous historical figures in clinical genetics due to his work at the Dight Institute, where he counseled thousands of couples on their reproductive futures. Reed’s commitment to genetic education and individual decision-making greatly shaped the principles and practices of the modern profession. Despite the merit in claiming Reed as genetic counseling’s most notorious origin story, it is clear that other individuals and organizations were moving in similar directions, performing similar

¹⁸⁷ Ibid.

functions, and meeting similar ends to Reed's work in Minnesota. Both Paul Popenoe and Sheldon Reed were concerned about the prevalence of divorce in the U.S., which they believed resulted from a lack of public education and preparedness for marriage. Between the 1930s and 1960s, Popenoe emphasized the value of marriage counseling and family planning in furnishing a successful family life, and producing healthier, genetically-sound children, working through first the HBF and then the AIFR. The Human Betterment League (turned Human Genetics League) of North Carolina began as a eugenics organization in 1947 but later adopted a focus on population control and genetic counseling, an endeavour for which they sought Reed's guidance. It seems, then, that genetic counseling has a much more diverse history and many more points of origin that only come to light if we refrain from concentrating solely on Sheldon Reed as the "father" of genetic counseling.

Genetic counseling developed from a variety of institutional, geographic, and temporal settings, and amidst significant shifts in cultural meanings and material practices in the mid-twentieth century United States. While these shifts were dominant after the Second World War, it is clear that there existed subjugated ideologies and practices throughout the twentieth century, and that there was considerable overlap between the old eugenics and the new genetics. Genetic counseling, in turn, contributed to the persistence and pervasiveness of the very shifts conditioning the field's evolution. Reed's ethic of patient autonomy in decision-making, and Popenoe's subscription to Carl Rogers' counseling philosophies, became engrained in the profession of genetic counseling; the incorporation of the values of non-directiveness and client-centeredness as the

profession's ethical principles contributed significantly to the promulgation of bioethical principles in scientific research and practice. Moreover, while the emergence of genetic counseling was influenced by growing interest in population policy and family planning, these fields were legitimized by their association with a new clinical specialty founded upon cutting-edge scientific principles in an age of rapid biomedical advancement. Finally, genetic counseling was spawned in part by post-war advances in genetic research and knowledge, but the field helped promote even greater support for research in genetic diseases by demonstrating how genetics could be socially and medically useful.

Discussions about the extent to which eugenics and genetics overlap, or the reasonable amount of distance genetics can claim from eugenics, affected the professional trajectory of genetic counseling. Debates about the new genetics persisted in public discourse into the 1990s and 2000s, particularly as our everyday encounters with genetics have become more frequent as a result of living in a society characterized by ever-greater geneticization

Chapter 2: “A Nice Comfort Zone for Women”: The Professionalization and “Feminization” of Genetic Counseling, 1947-1979.

In the winter of 1988, Debra Collins, then-president of the National Society of Genetic Counselors (NSGC), celebrated the exceptional progress of the field in the past ten years. She exclaimed to the NSGC membership that, “we have watched our profession become increasingly recognized as an integral part of health care to the point where even *Glamour* magazine listed it in its April edition as one of the top 20 careers for women in the 1990’s.”¹ Collins’ (and *Glamour*’s) emphasis on genetic counseling as a women’s profession illustrates the field’s transformation throughout the late-twentieth century. Between the 1940s and 1980s, genetic counseling evolved from something male physician-geneticists occasionally did at the periphery of their clinical practice or research, to a profession dominated by women with Masters degrees.

During this transformation, genetic counseling became increasingly routinized in North American prenatal and pediatric healthcare settings. By 2000, genetic counseling was also part of cancer risk assessments, the diagnosis of adult-onset conditions, and preventive healthcare initiatives. In the more than sixty years since the official naming of genetic counseling in 1947, Masters-level genetic counselors and their physician-geneticist counterparts continuously renegotiated what it meant to be a genetic counselor, who could practice, and how the profession should look. These complex, sometimes tense, medical encounters shaped the profession’s historical trajectory. Significant achievements include genetic counselors’ own professional society and credentialing

¹ Debra L. Collins, “Corner Thoughts,” *Perspectives in Genetic Counseling* 10, no. 4 (Winter 1988), 2.

board, an annual education conference, and an academic journal. Today there are more than twenty-eight fully-accredited training programs in North America and 3,000 practicing genetic counselors in the U.S.² As one counselor commented, in a testament to the profession's value and demand for counseling services, "there aren't enough genetic counselors to go around."³

I am interested in two aspects of this professionalization process. First, the professional trajectory of genetic counselors simultaneously conforms to, but also challenges, hegemonic accounts of modern, Western medical professionalization. On the one hand, counselors fit comfortably into standard narratives of medical professionalization. They have achieved many professionalization landmarks including what sociologist William J. Goode identified as the two core stages: a "prolonged specialized training in a body of abstract knowledge," and a "collectivity or service orientation." Counselors have also obtained standardization of training, the development of professional organizations, and a certain degree of autonomy.⁴ The evolution of genetic counseling fits into standard narratives of twentieth-century medical professionalization which have emphasized the increasing authority and medical dominance of physicians throughout the early-twentieth century. David Coburn and others then characterized the post-WWII period (particularly the 1960s onward) as an era marked by the rise of new health workers (sometimes called paramedical or auxiliary personnel), and the fracturing

² Stern, *Telling Genes*, 9.

³ Interview with GCS00I20, 5 October, 2010.

⁴ William J. Goode, "Encroachment, Charlatanism, and the Emerging Profession: Psychology, Sociology, and Medicine," *American Sociological Review* 25, no. 6 (1960), 903. See also Freidson, *Profession of Medicine*. Both Goode and Freidson place a premium on autonomy as the ultimate condition for professionalism.

of physician duties with increasing specialization.⁵ Genetic counselors fit this narrative as healthcare workers who emerged in an era characterized by heightened interest in genetics and biomedicine, and who assumed responsibilities that were formerly the providence of physicians throughout the 1960s.

On the other hand, the professionalization of genetic counseling can act as a counter-narrative to dominant perspectives of twentieth-century Western biomedicine. The hegemonic account of medical professionalization in the nineteenth- and twentieth-century U.S. (and in Britain and Canada) typically posits the exclusion of female practitioners at the hands of male physicians and (bio-) medicine. The relationships of female physicians with their male counterparts were often characterized by attempts at subordination and segregation.⁶ Female midwives were ousted from their craft first by male midwives, then by male physicians, between the seventeenth and twentieth centuries in Britain.⁷ Nursing provides another example of the ascendancy of male biomedicine and subordination of female healers, who Barbara Ehrenreich and Deirdre English described vis-à-vis doctors as “ancillary workers” who are “alienated from the scientific substance

⁵ David Coburn, “Professionalization and Proletarianization: Medicine, Nursing and Chiropractic in Historical Perspective,” *Labour/Le Travail* 34 (Fall 1994), 139-162. See also Paul Starr, *The Social Transformation of American Medicine* (New York: Basic Books, 1982). Sociologists have written about the medical profession’s relative decline in prestige and professional control after WWII. See, for example, John B. McKinlay and Joan Arches, “Towards the Proletarianization of Physicians,” *International Journal of Health Services* 15, 2 (1985), 161-195. Some even began talking about “deprofessionalization.” See, for example, Franz J. Ingelfinger, “Deprofessionalizing the Profession,” *New England Journal of Medicine* 294, no. 6 (1976), 334-335; Marie R. Haug, “The Deprofessionalization of Everyone?” *Sociological Focus* 8, no. 3 (1975), 197-213.

⁶ Morantz-Sanchez, *Sympathy and Science*; Ellen S. More, *Restoring the Balance: Women Physicians and the Profession of Medicine, 1850-1995* (Cambridge: Harvard University Press, 1999).

⁷ Jean Donnison, *Midwives and Medical Men: A History of Inter-Professional Rivalries and Women’s Rights* (London: Heinemann Educational Books, 1977).

of their work” and told that “doctor knows best.”⁸ In their rise to the apex of the medical hierarchy, physicians also subordinated other practitioners including chiropractors, herbalists, homeopaths, eclectic, Thomsonians, and anyone else loosely termed a “quack.”⁹

An historical analysis of genetic counseling reveals a different pattern of professionalization, one that entailed the transformation from a field initially led by male MD and PhD geneticists in the 1940s through 1960s, to one dominated by women with Masters degrees by the 1980s and 1990s. For the last three decades, the field has been comprised of approximately 95 percent women (predominantly white, middle-class women) and 5 percent men.¹⁰ I suggest that the professionalization process of genetic counselors modifies or enhances our understanding of modern, Western medical professionalization to include a greater range, and a more nuanced roster, of professionalization experiences.

A history of genetic counseling highlights the myriad ways in which the profession has been profoundly influenced by encounters with many other health professionals, particularly MDs, PhD geneticists, nurses, and others who practiced genetic counseling in the field’s early days. Professionalization in genetic counseling demonstrates the

⁸ Barbara Ehrenreich and Deirdre English, *Witches, Midwives and Nurses: A History of Women Healers* (New York: The Feminist Press, 1973), 3.

⁹ See Roy Porter, *Health for Sale: Quackery in England, 1660-1850* (Manchester: Manchester University Press, 1989); David Coburn, “Professionalization and Proletarianization”; W. Bynum and Roy Porter, eds. *Medical Fringe and Medical Orthodoxy, 1750-1850* (London: Croom Helm, 1987); George Rosen, *The Structure of American Medical Practice, 1875-1941*, ed. Charles E. Rosenberg (Philadelphia: University of Philadelphia Press, 1983); Paul Starr, *The Social Transformation of American Medicine*.

¹⁰ The percentages of women working in genetic counseling are as follows: 90 percent in 1981; 96 percent in 1986; 95 percent in 1987; 93.3 percent in 1990; and 94.8 percent in 1992. These statistics are from Professional Status Surveys published in *Perspectives in Genetic Counseling* 3, no. 4 (1981); 8, no. 2 (1986); 9, no. 2 (1987); 12, no. 2 (1990); and 14, no. 2 (1992).

importance of exploring the evolution of healthcare professions in the context of what Andrew Abbott termed a “system of professions.” This model stresses the interrelated, interdependent, and competitive nature of professions. For Abbott, competition occurs over issues of “jurisdiction,” or proprietorship over professional tasks. Jurisdiction is a “more-or-less exclusive claim” so that one professional’s jurisdiction precludes another’s, and “every move in one profession’s jurisdiction affects those of others.”¹¹ Investigating the professionalization of genetic counselors in terms of a “system of *genetics* professions” elucidates how various healthcare professions have the ability to shape, and be shaped by, others. Abbott’s concept also provides a more complex understanding of the professional evolution of other medical professionals. These healthcare workers, alongside genetic counselors, comprise an important component of modern American healthcare systems devoting ever-increasing attention and funding to genetic health.

This chapter and the one that follows find their roots in an extensive literature on the professions and theories of professionalization. Sociologists such as Carr-Saunders and Wilson, David Mechanic, and Eliot Freidson analyzed how medical professions are organized and how they achieve professional legitimacy. These scholars (and Freidson in particular) tended to situate the medical profession as “the prototype of professionalism upon which all would-be healing professions model themselves,” and focused on how

¹¹ Abbott, *The System of Professions*, 20, 33-34. In “Genetic Counseling: The Development of a New Interdisciplinary Occupational Field,” Regina H. Kenen took a “power approach” to the study of genetic counseling vis-à-vis physicians and other healthcare occupations (541). This approach resembles Abbott’s concept of “jurisdiction.” David Coburn also used the “system of professions” in “Professionalization and Proletarianization.”

physicians obtained professional dominance and autonomy over their work.¹² The history of medical professionalization has been studied by such historians as Richard H. Shryock, John Duffy, and John S. Haller. In most cases, however, their analyses concluded before my period of study (and always before 1965); they also concentrated so narrowly on the progress of medical men that they ignored almost completely their interactions with other healthcare professionals like midwives and nurses.¹³

The professional experiences of these female healthcare occupations, and those of female physicians, have been carefully studied by historians interested in the intersection of gender and medicine such as Regina Markell Morantz-Sanchez, Mary Roth Walsh, Jean Donnison, Charlotte Borst, and Barbara Melosh. These scholars demonstrated the value of analyzing one medical group's professionalization but with continued concern for their relationship to the larger healthcare hierarchy through a gendered perspective.¹⁴ My work draws from this approach and elaborates Abbott's discussion of medical professionalization, which is centered largely on physicians as the prototypical medical profession and based on examples drawn from their mid-nineteenth century

¹² Friedson, *Medical Dominance*, 16; Carr-Saunders and Wilson, *The Professions*; Eliot Freidson, *Profession of Medicine*; David Mechanic, *Medical Sociology*.

¹³ Shryock, *Medical Licensing in America*; Shryock, *Medicine and Society in America*; John Duffy, *The Healers: The Rise of the Medical Establishment* (New York: McGraw-Hill, 1976); John S. Haller, *American Medicine in Transition, 1840-1910* (Urbana: University of Illinois, 1981). While Haller discussed midwives, they mostly appeared in his narrative as an obstacle to the professionalization of physicians. Duffy addressed women and "minorities" in a separate chapter from his larger narrative.

¹⁴ Morantz-Sanchez, *Sympathy and Science*; Donnison, *Midwives and Medical Men*; Borst, *Catching Babies: The Professionalization of Childbirth, 1870-1920* (Cambridge: Harvard University Press, 1995); Mary Roth Walsh, *"Doctors Wanted: No Women Need Apply": Sexual Barriers in the Medical Profession, 1835-1975* (New Haven: Yale University Press, 1977); Barbara Melosh, *"The Physician's Hand": Work Culture and Conflict in American Nursing* (Philadelphia: Temple University Press, 1982). The literature on the history of social work also explores gender tensions in the professionalization of social work, and struggles of power and authority over unmarried mothers. See, for example, Linda Gordon, *Pitied but Not Entitled: Single Mothers and the History of Welfare, 1890-1935* (New York: Free Press, 1994) and Regina G. Kunzel, *Fallen Women, Problem Girls: Unmarried Mothers and the Professionalization of Social Work, 1890-1945* (New Haven: Yale University Press, 1993).

professionalization initiatives. I infuse Abbott’s system of professions with a gendered analysis, and explore its applicability in the late-twentieth century through a case study of the professionalization of genetic counseling between 1947 and 2000.

I analyze the encounters between genetics healthcare professionals with an interest in how counselors’ gender and educational credentials influenced their professionalization experiences. These themes coalesce in, and are best explored through, genetic counselors’ participation within a system of genetics professions from a positionality located somewhere between “sympathy and science,” or what Morantz-Sanchez described as “the hard and soft sides of medical practice.”¹⁵ Indeed, genetic counselors claim strong science backgrounds and advanced degrees, albeit “lesser” qualifications to MDs or PhDs, and their professional duties often overlap significantly with those of physician-geneticists. The emotional and caring aspects of their jobs, however, and the fact that the profession has long been predominantly-female, has subjected counselors to expectations of “proper” women’s healthcare roles.¹⁶ Counselors’ gender and credentials have meant that they often fit uneasily into a larger system of genetics professions. As one counselor put it, “We have a stiff backbone of solid science behind us. They don’t just teach us how to hold hands and pass Kleenex.”¹⁷ Counselors’ position between sympathy and science was more pronounced in the 1960s and 70s than in the twenty-first century; nevertheless, they have continually faced the assumption that their profession was less scientific or

¹⁵ Morantz-Sanchez, *Sympathy and Science*, 5.

¹⁶ Diane B. Paul noted that women participated in eugenic fieldwork from a similar position. They were used as field workers based on assumptions of their “cooperativeness, emotional sensitivity, perseverance, patience, close attention to detail” (Paul, *Controlling Human Heredity*, 55).

¹⁷ Interview with GCS26I15, 12 August, 2010.

medically-significant than others positioned higher on the hierarchy of genetics healthcare providers.

This chapter explores the professionalization of genetic counseling between 1947 and 1979. Both this and the subsequent chapter emphasize the voices and perspectives of genetic counselors. Their interviews illuminate the complexities of medical professionalization, and lend personality and insight to the field's professional evolution in ways written sources simply cannot. I have chosen to highlight certain key moments in the professional evolution of genetic counseling through which I raise questions about medical hierarchies, and the shifting axes of power and authority within a system of genetics professions.

Medical Dominance in Practice: Physician-Geneticists and Genetic Counseling, 1940s-1960s.

Between the late-1940s and the late-1960s, the individuals practicing genetic counseling were primarily male geneticists like Sheldon Reed who became counselors through a broader interest in genetics. Often, their original genetics expertise lay in plant or fruit fly genetics, the model species for many discoveries in human genetics.¹⁸ Their primary professional goal was to contribute to scientific knowledge by making significant discoveries in the budding field of genetic research.¹⁹ In the immediate post-war period, and before the routinization of amniocentesis and other prenatal technologies, the role of the genetic counselor was primarily to “provide people with information regarding the

¹⁸ Beverly R. Rollnick, “Why A National Society of Genetic Counselors,” *Perspectives in Genetic Counseling* 2, no. 3 (September 1980), 3.

¹⁹ Kenen, “Genetic Counseling,” 542.

genetic problems they have in their families,” and the likelihood of these “problems” appearing from generation to generation.²⁰ The role of the genetic counselor was essentially limited to providing a couple with risk calculations based on a family pedigree, and giving information about the particular genetic condition of concern. It is not surprising that geneticists took on genetic counseling as peripheral to their central professional tasks in clinical or research genetics given the narrowly-defined responsibilities of the counselor in the two decades following WWII.²¹

Sheldon Reed is an intriguing example of the type of professional performing genetic counseling in the early Cold War era. Counseling was but one function of the Dight Institute, which also focused on genetics research and public education.²² Indeed, Reed himself performed many roles besides that of counselor. He taught courses in human and behavioural genetics at the University of Minnesota and was also a frequent lecturer on the international genetics conference circuit. He also published prolifically on medical genetics (his *Counseling in Medical Genetics* was one of the field’s seminal texts) and conducted research on a wide range of topics in genetics and heredity.²³ Reed was, however, particularly committed to, and enthusiastic about, genetic counseling and its development as a specialty within medical genetics.

Reed’s interest in genetics and genetic counseling was echoed by other American geneticists including James V. Neel, whose heredity clinic in Michigan opened around the

²⁰ Sheldon Reed, “Counseling in Human Genetics, Part III,” *The Dight Institute of the University of Minnesota Bulletin* 8 (1953), 15, Dight Institute Info File, DI.

²¹ Paul, *Controlling Human Heredity*, 128.

²² Reed, “Reactivation of the Dight Institute,” 2-6.

²³ Ladd-Taylor, “A Kind of Genetic Social Work,” 69-70.

same time as the Dight Institute under Lee R. Dice.²⁴ Often celebrated as the driving force behind modern medical genetics, Neel was instrumental in developing the University of Michigan's Department of Genetics. He conducted important studies the effects of radiation on atomic bomb survivors in Hiroshima, and his academic papers appeared frequently in medical journals like the *American Journal of Human Genetics*.²⁵ He initially encountered genetic counseling as part of his greater research interest in medical genetics but Neel, like Reed, was passionate about this new clinical field. He advocated a similar patient ethos of autonomy in decision-making, and shared Reed's attempts to distance modern genetic counseling from its early-twentieth century eugenic legacy.²⁶ In a further testament to geneticists' growing interest in genetic counseling, ten heredity counseling centers had cropped up in the U.S. by 1951, all of which were headed by well-known geneticists of the period including C. Nash Herndon, Franz J. Kallmann, Charles W. Cotterman, and William Allan.²⁷

Throughout the 1950s, increasing numbers of PhD geneticists but also MDs infused their practice with elements of genetic counseling. Rarely, however, did these predominantly male doctors and scientists match Reed and Neel's enthusiasm for heredity counseling.²⁸ James Sorenson has carefully elucidated the post-WWII trend of geneticists

²⁴ Comfort, *The Science of Human Perfection*, 108-111.

²⁵ *Ibid.*, 141. Neel published over 60 articles in the *American Journal of Human Genetics*.

²⁶ James Neel, *Physician to the Gene Pool: Genetic Lessons and Other Stories* (New York: John Wiley & Sons, 1994), 24, 28-31. I have emphasized the similarities between Reed and Neel but, as Stern has adeptly elucidated, differences also existed between these two geneticists. Quite interesting, for example, is the fact that both Neel and Herndon accepted funding from Wickliffe Draper and the Pioneer Fund, known for their support of biological racism, while Reed abstained (*Telling Genes*, 58-63).

²⁷ Robert G. Resta, "Eugenics and Nondirectiveness in Genetic Counseling," *Journal of Genetic Counseling* 6, no. 2 (1997), 255.

²⁸ We can reasonably classify most MDs at this time as male since between the 1920s and 1960s, women comprised only 4 or 5% of medical school students (Morantz-Sanchez, *Sympathy and Science*, 314).

taking up the mantle of genetic counseling. While physicians had long been fascinated by the causes, diagnoses, and treatments of hereditary disease, the generation of geneticists practicing genetic counseling in the 1940s through 1960s did so “almost by accident.” They became counselors through their expertise in genetics research or their clinical interest in the practical applications and manifestations of genetic knowledge. They did not, however, see this work as central to their professional duties or status. Sorenson characterized this group of practitioners as “more ‘scholarly’ than ‘consulting’ professionals” since they focused more on providing genetic information and education, and less on clients’ decision-making processes or the psychological and emotional counseling that characterizes the contemporary profession.²⁹ These researchers sought affiliation with a respected medical institution that could provide the growing field of genetics with financial support, while legitimizing and distancing it from early-twentieth century eugenics.³⁰

Although they may have started doing genetic counseling “almost by accident,” MDs and PhD geneticists nevertheless attempted to assert their professional authority and claim jurisdiction over the field throughout the 1950s and 60s. During this period, medicine was further tethered to genetics through major discoveries in cytogenetics.³¹ As physicians in particular became integral to the diagnosis and treatment of hereditary

²⁹ James R. Sorenson, “Genetic Counseling: Values That Have Mattered,” in *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, eds. Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan (New York: Aldine de Gruyer, 1993), 6-7. Sorenson’s distinction between “scholarly” and “consulting” professionals was drawn from Eliot Freidson, who suggested that while scholars “tend to maintain an ‘ideology of technical neutrality’ about their expertise, consulting professionals tend to become ‘participants in decisions’” (7).

³⁰ Ibid.

³¹ Kenen, “Genetic Counseling,” 543.

diseases, their interest in genetics and genetic counseling intensified. They came to view counseling as simply another part of their interaction with patients.³² Sheldon Reed conceded that many health professionals were capable of doing genetic counseling, but maintained that, “the function of a counselor in human genetics has been inherited mainly by the physician, which is as it should be, for the problems are very often medical as well as genetic.”³³ In her oral history of the National Society of Genetic Counselors, founding member Audrey Heimler recalled such a sentiment persisting amongst MDs and PhD geneticists even into the 1970s. She remembered the words of well-known physician-geneticist Charles Epstein who, in an argument over which healthcare workers could be called a genetic counselor, said,

To me, the term ‘genetic counselor’ connotes one who is capable of giving genetic counseling, with all that it entails. It is my contention, and I am prepared to be proven wrong, that except in the rarest of instances, non-medically trained individuals are not so prepared...because counseling must be done based on the medical implications of an accurate diagnosis...I do not see how anyone without medical training can honestly accept responsibility in these areas.³⁴

Epstein’s view – that counselors should be medically trained, and preferably hold an MD – was fairly pervasive amongst physician-geneticists in the immediate post-war period.³⁵

Some of the earliest professionally-trained, Masters-level genetic counselors recalled this earlier trend, and the way in which geneticists subsumed counseling under their

³² Reilly, *Genetics, Law and Society Policy*, 161.

³³ Reed, “A Short History of Genetic Counseling,” 5-6.

³⁴ Heimler, “An Oral History,” 318. Charles Epstein served as president of the American Society of Human Genetics, and editor of the *American Journal of Human Genetics*. He also sat on the Board of the American Board of Medical Genetics, and was later intimately involved with its incorporation into the American Board of Medical Specialties. Epstein later recanted his earlier criticisms and became a supporter of genetic counselors (Stern, *Telling Genes*, 17).

³⁵ Reilly, *Genetics, Law, and Social Policy*, 161.

larger practice. One counselor said, “when you’re talking about [genetic counseling in] the 1940s, I think you’re not talking about a profession, you’re talking about an attitude.”³⁶ While physician-geneticists demonstrated great knowledge of genetics and a positive attitude towards the value of genetic counseling, they were not genetic counselors by training and their practice of genetic counseling could not be characterized as a profession. The professional status of genetic counseling began to change in the 1960s and 1970s with the development of chorionic villus sampling (CVS) and maternal-serum screening, as well as ultrasound imaging technologies by the 1980s. Amniocentesis in particular held overwhelming significance for the field of genetic counseling as it allowed genetic counselors to assess the presence of hereditary disorders through much more scientific (and intimate) means.³⁷ Additionally, the identification of the genetic components of many diseases, and the overall rapid growth of biomedical healthcare systems in the post-war period, accelerated the need for genetic healthcare workers. These transformations, along with changing ideas about reproductive choice, and women’s rights to education and employment, further emphasized the need to establish genetic counseling as a distinct and identifiable profession.

Infusing Clinical Genetics with “Gender Equality”: The “Feminization” of Genetic Counseling, 1969-1979.

The advent of Masters-level graduate training programs in genetic counseling marked a radical departure for the field’s professionalization. These programs evolved from a demand to fill a gap in the provision of genetic services, and a concern that physician-

³⁶ Interview with GCS00119, 4 October, 2010.

³⁷ Harper, *A Short History of Medical Genetics*, 355-56.

geneticists lacked in counseling skills.³⁸ Additionally, as technological innovations gave physician-geneticists more information and options to convey (and more decisions for the patient to weigh), counseling sessions became more time-consuming. Hospital personnel with nursing or social work backgrounds emerged to help offset physician-geneticists' patient load by contacting clients, discussing major concerns, and taking a family history. The next rational step was to create professional training programs to set an educational standard for this diverse group of practitioners.³⁹

The first such program was established by Melissa Richter, a biology professor at Sarah Lawrence College, in Bronxville NY, in 1969. At the time, Richter was Sarah Lawrence's Dean of Graduate Studies, and was a likely candidate to take over the college's Center for Continuing Education (founded in 1962). The Center's purpose was to support young women, who had taken a hiatus from their post-secondary education to get married and have families, in their efforts to complete undergraduate and even advanced degrees.⁴⁰ Richter considered this female demographic to contain prime candidates to pursue counseling since "they generally are more concerned with health and the preservation of life."⁴¹ Women were also considered an ideal workforce as early counseling took place almost exclusively in pediatric and prenatal settings, making it

³⁸ Joan H. Marks and Melissa L. Richter, "The Genetic Associate: A New Health Professional," *American Journal of Public Health* 66, no. 4 (April 1976), 388-390.

³⁹ Harper, *A Short History of Medical Genetics*, 323-325; Tabitha M. Powledge, "Counselors Without Doctorates," in *Genetic Counseling: Facts, Values, and Norms*, eds. Alexander M. Capron et al. (New York: Alan R. Liss, 1979), 104-107.

⁴⁰ Alexandra Minna Stern, "A Quiet Revolution: The Birth of the Genetic Counselor at Sarah Lawrence College, 1969," *Journal of Genetic Counseling* 18 (2009), 2; Kenen, "Genetic Counseling," 543-544.

⁴¹ This excerpt is Stern quoting Richter in "A Quiet Revolution," 3. Stern also explored Richter's significant role in the history of genetic counseling in *Telling Genes*, Chapter 5: Women: Transforming Genetic Counseling, 102-122.

what one counselor, who graduated from Sarah Lawrence in 1978, described as “sort of a nice comfort zone for women...Children, other pregnant women, we can relate to that.”⁴²

Richter took advantage of the socio-political spaces opened up to women in the 1960s and 1970s by the Civil Rights movement and Second-Wave Feminism, as well as the increasing numbers of college-educated women. One pioneering counselor described the emergence of genetic counseling as an “attempt to get gender equality into clinical genetics settings.” She explained that introducing female genetics workers to the clinic “enhanced sensitivity to women’s concerns at a time that society was in transition to more gender equity in the workplace and more patient-centered medical practice.”⁴³ Richter’s efforts proved successful. By the fall of 1969, Sarah Lawrence welcomed ten women into the first Masters-level genetic counseling training program in the United States, with two more enrolling in the winter semester.⁴⁴ One counselor who attended Sarah Lawrence’s inaugural program remembered that, “Among the students, and amongst the faculty that taught us, there was definitely a sense of excitement...There was a definite feeling of launching something new.” She was convinced of the need to perform well “because the future of our profession depended on the impression that was made by our first class.” She remembers, though, that when Richter “described the profession in her view, I just knew this is what I wanted to do.”⁴⁵ This incoming class marked the beginning of a shift

⁴² Interview with GCS00I21, 12 November, 2010.

⁴³ Interview with GCS00I24, 19 November, 2010.

⁴⁴ Stern, “A Quiet Revolution,” 3. See also Marks and Richter, “The Genetic Associate: A New Health Professional,” 388-390.

⁴⁵ Interview with GCS00I25, 27 October, 2011.

towards what Alexandra Minna Stern described as the “feminization” of the profession and the genesis of the full-time genetic counselor.⁴⁶

Reflecting on the early days of the first Masters-level training programs and the women who attended, a second-generation male counselor commented that,

when I first started working, there were a lot of counselors who could come to counseling late in life. In fact, I think the entire first class at Sarah Lawrence were all women who had been science majors, had stopped and had a family, and then were coming back. I think many in the class were interior decorators because at the time, that was something you could do as a housewife.⁴⁷

Richter echoed Reed when she conceived of genetic counselors as “medical social workers.” Once in the program, students’ learning was centered on Mendelian and molecular genetics, as well as developmental biology, human physiology, and cytogenetics. This was clearly a science-based curriculum. This foundation was then undergirded by courses geared towards students’ counseling training like social psychiatry. The program was framed by Richter’s personal commitment to bioethical principles and reproductive choice. Additionally, students were instructed in laboratory techniques and gained clinical experience at various New York City hospitals, where amniocentesis was beginning to take hold.⁴⁸

Throughout the 1970s, a handful of other genetic counseling training programs cropped up at various U.S. institutions including Rutgers University, as well as the universities of Pittsburgh, Wisconsin, Colorado, California, and Michigan.⁴⁹ Most

⁴⁶ Stern, “A Quiet Revolution,” 8; Stern, *Telling Genes*, 114.

⁴⁷ Interview with GCS38110, 5 August, 2010.

⁴⁸ Stern, “A Quiet Revolution,” 5-6. See also Joan Marks, “The Training of Genetic Counselors: Origins of a Psychosocial Model,” in *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, eds. Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan (New York: Aldine de Gruyter, 1993), 17-18.

⁴⁹ Stern, *Telling Genes*, 115.

programs emphasized the principles of non-directiveness and client-centeredness which became the cornerstones of the profession. While Reed had himself articulated the necessity of patient autonomy, the inculcation of non-directiveness and client-centeredness into graduate program curricula marked an overt commitment to a patient-focused code of professional conduct. One Sarah Lawrence graduate recalled that by the mid-1970s, Carl Rogers' approach to client-centered counseling guided the program's psychosocial and emotional counseling training; counselors from other programs also remembered that these ideas formed a significant component of their training, although they were taught in perhaps less formalized ways.⁵⁰

Early genetic counseling training programs exhibited few commonalities, and there remained little or no standardization between programs despite a mutual subscription to Carl Rogers' philosophies. Some counseling programs emphasized the emotional and psychosocial aspects of counseling while others concentrated almost exclusively on scientific knowledge. One Rutgers graduate recalled of the early programs that,

The early programs preceded NSGC (National Society of Genetic Counselors), ABGC (American Board of Genetic Counseling), core competencies, standards of care or approved curricula. Therefore, training programs used the resources they had. Mine was housed in a biology department so I had a lot of education about basic genetics, how to find genes, how to provide risk assessment based on pedigree analysis and Bayesian calculations...The counseling component of my program was less developed. I think I only had one or two counseling classes, mostly focusing on grief counseling.⁵¹

⁵⁰ Interviews with GCS00I21, 12 November, 2010, and GCS00I22, 12 November, 2010. Psychosocial counseling refers to an approach that strives to understand the cognitive, emotional, social, family, and moral perspectives of the patient.

⁵¹ Interview with GCS00I24, 19 November, 2010.

Another counselor was taught by “a real old pro clinical social worker.” She felt that her professional skill-set came more from a social work domain and was then “followed or overlaid with the genetics piece.”⁵²

Genetic counseling programs also intersected with schools of public health, nursing departments, and other faculties. A mid-1970s graduate of the University of California Irvine received a degree in Social Ecology rather than in genetic counseling. She remembered that her program “trained us in a whole host of different areas they thought might be important for getting a job” including conducting developmental assessments and working in an early intervention program for children with spina bifida or Down syndrome. This counselor also spent time in a cytogenetics laboratory where she “learned to do everything from drawing the blood to growing the cells to doing the darkroom work and assembling the karyotypes.”⁵³ Another pioneering counselor encountered genetics as a nurse in the late-1970s through a federally-sponsored program at Emory University that taught genetics to public health nurses. As such, she described her counseling training as “case-by-case” but from a firm background in biology, anatomy, and physiology, as well as experience with psychosocial issues and patient interaction.⁵⁴ Despite this diversity in training experiences, counselors were united by their positionality as emerging healthcare professionals with advanced degrees but who, partially on account of their gender, were funnelled into a branch of clinical genetics that emphasized caring.

⁵² Interview with GCS00I22, 12 November, 2010.

⁵³ Ibid.

⁵⁴ Interview with GCS00I23, 17 November, 2010.

Professional Closure: Physician-Geneticists, Genetic Counselors, and Issues of Jurisdiction.

As graduation approached, the 1971 Sarah Lawrence class had to invent jobs where none had previously existed for this new profession. One pioneering counselor recalled that, “I approached two medical centers, and was offered part-time jobs at both.”⁵⁵ Other counselors remember encountering an incredibly precarious job market and extremely scarce employment opportunities for two reasons: first, a general lack of public and professional awareness about the new profession of genetic counseling; and second, that MDs, PhD geneticists, nurses and even some social workers already held jurisdiction over much of the expertise and skills claimed by genetic counselors. A male counselor who graduated in the mid-1970s explained that, “nobody knew who genetic counselors were, what they were, why they were.”⁵⁶

Reflecting on employment opportunities as a genetic counselor in the 1970s, one counselor remembered that, “You pretty much had to make your own job,” and that at one of the only jobs available to her, the starting salary was just \$13,000 a year.⁵⁷ Another counselor who graduated from Sarah Lawrence in 1974 recalled that, “Very frankly, there were practically no jobs available. I was fortunate because I got paid. Some people volunteered.”⁵⁸ Several female counselors who graduated in the 1970s found work in Planned Parenthood (PPFA) clinics. For some, working for the PPFA may have been based primarily on opportunity and circumstance, but it also reflected

⁵⁵ Interview with GCS00I25, 27 October, 2011.

⁵⁶ Interview with GCS00I20, 5 October, 2010.

⁵⁷ Interview with GCS00I22, 12 November, 2010.

⁵⁸ Interview with GCS00I19, 4 October, 2010.

many counselors' self-identification with, and commitment to, reproductive rights and feminist ideas. One counselor was offered a job in a naval hospital, where she would have been given the equivalent classification as an x-ray technician, or at institutions designed to deal with disabled or mentally challenged individuals. If a counselor could find work in a clinical genetics setting at a university medical center, it was often part-time.⁵⁹ Not surprisingly, only a small portion of those who graduated from Masters programs during this time remained genetic counselors. One counselor recalled that of his graduating class, three or four continued to practice genetic counseling, with others moving on to become obstetricians, dysmorphologists, dentists, ophthalmologists, or nurses.⁶⁰

As a new profession, the goal for counselors in the 1970s was “really just showing their value” to others in their system of professions.⁶¹ Some counselors recalled working with very supportive physicians and geneticists (if they were able to obtain a job in a hospital setting) who did not see them as competing with their professional jurisdiction. In fact, pioneering genetic counselor Joan Marks recounted that many prominent physicians supported the establishment of the Sarah Lawrence program and helped to plan the curriculum. This enthusiasm was likely due, at least in part, to the

⁵⁹ Interviews with GCS00I21, 12 November, 2010; GCS00I22, 12 November, 2012; GCS00I24, 19 November, 2010; and GCS00I19, 4 October, 2010.

⁶⁰ Interview with GCS00I20, 5 October, 2010.

⁶¹ Interview with GCS38I10, 5 August, 2010. See also Beverly Rollnick's history of genetic counseling, “The National Society of Genetic Counselors,” 4.

fact that the objective was to train “assistants to physicians,” who would allow clinical geneticists to better allot their time.⁶²

Most frequently, genetic counselors, MDs and PhD geneticists interacted in clinical settings. Some counselors who worked in hospital settings remembered being readily incorporated into a genetics team. They felt that their expertise was respected, and that they were relatively autonomous in making counseling decisions and structuring patient interactions. One counselor who graduated from Sarah Lawrence in 1974 recounted that, “I worked with a very lovely person and he just gave me the freedom to do what I wanted to do, so I did.” She recalled that often when working in a prenatal setting and determining the procedure for amniocentesis,

I was sort of left to myself to decide...and I think that’s not so common anymore, that the genetic counselor definitively makes a decision...I was given a lot of leeway, so I did pretty much what I wanted to. I counseled the way I wanted to, I took care of patients the way I wanted to.⁶³

Part of this autonomy may simply have been the result of an amicable relationship between counselor and geneticist, or that some geneticists recognized that there was enough demand for multiple genetics professionals to be of use. It is also likely that counselors were able to carve some professional inroads given the nature of the field of genetics, which was still fairly new, evolving, and malleable as it took shape post-WWII.

At the same time, it seems that in many cases, the still-precarious position of genetics made MDs and PhD geneticists somewhat defensive of their professional

⁶² Marks, “The Training of Genetic Counselors,” 17; Rollnick, “The National Society of Genetic Counselors,” 3.

⁶³ Interview with GCS00119, 4 October, 2010.

jurisdiction. According to many pioneering genetic counselors, there could be tension amongst genetics professionals on account of geneticists' resentment that predominantly-female genetics workers with "lesser" qualifications were encroaching upon their territory.⁶⁴ It would be inaccurate to assume that the everyday working relationships of genetic counselors with physician-geneticists and others were combative and wrought with hostility. Tensions did, however, reappear at junctures of professional evolution, and were inherent in moments of professionalization that are significant to the history of genetic counseling and its development alongside other genetics professionals.

Alexandra Minna Stern described such professional tensions, particularly the ways in which genetic counselors could encounter hostility by MDs and PhD geneticists who felt they were the only professionals suited to do genetic counseling, and who viewed genetic counselors as "mere appendages" at best.⁶⁵ Charles Bosk noted that in the pediatric hospital he studied, "counseling patients was a jealously guarded physician prerogative," wherein the efforts of Masters-level counselors to see patients independently were "hotly contested" and "consistently denied."⁶⁶ One counselor remembered that, "it used to be that some physicians thought the genetic counselor was totally useless, stupid," and that she would characterize the attitude of some physicians towards genetic counselors as "denigrating."⁶⁷ This attitude was likely related to the typical historical characterization of female healthcare workers,

⁶⁴ Kenen, "Genetic Counseling," 545.

⁶⁵ Stern, "A Quiet Revolution," 3.

⁶⁶ Charles Bosk, *All God's Mistakes*, 24.

⁶⁷ Interview with GCS00119, 4 October, 2010.

midwives or nurses being the most prominent.⁶⁸ Midwifery, although once an autonomous female field, was severely regulated under the influence of male physicians in nineteenth- and twentieth-century America, while nursing was established specifically as a female vocation intended to provide physician support.⁶⁹ The professionalization of genetic counseling was itself part of a tradition of gendering health work. Women's supposed caring nature made them well-suited to offer emotional counseling to other women about pregnancy and motherhood in prenatal or pediatric settings.

Counselors' early interactions with geneticists were structured by assumptions about women's place within a system of professions, as well as engrained (albeit slowly changing) notions of their status in the American workplace. A male genetic counselor who graduated from the University of California Irvine in the early 1980s explained the problematic occupational hierarchy counselors faced vis-à-vis geneticists, saying,

The physicians were the MD geneticists who did their medical thing, and the females [sic], I would say, in the '70s in particular, probably had more of a...I don't know if subservient role is the right word to use, but they were sometimes glorified secretaries. So they were there if the doctor needed a textbook to look something up, or needed some records to be gotten. Not uncommonly it was a genetic counselor who was doing that work but it didn't really require someone who could do counseling...So I think it took a while for the females [sic] to become accepted as roughly co-equals, people who

⁶⁸ Regina H. Kenen noted several important similarities between genetic counselors, nurses and midwives. These similarities included the "sex-labelling" of women as particularly nurturing and suited to auxiliary healthcare work, and whose compensation and status reflected a semi-profession ("Genetic Counseling," 544).

⁶⁹ Borst, *Catching Babies*; Melosh, "*The Physician's Hand*." Social work is another example of a predominantly-female profession whose work was partially overtaken by physicians at various times. For example, physicians often intervened in social work through the medicalization of motherhood implemented through early-twentieth century maternalist, public health, and eugenics initiatives.

added value to the patient encounter from the physician perspective beyond typing up some letters or getting records or taking care of the emotions.⁷⁰

A pioneering female genetic counselor echoed this feeling, saying,

I think that initially many counselors assumed a ‘handmaiden to the physician’ role. This original physician-extender model (which I jokingly refer to as the ‘hamburger helper’ model) relieved the doc of certain tasks, such as obtaining history, constructing pedigrees, and explaining inheritance that were critical to the evaluation, but that did not require skills in physical diagnosis.⁷¹

In a recollection that speaks explicitly to the gendered expectations surrounding the counseling profession, a second-generation male counselor explained that when first on the job market, half a dozen potential employers said to him, “We really want a woman in this job,” and even “Your breasts aren’t as big as the other ones.”⁷² It appears that genetic counselors encountered specific expectations about the nature of women’s health work upon entering a system of genetics professions.

Genetic counselors’ early roles were also affected by issues related to their professional credentials. A male genetic counselor noted that there was tension over jurisdiction since “we compete with medical geneticists because we can do some of what they do, they can do some of what we do.”⁷³ At the same time, however, counselors entered the field of genetics from a position of relative weakness. One pioneering counselor recalled that, “Historically, genetic counselors have been undervalued and somewhat economically vulnerable because we don’t do medical

⁷⁰ Interview with GCS50I03, 27 July, 2010.

⁷¹ Interview with GCS00I22, 12 November, 2010.

⁷² Interview with GCS50I03, 27 July, 2010.

⁷³ Interview with GCS38I10, 5 August, 2010.

procedures and we don't have doctoral degrees.”⁷⁴ Counselors' Masters degrees were less prestigious than the qualifications of MDs and PhD geneticists, while the value of counseling skills was less obvious to other health professionals and the public than a physician's medical practice. Although skilled in karyotyping, Bayesian analyses, and other duties performed by physician-geneticists, as a profession that involved emotional and psychological counseling they lacked the status associated with a PhD or an MD whereby they could diagnose, prescribe, and treat patients in a more traditional, familiar way.

In some cases, male genetic counselors believed that their gender allowed them to interact with physician-geneticists on a more even footing. One male counselor commented that he felt his gender helped him in his career as men always made slightly more money; his gender also allowed him to better “relate to other male-dominated fields” like MDs and PhD genetics specialists.⁷⁵ At the same time, both male and female counselors alike were affected by the hierarchy of genetics credentials. This hierarchy was intertwined with gendered assumptions about genetic counseling as an appropriate place for women in clinical genetics, and counselors' early intended roles as allied health workers trained for physician support. As such, many male counselors faced the same denigrating attitudes described by female counselors in the profession's early days.

⁷⁴ Interview with GCS00I24, 19 November, 2010.

⁷⁵ Interview with GCS38I10, 5 August, 2010.

A pioneering genetic counselor who graduated from Rutgers in 1975 recalled the defensiveness of some physicians towards genetic counselors regarding their credentials and status within a larger healthcare hierarchy. He remembered that,

I was introduced to this high-risk obstetrician who was probably the most well-known obstetrician in the state. [My employer said to this obstetrician], '[He's] a genetic counselor. He'll be able to talk to your patients about situations with family histories, or questions about testing.' And the guy looks at me and says 'Nobody talks to my patients except me'....I [also] remember talking to one guy [another physician in a more rural part of the state], and said 'I know you have a patient that just delivered a baby with anencephaly. I'd be happy to come up to talk to her and help her out.' And he said 'I'll tell you what. When I need your help, it's 'cause her car's stuck in the mud on the way to visit me and you can help push her out. That's when I'll need your help.'⁷⁶

In this situation, the counselor and obstetrician's shared gender identity mattered little. His poor treatment was instead intimately connected to being part of a predominantly-female profession originally established to support physician-geneticists.

It seems that for better or worse, working in a support role was often necessary if one wanted to practice as a genetic counselor in a hospital or university medical center in the early 1970s. It was difficult to practice as a genetic counselor without encountering other genetics professionals since genetics was institutionalized in academic medical centers in the post-WWII period with MDs and PhD geneticists at the helm. One pioneering counselor who attended the Sarah Lawrence program recalled that, "I think the reality was that you could not really practice as a genetic counselor unless you were in a professional relationship with a geneticist because your roles were often in the diagnostic realm. So there was a relationship that had to be

⁷⁶ Interview with GCS00I20, 5 October, 2010.

cultivated, and you had to maintain it.”⁷⁷ Genetic counselors, then, sought to establish gradual inroads in workplaces where well-established physician-geneticists were clinging to professional jurisdiction.

Despite the necessity of forging relationships within the system of genetics professions, counselors did not allow themselves to be dominated by geneticists. One counselor described that the first graduates of Masters programs, specifically “the New York ladies” of Sarah Lawrence,

were pretty pioneering-spirited people. They weren’t wilted-flower type women. They were very strong-willed, so people like Audrey Heimler and people like Elsa Reich, they’d stand up and talk at meetings about their feelings. They were very upfront about what they wanted or didn’t want. They really advocated for themselves, and I think they were always appreciated and respected...And I guess there was a tension [with geneticists]. Believe me, there was a tension. But these women weren’t going to back down to it. They were pretty strong-willed and I think that’s how they actually carved a niche for themselves.⁷⁸

The first generation of professionally-trained genetic counselors (the same women who had been undergraduate science majors and sometimes interior decorators) continued to insist upon their place within a larger medical hierarchy and, more specifically, within the provision of genetic services. Although still often forced to assume a “handmaiden to the physician” role, counselors were encouraged by the increasing numbers of training programs and numbers of graduates in genetic counseling. They and began to consider more independent roles by the late-1970s. This interest in autonomy produced mixed reactions and, in some cases, “made physician-geneticists anxious.”⁷⁹ Some genetic

⁷⁷ Interview with GCS00I21, 12 November, 2010.

⁷⁸ Interview with GCS64I09, 4 August, 2010.

⁷⁹ Interview with GCS00I21, 12 November, 2010.

counselors, however, remember that with the increasing routinization of prenatal services in particular, physicians started to realize that, “Look. There aren’t a lot of us MD-type geneticists. In order to see the increased number of patients we’re going to need people to help us.’ And they were very welcoming of having genetic counselors.”⁸⁰

Importantly, MDs practiced as genetic counselors into the early 1980s, and continue to perform tasks related to genetic counseling in their clinical practice. They also kept one foot in counselors’ camp by acting in a supervisory capacity at university medical centers. Indeed, in a 1981 survey, 85 percent of counselors reported that their supervisors were most often MDs.⁸¹ In a testament to the changing professional characteristics of genetic counselors, however, a 1973 survey reported that of 650 individuals doing genetic counseling in the U.S., 475 (73 percent) were physicians while seventy-two (11 percent) were masters-trained or RN counselors. By 1980, genetic counseling training programs had produced 300 new graduates.⁸² In the three decades since Sheldon Reed coined the term “genetic counseling,” counselors made significant headway advocating for their expertise and status within a larger system of genetics professions. They successfully challenged physician-geneticists’ monopolization of genetic counseling services between the 1940s and 1960s by developing and institutionalizing Masters-level genetic counseling training programs as the field’s new educational standard. In the late-1960s and 1970s, the new professional genetic counselor worked to carve a niche vis-à-vis other genetics healthcare professionals and, although they sometimes met challenges to their

⁸⁰ Interview with GCS64I09, 4 August, 2010.

⁸¹ Michael L. Begleiter, Debra L. Collins, and Karen Greendale, “NSGC Professional Status Survey,” *Perspectives in Genetic Counseling* 3, no. 4 (December 1981), 2.

⁸² Rollnick, “Why a National Society,” 3.

status based on gender and credentials, began the drive for greater autonomy that characterized the field's professionalization initiatives between 1979 and 2000.

Chapter 3: The Drive to “Design Our Own World”: The Organizational and Institutional Professionalization of Genetic Counselors, 1979-2000.

In March 1979, first president of the National Society of Genetic Counselors Audrey Heimler summarized the recent accomplishments of genetic counselors in organizing as a professional group. Writing on the first page of the inaugural edition of *Perspectives in Genetic Counseling*, she declared that,

Close to 200 genetic counselors have submitted a fee in support of the Committee to Form the National Society of Genetic Counselors...The Society is incorporated as a not-for-profit organization and has applied for tax-exempt status...Communication and friendships have developed among genetic counselors across the country. The first newsletter has been published. And all within one year!¹

Heimler concluded her piece with the sentiment that, “for the future, it is my hope that genetic counselors everywhere will join in the efforts of the Society to accomplish our goals.”²

The establishment of the National Society of Genetic Counselors (NSGC) was the first step in counselors’ collective pursuit of greater autonomy. No longer content to act as a “handmaiden to the physician,” counselors sought increased professional status and self-determination in the field of clinical genetics by the late-1970s. This goal, like their earlier professionalization initiatives, could cause friction with their physician-geneticist counterparts. After founding their professional society in 1979, the group established their own professional meeting, the NSGC’s Annual Education Conference, in 1981. They also created a counseling-specific credentialing board, the American Board of Genetic

¹ Audrey Heimler, “From Whence We’ve Come: A Message From the President,” *Perspectives in Genetic Counseling* 1, no. 1, (March 1979), 1.

² *Ibid.*

Counseling, in 1993. Counselors further strengthened control over their production of knowledge through the establishment of their peer-reviewed journal, the *Journal of Genetic Counseling* (founded in 1992), and contributions in the NSGC's newsletter, *Perspectives in Genetic Counseling*. Genetic counselors addressed a range of professional issues by the 1990s (including marketing their professional value to physicians and the American public), but did so from a position of augmented professional status. Looking back in 1992 on the profession's gains, Joan A. Scott remarked that, "I cannot help but be impressed with our accomplishments through the work, enthusiasm, and vision of a group of committed individuals." She was enthusiastic at the prospect of "many exciting years ahead of us" and asserted that, "The future truly does hold much promise."³

This chapter analyzes the professionalization of genetic counseling between 1979 and 2000. Whereas the previous chapter focused on counselors' early jurisdictional challenges to physician-geneticists, here I explore their systematic and organized efforts to break away from their PhD and MD counterparts through self-advocacy and institution building. The shape of the National Society of Genetic Counselors and the professional steps taken by genetic counselors in the 1980s and 1990s were profoundly influenced by their experiences with the American Society of Human Genetics (ASHG) and the American Board of Medical Genetics (ABMG). The evolution of genetic counseling inside a system of professions is everywhere in evidence. In their pursuit of greater self-determination, clashes over jurisdictional boundaries amongst physician-geneticists and genetic counselors intensified but were centered once again on issues of gender, credentials, and

³ Joan A. Scott, "Introductory Comments," *Journal of Genetic Counseling* 1, no. 1 (1992), 5, 7.

professional status; in essence, their continued positionality between sympathy and science.

Ultimately, questions of who is best suited to perform genetic counseling, and how should the relationship between physician-geneticists and genetic counselors be defined, became more poignant as genetic reproductive technologies multiplied, and as counselors' role in prenatal diagnosis became more routine. Counselors' professionalization experiences demonstrate their field's ability to mould the professional trajectories of their MD and PhD counterparts at the same time that these physician-geneticists shaped the evolution of genetic counseling. Since the 1990s, the result of decades-long inter-professional competition has often been collaboration between physicians and genetic counselors with patients over matters of genetic health. In many cases, counselors are deferred to as the resident genetics specialists.

“To Speak with a Unified Voice”: Genetic Counselors Establish the NSGC.

Genetic counselors first laid plans for the creation of a professional society in the late-1970s, just as the number of Masters-level programs was growing.⁴ The timing was also prescient as the early 1970s were characterized by intense debates over what genetic counseling was and who was qualified to perform counseling services. The American Society of Human Genetics' Ad Hoc Committee on Genetic Counseling attempted to delineate the field as the province of physician-geneticists in 1974. The Committee invited genetic counselors to participate in debates throughout the mid-1970s on the scope and intent of genetic counseling, and physician-geneticists slowly became more

⁴ Stern, *Telling Genes*, 115.

welcoming of Masters-level counselors. Nevertheless, there was evidently still a drive for these female genetics specialists to strike out on their own.⁵

The individuals responsible for the creation of the NSGC were predominantly graduates of, or students in, the Sarah Lawrence program including well-known counselors Joan Marks, Luba Djurdjinovic, Deborah Eunpu, and Audrey Heimler. One of the immediate reasons for the Society's founding was that Masters-level genetic counselors and others within their system of professions began discussing certification as the next step in their collective professionalization process. Joan Marks, for example, felt that counselors' certification and other professional issues would be most adequately addressed through an organization that could act as the cohesive, unified voice of genetic counselors.⁶ The Society's comprehensive goals were to "further the professional interests of genetic counselors, to promote a network of communication within the genetic counseling profession, and to deal with issues related to human genetics"; the Society would also insure "a high standard for the training of genetic counselors, genetic counseling services and educational programs in genetics."⁷ Marks remembered that the first meeting on the possibility of a national organization "was an emotional experience to see, for the first time, 100 genetic counselors in one room and to observe them considering the implications of unifying as a society."⁸ This general excitement was, however, undercut by the hesitancy of some genetic counselors, who worried that an aggressive push for a professional society might erode any ground gained with geneticists

⁵ Ibid., 15-18.

⁶ Heimler, "An Oral History," 316.

⁷ Heimler, "From Whence We've Come," 1.

⁸ Joan Marks as quoted in Heimler, "An Oral History," 316.

- and within their system of professions - in recent years. A negative response to the organizational efforts of a collective, unified group might jeopardize the progress made by individual counselors.⁹

The first job was to establish an ad hoc board of directors until a formal election could be held. The board then formed the By-Laws Committee charged with three primary concerns: issues of national representation, the criteria for membership, and the terminology used in the organization's name and to designate professionals practicing genetic counseling. In the 1970s, naming the profession was a significant site of conflict which reflected existing tensions over credentials and, to some extent, gender as well. Medical geneticists preferred the term "genetic associate," which could be applied to a broad range of healthcare workers who performed genetic counseling but were not necessarily Masters-level genetic counselors. Others, primarily the women trained in the Sarah Lawrence and other graduate training programs, saw themselves as "genetic counselors," a label they thought more accurately reflected their professional expertise; "genetic associate," they felt, posited a dependent role. One counselor called it "a kind of demeaning term [with regards to] having a Masters degree and then being told you could only be an assistant to somebody without autonomy in terms of how you worked as a genetic counselor."¹⁰

Medical geneticists, many of whom considered themselves practicing genetic counselors, rejected the term genetic counselor to designate Masters-level practitioners from social work, public health, or genetic counseling backgrounds. They argued that

⁹ Heimler, "An Oral History," 317. See also Scott, "Introductory Comments," 5-7.

¹⁰ Interview with GCS00125, 27 October, 2011; Heimler, "An Oral History," 318.

such individuals were “associates, assistant aides, collaborators, yes; counselors, no!”¹¹ One counselor who graduated from the University of California Irvine in the mid-1970s remembered this issue of professional jurisdiction, saying, “At that time [we] were called ‘genetic associates,’ and there was a lot of turf battle at that point about who should even be able to call themselves a ‘genetic counselor.’ Many physicians really felt that it was not an appropriate term.”¹² The end result was a consensus between physicians and genetic counselors that students currently in training programs would be called genetic associates, while the label of genetic counselor would apply to individuals actively involved in the provision of genetic services.¹³

The tension surrounding the Society’s name and the professionals it represented was part of a greater struggle to determine the criteria for membership. Geneticists with advanced degrees argued for a heterogeneous society that did not use the term genetic counselor as this might exclude physicians, nurses, and social workers who already performed genetic counseling services. Conversely, Masters-level genetic counselors argued that a society specifically for professionally-trained genetic counselors would greatly enhance their professional autonomy and foster an independent professional identity.¹⁴ The decision to use “genetic counselors” in the Society’s title was met with consternation and contention by physician-geneticists who felt they were being deliberately excluded from an organization representing part of their practice. Nevertheless, the By-Laws Committee ultimately decided that graduates of Masters

¹¹ Heimler, “An Oral History,” 318. See also Charles J. Epstein, “Editorial: Organized Medical Genetics at a Crossroad,” *American Journal of Human Genetics* 51, no. 2 (1992), 231-234.

¹² Interview with GCS00I22, 12 November, 2010.

¹³ Heimler, “An Oral History,” 320.

¹⁴ *Ibid.*, 319, 321.

programs were the best-trained candidates to practice genetic counseling, and that this would be reflected in the Society's official name.¹⁵

Despite this decision, there remained much debate about membership criteria, particularly over the inclusion or exclusion of other professionals like nurses and social workers. One counselor remembered that,

There were a lot of the early genetic counselors who had been trained on the job and were doing genetic counseling functions. They may have come from a social work background, or from a nursing background, or whatever. There were also people who had only a bachelor's level degree, and others who had come through Masters level genetic counseling programs. There was a lot of pushing and pulling around that initially.¹⁶

Another counselor who worked on the By-Laws Committee recounted that, “the professional agenda was ‘we don't even know the genetic counselors who are out there.’” The Committee therefore focused on “defining a profession of individuals who were trained through these instructive programs, but also honouring people who were doing this work before there was something called genetic counseling, and these were nurse clinicians primarily.”¹⁷ The By-Laws Committee was thus torn between establishing an autonomous organization with firm, identifiable professional standards, and including professionals who had already been doing genetic counseling although not perhaps under the title of genetic counselor. The committee ultimately decided that full membership would apply to individuals with a Masters or PhD (although PhDs were exceedingly rare) from a recognized genetic counseling training program, or in a related field including nursing or social work where their primary responsibility was genetics-related.

¹⁵ Importantly, the term “genetic associate” was still used alongside “genetic counselor” into the mid-1980s.

¹⁶ Interview with GCS00I22, 12 November, 2010.

¹⁷ Interview with GCS00I21, 12 November, 2010.

Physicians, dentists, social workers, and nurses who did not qualify for full membership but still had an interest in genetics could become associate members, but did not have the right to hold office, serve on the NSGC board, or vote.¹⁸ A graduate of the Sarah Lawrence inaugural program, and active NSGC member, remembered that the concern was “if the doctors had a vote, a full vote, we would soon find ourselves run by the medical geneticists instead of by our own professional members.”¹⁹ Indeed, by 1981, 80 percent of NSGC members held Masters degrees from a genetic counseling training program, and 90 percent of genetic counselors were female.²⁰

The third professional issue at stake in the NSGC’s formation was national representation. Many counselors worried that with Sarah Lawrence as the birthplace of graduate-level training programs in genetic counseling, the north-eastern United States would be over-represented within the Society. One pioneering Rutgers graduate remembered that, “In California, I felt very cut off because the leadership of the NSGC was drawn from graduates of the Sarah Lawrence program. They were all on the east coast in the New York, New Jersey metropolitan area. I felt very disenfranchised.”²¹ The By-Laws Committee recognized the impossibility of founding a nationally-representative society if such feelings of exclusion existed; they therefore established six regions that coincided with those delineated by the Department of Health, Education and Welfare. Each region then had a representative on the NSGC board. Amongst other responsibilities, the representatives were charged with relaying the concerns of their

¹⁸ Ibid.

¹⁹ Interview with GCS00I25, 27 October, 2011.

²⁰ Begleiter, Collins, and Greendale, “NSGC Professional Status Survey,” 1.

²¹ Interview with GCS00I24, 19 November, 2010.

districts to the national organization and co-ordinating yearly regional education meetings to address local professional issues. Planning the Society's local component was the last step in establishing the NSGC, which was incorporated October 1, 1979. The Society was founded as a Not-For-Profit Corporation with Audrey Heimler as president, and with the support of 200 members. The NSGC created positions for Vice-President, Secretary, Treasurer, and Chairs for a variety of committees including social issues, professional issues, and membership.²² At the close of the 1970s, the National Society of Genetic Counselors had its organizational structure in place and was ready to begin its important professional work.

Most interview participants spoke enthusiastically of the NSGC and its role within the profession during its early years. One counselor who began working in the mid-1990s expressed that,

I think the NSGC is critical to the profession, was critical to the establishment of the profession as a true profession. In other words, if we have a national organization, we're clearly something, something that brings us together, represents us...I think without it, we wouldn't have gone anywhere, or we'd still be fumbling around in low-paying jobs.²³

A second genetic counselor recounted that, "In the beginning it was essential because there weren't that many genetic counselors... I think it was really important in terms of giving us a chance to speak with a unified voice."²⁴ A third counselor, who graduated from the University of Colorado in 1983, recalled the enthusiasm surrounding the early days of the NSGC, saying,

²² Heimler, "From Whence We've Come," 1; Rollnick, "The National Society of Genetic Counselors," 3-7.

²³ Interview with GCS50I03, 27 July, 2010.

²⁴ Interview with GCS49I18, 20 September, 2010.

I thought it was very important in networking and understanding what the profession was. Yes, I remember going to conferences were 300 people in the room and that was the NSGC. At that time, we were all women, and we all were smart and we all worked hard. And it was kind of like a clique. We all knew each other, we all cared about each other, we helped each other through difficult things. I think it was more of a support group almost. And then, of course, over time it had to evolve if it was going to be a true professional organization.²⁵

Gender and educational commonalities were extremely helpful in the construction of a professional genetic counseling organization. The NSGC, in turn, provided genetic counselors with a more formalized, cohesive vision of the profession's identity. The Society was essential for the field's professionalization as it fostered a sense of community, independence, and shared experience within a larger genetic healthcare system.

Physician-geneticists continued to perform genetic counseling, or at least some of the services that overlapped with counselors' realm of expertise, throughout the 1970s and even into the 1980s. At the same time, the NSGC pursued several initiatives that significantly influenced the professional trajectory of genetic counselors. One major issue was standardization of training amongst both individual counselors and genetic counseling training programs. A series of meetings known as the Asilomar conferences (the first being held in 1974) provided a forum to "consider issues related to genetics associate training and the future of the non-MD genetics counselor," as well as to "set training goals."²⁶ By the third Asilomar meeting in 1979, the agenda focused more narrowly on evaluating the curriculum of genetic counselor/associate training programs in

²⁵ Interview with GCS59I11, 6 August, 2010.

²⁶ Ann Walker, "Asilomar East," *Perspectives in Genetic Counseling* 1, no. 3 (September 1979), 1. One of the more famous Asilomar meetings was on recombinant DNA in 1975.

an attempt to establish a minimum level of standardization between programs.²⁷ Conference participants spoke of the need for continuing education amongst genetic counselors and so established the NSGC Continuing Education Committee. Asilomar conferences were also held in 1986 and 1989. The later meeting in particular was intended “to reevaluate training program curricula, both didactic and experiential; to discuss the need for and desirability of advanced graduate education in genetic counseling; and to consider whether alternatives to master’s-level training are needed to overcome a growing manpower shortage in the provision of genetic services.”²⁸

Continuing education opportunities for the field were another important initiative for the NSGC and pioneering genetic counselors. The NSGC made post-graduate continuing education a “prime goal” intended to “increase our exposure to the varied aspects of genetic counseling so that we will be better equipped to meet the needs of the diverse communities we serve.”²⁹ In 1981, the NSGC held its first National Education Conference (later called the Annual Education Conference) in San Diego, California. The two-day workshop followed the March of Dimes Birth Defects meeting and was timed to occur simultaneously with the American Society of Human Genetics conference. These meetings, especially the ASHG, were the major genetics conferences and crucial for genetics healthcare professions to stay up-to-date with the field’s scientific evolution. Counselors’ participation in the ASHG meeting is a testament to their scientific skills and

²⁷ Ibid.

²⁸ Ann P. Walker et al., “Report of the 1989 Asilomar Conference on Education in Genetic Counseling,” *American Journal of Human Genetics* 46, no. 6 (1990), 1223. See also Joan A. Scott et al., “Genetic Counselor Training,” 191-199.

²⁹ Judith Dichter and Roberta Spiro, “Results of the Continuing Education Needs Assessment Questionnaire,” *Perspectives in Genetic Counseling* 2, no. 1 (March 1980), 1.

knowledge, and the interwoven expertise of professionals practicing within a system of genetics professions. The AEC complimented the overtly-scientific content of the ASHG conference by acting as a forum to “review the state of the art, to learn new techniques, and to share counseling experiences” that comprise a major and unique part of genetic counselors’ jobs.³⁰

By the early 1980s, NSGC members, often led by Beverly Rollnick, advocated continuing education as a mandatory part of counselors’ professionalization.³¹ The Annual Education Conference became a yearly staple for practicing genetic counselors not only to obtain Continuing Education Credits (which are required to stay certified by the American Board of Genetic Counseling) but to stay abreast of current topics in genetic counseling and medical genetics. One counselor commented of the meetings that, “the Annual Education Conference is a great thing that [the NSGC does] for the profession. It’s one place you can go to catch up with counselors, catch up with all the hot topics in the profession, feel involved in the group.”³²

The NSGC also pursued its mandate to act as a national voice and foster communication amongst genetic counselors throughout the 1980s and into the 1990s. This goal was of ever-greater importance as the organization’s membership grew to 400 counselors by the mid-1980s.³³ The Society’s newsletter *Perspectives in Genetic Counseling* was, and continues to be, instrumental in keeping counselors informed of

³⁰ Beverly R. Rollnick, “How the NSGC is Serving Its Members,” *Perspectives in Genetic Counseling* 3, no. 1, (March 1981), 2.

³¹Ibid. Audrey Heimler described that Rollnick was the earliest driving force behind continuing education in genetic counseling (“An Oral History,” 329).

³² Interview with GCS61I06, 30 July, 2010.

³³ Ann C.M. Smith, “The Presidential Address to the National Society of Genetic Counselors: The Evolutionary Growth of the NSGC,” *Perspectives in Genetic Counseling* 3, no. 4 (December 1981), 5.

current issues related to their professionalization including upcoming conferences, book reviews, suggested readings related to counseling, job postings across the U.S., and articles on any number of genetic diseases and counseling techniques. By the mid-1980s, *Perspectives* included political pieces to inform counselors of legislative initiatives affecting their profession. For example, the newsletter featured articles on challenges to reproductive rights, pro-choice political lobbying, and federal welfare and healthcare spending.³⁴ The newsletter also acted as a forum for debating thorny ethical issues related to counseling including reproductive rights, disability advocacy, and the profession's founding principle of non-directiveness.³⁵ In the 1990s, the NSGC created a website and a listserv, and counselors began publishing their own peer-reviewed scholarly journal. Professional Status Surveys (PSS) allow the NSGC to monitor change and continuity in the profession's status. Used to review membership demographics, salaries, educational backgrounds, and employment, the first PSS from 1981 concluded that "the position of genetic counselor is firmly entrenched in the field of clinical genetics."³⁶

In the 10 years after its founding, the NSGC and its membership counted many achievements in professional status and autonomy. Genetic counselors reported in a Professional Status Survey published in 1986 that they saw 74 percent of patients alone (that is, without the supervision of a physician-geneticist) to obtain a medical history.

³⁴ See *Perspectives in Genetic Counseling* 3, no. 4, (December 1981); *Perspectives in Genetic Counseling* 7, no. 4, (December 1985).

³⁵ See Ruth Hubbard, "A Feminist Views Prenatal Diagnosis," and Marsha Saxton, "Rights of the Disabled: A Message to Professionals," *Perspectives in Genetic Counseling* 10, no. 2, (Summer 1988), 1, 4, 12; Karen Copeland, "Can Non-Directiveness Be Non-Helpful?," *Perspectives in Genetic Counseling* 11, no. 3 (Fall 1989), 3; Nora Kizer Bell, "Medical Ethicist Responds to Issue of Non-Directiveness in Genetic Counseling Setting," *Perspectives in Genetic Counseling* 12, no. 4 (Winter 1990), 5.

³⁶Begleiter, Collins, and Greendale, "NSGC Professional Status Survey," 2.

They also worked autonomously when seeing 82 percent of families to acquire a family history, and 64 percent to conduct primary genetic counseling.³⁷ By 1987, genetic counselors were branching out professionally with 61 percent of NSGC members involved in research in clinical genetics, prenatal diagnosis, and cytogenetics, amongst other fields. Counselors also became involved in education. 26 percent of genetic counselors held faculty teaching positions, 80 percent of which were in medical schools, while another 48 percent of counselors gave up to 10 lectures a year.³⁸ Indeed, counselors demonstrated that a profession situated between sympathy and science was capable of large-scale organization and the creation of an autonomous identity separate from, but still affiliated with, other genetics professionals. This new-found sense of self endowed counselors with greater confidence in their quest for self-determination and attempts to assert their professional jurisdiction (within a system of genetics professions).

In Pursuit of Greater Autonomy: Genetic Counselors' Changing Relationships with Professional Genetics Organizations.

The National Society of Genetic Counselors marked a significant step in the professionalization of genetic counseling, but it by no means resolved counselors' complicated relationships with their physician-geneticist counterparts. In the late-1970s and 1980s, as they negotiated with geneticists over the terminology of genetic counseling and NSGC membership, genetic counselors maintained professional linkages to the broader genetics community. They continued to work alongside physician-geneticists, and

³⁷ Debra L. Collins, "Results of the Third Professional Status Survey," *Perspectives in Genetic Counseling* 8, no. 2 (June 1986), 1.

³⁸ Debra L. Collins, "Results of the NSGC Professional Status Survey," *Perspectives in Genetic Counseling* 9, no. 2 (December 1987), 2.

interacted with other genetics specialists by attending the ASHG and March of Dimes Birth Defects conferences.³⁹ The scientific content of these meetings was undoubtedly useful for all brands of genetics professionals, but genetic counselors remarked that they were “disappointed at the lack of papers and presentations that dealt specifically with genetic counseling.” This dissatisfaction led them to discuss the possibility of holding their own conference as early as 1979.⁴⁰

As of 1980, genetic counselors were also affiliated with the larger genetics community through the incorporation of the American Board of Medical Genetics (ABMG). One pioneering counselor remembered that,

Right after the National Society of Genetic Counselors was formed, so it would have been about 1980, the American Society of Human Genetics decided that the professionals should be accredited, board-certified...What was happening was that doctors from any discipline decided they liked genetics and made themselves medical geneticists, but they weren't specifically trained in medical genetics or counseling, and certainly not even in genetics. They just learned on the job. The feeling was that this should be formalized.⁴¹

The ASHG then founded the ABMG “to certify persons delivering genetic services and to accredit programs for training them.”⁴² The Board became the official certifying body for genetic counselors along with five other specialties including medical genetics, clinical genetics, biochemical genetics, clinical immunogenetics, and clinical cytogenetics.⁴³ The establishment of the ABMG marked a significant professionalization landmark for medical genetics professionals by setting firm standards for practice within the field, and

³⁹ “ASHG to Meet in Minneapolis,” *Perspectives in Genetic Counseling* 1, no. 2, (June 1979), 3.

⁴⁰ Linda Nicholson, “District II Meets,” *Perspectives in Genetic Counseling* 1, no. 4, (December 1979), 3.

⁴¹ Interview with GCS00125, 27 October, 2011.

⁴² Epstein, “Editorial,” 231.

⁴³ Ann C.M. Smith and Audrey Heimler, “Certification of Genetic Counselors,” *Perspectives in Genetic Counseling* 2, no. 2, (June 1980), 1.

making certification and program accreditation the new professional criteria. While this was important for the professionalization of genetic counselors, they were significantly outnumbered by MDs and PhD geneticists within the ABMG. Once again, counselors risked subordination to the authority of physician-geneticists.

The American Board of Medical Genetics was responsible for administering the first ever certification examinations for individual genetic counselors and accrediting Masters-level genetic counseling training programs. To become certified by the American Board of Medical Genetics, genetic counselors practicing prior to the establishment of the new board could be grandfathered-in. New graduates, on the other hand, were required to take a two-part examination: part I, which was taken by all subspecialties and focused on general genetics, and part II, which was specific to that subspecialty.⁴⁴ An administrator who worked for the ABMG since the 1980s recalled that to be eligible to sit for the exam, “you needed to complete a Masters degree program, you needed a log book of cases, and you had to finish your program in order to be eligible to take the board exam.”⁴⁵ The exams ran every two years until 1987, at which time they began to follow a three year schedule.

Many pioneering genetic counselors vividly recalled the early days of the American Board of Medical Genetics and the certification of genetic counselors. One counselor who was elected to the ABMG in 1983 as a genetic counseling representative recounted that, “The Board had formed and given the certification exam for the first time for all geneticists regardless of whether they were physicians, PhD geneticists, or whatever. This

⁴⁴ Ibid.

⁴⁵ Interview with GCS00I07, 30 July, 2010.

was very unusual for a medical board and occurred in response to pressure from some of the physician-geneticists who felt that genetic counselors should be certified by this board as well since they were part of the *team* that provided genetic services.”⁴⁶ The pressure to include counselors could be seen (quite cynically) as an attempt by physician-geneticists to control the accreditation of genetic counselors. Alternatively, it can be seen as a positive attempt at incorporating all genetics professionals under the same organizational umbrella, a move that could augment counselors’ professional status. Many counselors perceived of their certification by the ABMG, and this connection to other genetics professionals, to be of benefit to themselves and their profession. One genetic counselor, who has been practicing for twenty-five years (as of 2012), explained the certification process and its advantages, saying,

I think the first exam was in ’82 and I took the exam in ’87. When we took the general exam in ’87, everybody took the general exam, whether you were an MD, a PhD, genetic counselor. Everybody took the same general exam, and then you went back a second day and then you did your specialty exam. So if you were a genetic counselor, you took the genetic counseling exam. If you were a PhD cytogeneticist, you took the cytogenetics exam. And I think that really helped our field because I could say that I passed the same general exam as the MD geneticists...I think that helped us, and I think that helped with the professional status of the field. I remember Joan Marks saying this over and over, that ‘You can say you passed the same general exam as the MDs and the PhDs.’ And genetic counselors for many years passed at a higher rate than others. So I think that helped with our professionalization.⁴⁷

Close professional affiliation with a larger genetics community was perceived as extremely beneficial by many genetic counselors as it could augment their autonomy and professional status with their physician-geneticist counterparts

⁴⁶ Interview with GCS00I22, 12 November, 2010.

⁴⁷ Interview with GCS64I09, 4 August, 2010.

On the other hand, some genetic counselors were unenthusiastic about the ABMG's powers of certification over their profession. One reason was the cost of the exam (\$500), which many genetic counselors argued was out of synch with what they earned compared to other genetics professionals.⁴⁸ There was also tension around the exclusion of genetic counselors on the board of the ABMG responsible for writing the first certification exam. One counselor recalled that, "The committee that drew up the plans for the American Board of Medical Genetics proposed that there be representation from medical geneticists (MDs) and Ph.D scientists, but no representation from genetic counselors."⁴⁹ Indeed, in the first issue of *Perspectives* published in 1979, counselor Phyllis Klass described the NSGC's "first important professional issue": the lack of representation of non-doctoral genetic counselors on the ASHG's Council on Accreditation. She was also concerned about the ASHG's accreditation guidelines, specifically their proposal that would require counselors to "work under the direct supervision of a clinical geneticist or PhD medical geneticist" and demonstrate having completed the necessary coursework before being accredited despite the fact that PhD and Masters-level genetic counselors performed very similar work.⁵⁰ Two counselors, Audrey Heimler and Ann Smith, were eventually appointed to sit on the board to represent the genetic counseling profession, an important step in getting counselors to "participate in decisions affecting quality and delivery of genetic services, genetic education, certification and accreditation." Counselors' early

⁴⁸ Smith and Heimler, "Certification of Genetic Counselors," 1, 5.

⁴⁹ Interview with GCS00I25, 27 October, 2011.

⁵⁰ Phyllis Klass, "The Professional Issues Committee: A Report," *Perspectives in Genetic Counseling* 1, no. 1 (March 1979), 2.

exclusion, however, left many with an unfavourable impression of their professional counterparts.⁵¹

Affiliation with the ASHG and ABMG, although necessary, could be uncomfortable for many genetic counselors. Certification certainly enhanced their professional power and status within the system of genetics professions, but counselors were simultaneously circumscribed by physician-geneticists who heavily influenced the scientific education they received and were tested on for board certification. This awkward relationship became increasingly strained by the early 1990s, and culminated in the NSGC's disassociation from the ASHG in 1991/92. Counselors continued to attend ASHG meetings throughout the 1980s, even after the NSGC initiated its own annual education conference in 1981. The timing of the AEC was then planned to occur simultaneously with the ASHG, which continued to be the standard genetic conference of the day. Indeed, in 1984, 79 percent of genetic counselors surveyed were in favour of holding the NSGC meeting alongside that of the ASHG on the rationale that if funding for attending conferences was limited, the ASHG was the more important meeting to attend.⁵² By 1988, however, genetic counselors began discussing the need to assert their professional jurisdiction and autonomy. With a view to the Society's tenth anniversary, counselor Ed Kloza wrote of the need to think about the profession's evolution, asking, "But who will decide its future? Surely both the ASHG and ABMG will help guide the profession's direction.

⁵¹ Heimler et al., "Opinion: American Board of Medical Genetics Restructuring: Make an Informed Decision," *American Journal of Human Genetics* 51, no.5 (1992), v-vi.

⁵² "NSGC Members Prefer to Hold Annual Education Conference in Conjunction with the American Society of Human Genetics Meetings," *Perspectives in Genetic Counseling* 6, no. 1 (March 1984), 3.

It is critical, however, that the NSGC assume more leadership in developing long-term goals and objectives for the profession.”⁵³

Genetic counselors were again asked to consider the timing of the NSGC meeting and its connection to the ASHG in 1991; in particular, they were asked to think about whether it was time to “stand alone,” and what that would mean for their professional status.⁵⁴ Debates over the relationship between the NSGC and ASHG were also influenced by other considerations of professional principles as the upcoming Annual Education Conference for 1993 was to be held in Louisiana, which had one of the most stringent anti-abortion laws in the U.S.⁵⁵ The inhospitable location seemed to tip the scales in favour of splitting from the ASHG. One genetic counselor, who graduated from the Rutgers program and has been working since 1975, remembered,

We had always had our meetings in conjunction with the ASHG. We would piggy-back onto them because if you’re going to travel to ASHG, which many people did, if you’re already there then stay a few extra days for the NSGC. But the ASHG was committed to holding its meeting in the next year or so in New Orleans, and the Louisiana legislature had just come out with essentially a ban on abortions. The NSGC, because of our policies, said ‘We can’t support that. We can’t have a meeting in a state that is going against what our policies are.’”⁵⁶

The support of pro-choice initiatives is a prominent feature of NSGC policies, and one that dates back to the feminist leanings of the profession’s early practitioners. Indeed, many of the earliest genetic counselors who worked in the days when genetic counseling

⁵³ Ed Kloza, “Corner Thoughts,” *Perspectives in Genetic Counseling* 10, no. 3 (Fall 1988), 2.

⁵⁴ Susie Ball, “Meeting Logistics Examined,” *Perspectives in Genetic Counseling* 13, no. 2 (Summer 1991), 9.

⁵⁵ Roberto Suro, “Louisiana Lawmakers Adopt Toughest Anti-Abortion Law in U.S.,” *New York Times*, 27 June, 1990; *House Bill No. 112, 1991 La. ALS 26; 1991 La. ACT 26; 1991 La. HB 112, Regular Session 1991, Act 26*, accessed 9 May, 2013, <http://www.lexisnexis.com/hottopics/lnacademic/?verb=sr&csi=7341>

⁵⁶ Interview with GCS00120, October 5, 2010.

was based exclusively in prenatal and pediatric contexts self-identified as feminists. Many worked in Planned Parenthood clinics and participated in the reproductive rights movement and struggle for the decriminalization of abortion.⁵⁷

Later generations of genetic counselors and the NSGC as an organization have continued the commitment of pioneering counselors to pro-choice policies. A pro-choice professional philosophy is a core principle for most genetic counselors, particularly in a prenatal context, since abortion is one of the many choices counselors offer parents who have availed themselves of genetic testing and prenatal diagnosis. A 1985 Letter to the Editor of *Perspectives* expressed “a real and growing concern over the rapid expansion and vehemence of the antiabortion movement”; the letter also reminded counselors that, “We in the NSGC have an obvious interest in this country’s continuing commitment to *Roe v. Wade*. I urge all members of the society to support the right to choice vociferously.”⁵⁸ A survey conducted in 1987 reported that in response to the question “Do you believe the NSGC, as an organization, should publicly support pro-choice activities?,” 93 percent of counselors surveyed answered “yes.”⁵⁹ Members of the group participated in pro-choice and reproductive rights marches starting in 1985 in Washington, D.C. The NSGC also promoted awareness of, and involvement in, pro-

⁵⁷ Interviews with GCS00I21, 12 November, 2010; GCS00I22, 12 November, 2010; GCS00I24, 19 November, 2010; and GCS00I19, 4 October, 2010. The feminist leanings of pioneering genetic counselors are further elaborated in Chapter 5.

⁵⁸ Judith D. Widmann, “To the Editor,” *Perspectives in Genetic Counseling* 7, no. 4 (December 1985), 3.

⁵⁹ Trish Magyari, “‘Pro-Choice’ Update,” *Perspectives in Genetic Counseling* 9, no. 1 (March 1987), 2.

choice legislative initiatives and alliances with national pro-choice organizations such as Planned Parenthood and NARAL.⁶⁰

The decision to disassociate the NSGC from the ASHG was significant for asserting the professional identity and jurisdiction of genetic counselors. Perhaps even more important, however, was genetic counselors' split from the American Board of Medical Genetics in 1992. In the early 1990s, the ABMG (which had been responsible for the certification of genetic counselors since 1980) sought incorporation into the American Board of Medical Specialties (ABMS) which did not certify Masters-level practitioners. As such, the ABMG wanted to sever its relationship with genetic counselors.⁶¹ An administrator who served on the ABMG recalled that, "The board thought it was important to be recognized in the national arena of medicine and to be involved with the other physicians and physician organizations." She continued, saying, "In order to do that, you needed to be recognized by the American Board of Medical Specialties. Unfortunately, the American Board of Medical Specialties didn't recognize anyone who wasn't an MD. So they told us that we could no longer certify genetic counselors."⁶² One counselor recalled getting a call from a colleague who reportedly said,

"The American Board of Medical Specialties is ready to consider bringing medical genetics in as a medical specialty. But they did look at our membership. They noticed that so many of our members are non-MDs that they're freaking out. They won't allow this. They will allow PhDs because there is already a precedent for that with radiologists...but they will not allow

⁶⁰ Ibid. See also Trish Magyari, "Legislative Briefs," *Perspectives in Genetic Counseling* 11, no. 2 (Summer 1989), 12. NARAL is the now called NARAL Pro-Choice America but the acronym has, at different times, stood for National Association for the Repeal of Abortion Laws; National Abortion Rights Action League; and National Abortion and Reproductive Rights Action League.

⁶¹ Epstein, "Editorial," 233.

⁶² Interview with GCS00107, 30 July, 2010.

Masters-level people in any specialty in the American Board of Medical Specialties. So the genetic counselors are going to have to leave.’⁶³

This very contentious decision made many genetic counselors feel that they were being dumped by their PhD and MD colleagues. Audrey Heimler and associates recalled that as the American Board of Medical Specialties recognized the ABMG, and placed MDs and PhDs within what Charles Epstein called “the camp of the medical establishment,” counselors were “firmly excluded from this camp and the associated advantages.”⁶⁴ Once again, genetic counseling was not scientific enough, nor sufficiently medically-oriented, to merit the privileges conferred on physician-geneticists. Counselors were, however, divided into two camps; some felt abandoned by their physician-geneticists colleagues, while others thought that their disassociation from the ABMG would be a positive step for augmenting their professional status and self-determination. Genetic counselors held a fair amount of sway in the American Board of Medical Genetics, comprising 39 percent of its membership, and would have had a major impact if they had rejected the proposal; in the end, however, genetic counselors voted to secede from the ABMG.⁶⁵

Today, early genetic counselors still remember the early 1990s as a time of great debate and turmoil. Looking back, many counselors remain in some ways dissatisfied with the decision to separate from the ABMG (or what Heimler and others described as “the undoing of 10 years of shared certification”), arguing that it hurt their professional

⁶³ Interview with GCS00I20, 5 October, 2010.

⁶⁴ Heimler et al., “Opinion: American Board of Medical Genetics Restructuring”, vi.

⁶⁵ Edward M. Kloza, “ABMS Report...Evaluating the Counselors’ Status,” *Perspectives in Genetic Counseling* 14, no. 1 (Spring 1992); Betsy Gettig, “Restructuring of ABMG: NSGC to Move Toward Healing; Vision,” *Perspectives in Genetic Counseling* 14, no. 4 (Winter 1992), 3.

prestige within the system of genetics professions.⁶⁶ One early Sarah Lawrence graduate said, “I still have mixed feelings about the split and I was against dividing up the exams because I think one of the benefits for genetic counselors with respect to the general exam is that, in many instances, they proved their potential to provide good care because they did better than the MD and PhD candidates.”⁶⁷ Some counselors also had hard feelings towards medical geneticists who they felt cornered them into making an uncomfortable and momentous decision, the outcome of which would shape the professional trajectories of many genetics professions. One counselor recalled that,

I was called every name in the book because my position was that if we vote not to exclude ourselves from the American Board of Medical Genetics, and if medical genetics isn't recognized as a medical specialty, it's going to set the whole field back. MDs are going to hate us. They're going to point at us for saying, 'That's why medical genetics isn't recognized, because genetic counselors were stingy and egotistical and stubborn, and wouldn't let this happen.'⁶⁸

There was therefore a great deal of tension surrounding the decision, and much debate amongst genetic counselors as to their unified stance.

An American Board of Medical Genetics administrator recalled that while there was much apprehension and tension over the split, there was also “a positive look to see how this could benefit genetic counselors.” She remembered that, “there were a lot of emotions and some of them were positive, thinking what good this will do genetic counseling and the field of genetic counseling. And so genetic counselors could then make up their own rules for what they wanted or needed for certification.”⁶⁹ An early

⁶⁶ Heimler et al., “Opinion : American Board of Medical Genetics Restructuring,” v.

⁶⁷ Interview with GCS00I19, 4 October, 2010.

⁶⁸ Interview with GCS00I20, 5 October, 2010.

⁶⁹ Interview with GCS00I07, 30 July, 2010.

graduate of the University of California Irvine program reflected on the positive aspects of the split, which created an opportunity to enhance professional autonomy and status within a system of professions, saying, “We got to start from scratch and design our own world.”⁷⁰ Indeed, many genetic counselors, although initially feeling abandoned by their colleagues, were able to increase their professional autonomy through the founding of their own board in 1993, the American Board of Genetic Counseling (ABGC), to oversee the accreditation of genetic counseling programs and the certification of individual counselors. One genetic counselor recalled of this period that,

Fortunately, the ASHG and the American College of Medical Genetics and all the other medical societies said ‘Look. We understand what this is going to do, but what if we gave you a big chunk of money so you could set up the American Board of Genetic Counseling. You can determine your own fate, you take care of your own accreditation of programs, you take care of your own certification, you take care of it all yourself. Wouldn’t that be better?’ And I said ‘Yeah, I think it would be.’⁷¹

Although there were certainly feelings of resentment initially, genetic counselors (guided by the NSGC) moulded their exclusion from the ABMS as an opportunity to restructure and reshape their profession.

The foundation of the American Board of Genetic Counseling, and separation from the ABMG, had several major repercussions for genetic counselors and their profession. First, the establishment of the ABGC gave genetic counselors control over the accreditation of genetic counseling training programs. One pioneering counselor remembered that starting the ABGC “really did empower genetic counselors because they were in charge of their profession at every level.” She explained that,

⁷⁰ Interview with GCS00I22, 12 November, 2010.

⁷¹ Interview with GCS00I20, 5 October, 2010.

One important outcome [of founding the ABGC] was that in order for genetic counseling training programs to be accredited, genetic counselors would be appointed to do a site visit to determine that the program met board standards. Also, the ABGC ruled that accredited programs must have a board Certified Genetic Counselor as the director. This is something the early members of the profession never envisioned.⁷²

Additionally, the ABGC inherited control over the certifying examinations of genetic counselors from the ABMG. This allowed counselors to claim much greater influence over their own training and certification, which had previously been dominated by physician-geneticists, and the requirements necessary to be labelled a Certified Genetic Counselor (CGC). Second, and more broadly, the establishment of the ABGC represented an important departure for genetic counselors and a key step in their professionalization. Having their own credentialing board allowed counselors to augment their professional status, self-determination, and jurisdiction, and rival the standings of other genetics professionals within their system of professions. Of the leaps and bounds genetic counselors have made, one counselor commented that,

We have really done what I thought we would. We've grown more than the medical geneticists I think...Looking back over all this time, I'm extremely pleased with how the profession has grown, with the number of programs that have grown, the number of genetic counselors that have been licensed now and accepted. Everyone's complaining that there aren't enough genetic counselors to go around.⁷³

Increasing Visibility and Exhibiting Professional Value: Continued Professional Challenges in the 1990s and Beyond.

In the final decade of the twentieth century, the profession of genetic counseling was characterized by practitioners' continued negotiation of their place in a system of

⁷² Interview with GCS00I25, 27 October, 2011.

⁷³ Interview with GCS00I20, 5 October, 2010.

professions. The establishment of their own credentialing board, and the increasing visibility and influence of the NSGC, allowed counselors to simultaneously turn outward to address the field's public perception, but also inward to focus on intra-professional dynamics. In 1993, the NSGC launched a "Strategic Plan," an attempt to improve the Society and its activities at a time of overall professional restructuring.⁷⁴ This process was facilitated by Janet Unger of Unger Consulting Services in Philadelphia, who surveyed genetic counselors to ascertain what they perceived as the major issues facing the NSGC. She compiled a report that studied the communication, representation, and services of the Society, and targeted specific internal and external factors that would affect the field's professional trajectory.⁷⁵ Unger found that external factors influencing the trajectory of the profession included health reform at the national level, the NSGC's relationship with the ABGC, changes in available technology, and the greater demand for genetic counselors. Significant internal factors included issues related to governing the Board of Directors, Society finances, continuing education initiatives, and public education and consciousness about the profession.⁷⁶

The subsequent Strategic Plan played out within the NSGC in several ways. The Plan manifested itself in the complete overhaul of the Society's financial structure, regarding both long-term investments and day-to-day spending.⁷⁷ The NSGC also undertook

⁷⁴ The NSGC launched additional Strategic Plans in the 2000s to consistently re-evaluate the state of their profession and future directions.

⁷⁵ Betsy Gettig, "Interim Board Meeting Focuses on Strategic Plan; Society Issues," *Perspectives in Genetic Counseling* 15, no. 2 (Summer 1993), 1, 6-7. The Strategic Plan was first discussed in "Visioning the Future: Meet Janet Unger," *Perspectives in Genetic Counseling* 15, no. 1 (Spring 1993), 11.

⁷⁶ *Ibid.*

⁷⁷ Andy Faucett, "Spotlight on The Finance Committee: Pursuing a Secure Future," *Perspectives in Genetic Counseling* 16, no. 4 (Winter 1994), 3.

marketing initiatives to “introduce the genetic counseling profession to 265 million Americans” and “dispel myths and misconceptions about our profession.” To this end, the Society produced pamphlets on genetic counseling for public distribution, and created websites for the NSGC and ABGC.⁷⁸ This was increasingly important by the 1990s as American public awareness of genetics grew through the initiation of the Human Genome Project and the development of new genetic tests, which were often discussed in the popular press.⁷⁹ Counselors also emphasized their value to other healthcare professionals by attending physicians’ Grand Rounds meetings to market themselves as “‘solutions’ to physicians’ problems.”⁸⁰

Advertising their value to physicians in some ways reduced autonomy by acknowledging the continued need for MDs’ validation. At the same time, counselors took this action from a more well-established professional position than their earlier posture as the “handmaiden to the physician.” The marketing plan also intended to demonstrate the value of genetic counselors to third-party payer and managed care systems. Moreover, the NSGC encouraged research by genetic counselors with the initiation of GeneAMP, the organization’s “Applied Marketing Project.” Initiated in 1997, GeneAMP provided funding to members of the NSGC pursuing research in the field. The purpose was to increase counselors’ visibility and “document our value,

⁷⁸ Ann Boldt, “Marketing Focus Groups Convene to Explore the Issues,” *Perspectives in Genetic Counseling* 18, no. 4 (Winter 1996), 3.

⁷⁹ See Regina H. Kenen and Ann C.M. Smith, “Genetic Counseling for the Next 25 Years: Models for the Future,” *Journal of Genetic Counseling* 4, no. 2 (1995), 115-124. Coverage of genetics and genetic counseling in the mainstream American print media is analyzed in Chapter 6.

⁸⁰ Boldt, “Marketing Focus Groups Convene,” 3.

demonstrating cost effectiveness as well as our potential contributions in the expanding marketplace.”⁸¹

This new strategy and re-thinking of genetic counseling was necessary in the 1990s as the profession underwent many changes and continued to negotiate significant professional issues. Genetic counselors branched out into many different areas of medical genetics beyond the traditional counseling contexts. In 1992, 47 percent of counselors continued to do prenatal counseling, while 9.8 percent did pediatric and 25.4 percent did both.⁸² As the location, sequence, and function of the BRCA (breast cancer) 1 and 2 genes became fully characterized by 1994, however, counselors began performing cancer counseling in greater numbers. Cancer counselors meet with families with a known history of cancer (often breast and ovarian cancers) to determine patients’ chances of developing cancer and suggest methods of risk management. The addition of cancer to counselors’ professional roster also meant they interacted more frequently with oncologist and other cancer specialists, thereby bringing other healthcare professionals into the system of genetics professions.

As genetic counseling has become increasingly specialized, counselors also branched out into many “non-traditional” roles by working in large commercial genetics laboratories such as Genzyme; in government-sponsored agencies like the Centers for Disease Control and Prevention; and for non-profit organizations like Genetic Alliance.⁸³ Genetic counselors therefore began working in a greater variety of non-clinical settings

⁸¹ Edward Kloza and Beth Balkite, “Marketing Plan Unveiled: Funds Available for Members’ Projects,” *Perspectives in Genetic Counseling* 19, no. 1 (Spring 1997), 1, 9-12.

⁸² Wendy R. Uhlmann, “Professional Status Survey Results,” *Perspectives in Genetic Counseling* 14, no. 2 (1992), 7.

⁸³ Interviews with GCS89I17, 24 August, 2010 and GCS38I10, 5 August, 2010.

than ever before. The healthcare teams within which they work have also diversified and their system of professions has been broadened. The profession has evidently changed quite dramatically from the days when employment opportunities for genetics professionals were largely confined to prenatal or pediatric consultations in large university medical centers.

Changes in their professional purview and status exerted a significant impact on how genetic counselors understand their profession and professionalization process, as well as their relationship with their colleagues. Recent graduates of genetic counseling training programs (from the 1990s on) report very little tension between themselves and other genetics professionals. One counselor explained that, “the physicians are so happy to have us, that they can dump it all on us and not have to deal with it. They’re thrilled, so that tension is totally gone. And I don’t see any of the male/female conflict at all anymore.”⁸⁴ They also reported feeling a sense of professional camaraderie with their genetic counseling colleagues, with one counselor commenting that, “I definitely think when you are in a small profession, and you are all paving the way for future generations in this new field, that there’s definitely a sense of community.”⁸⁵

One genetic counselor who has practiced since the early 1980s recalled some tensions around counselors’ new roles, however, saying that, “anything new our field has trouble with. So I remember when cancer first started and there was a lot of resistance to it. A lot of people would say cancer counseling is very different from prenatal and I

⁸⁴ Interview with GCS59I11, 6 August, 2010.

⁸⁵ Interview with GCS19I14, 11 August, 2010.

would argue with them strenuously that they're actually very similar.”⁸⁶ Another genetic counselor who worked in a research setting at a well-known medical center in the north-eastern United States recalled that,

A lot of people say, ‘Oh, you don’t practice.’ But I’m still a genetic counselor. I like to think of myself as a counselor to other counselors. I still put out the psychological skills when I’m helping a physician or a counselor work through something. I’ve used ‘could you try explaining it like this?’ and ‘tell me what their assessment is.’ I’ve done that at the professional level. Of course, we’re not doing any deep-seated emotional analysis but I’ve used active listening, and I’ve used rephrasing and all of those things I learned in my counseling classes with other professionals. Just because I don’t sit down face to face with patients doesn’t mean I don’t get to use those skills.⁸⁷

Another genetic counselor commented on what she saw as a recent cause of friction: counselors branching out into commercial laboratories doing direct-to-consumer testing. She explained, “This is a source, I think, of some nastiness within the genetic counselor community because the perception is that people buying genetic tests can bypass genetic counselors altogether. Often what happens when they get results they or their doctor don’t understand is that another counselor has to come in late in the process and undo the damage.”⁸⁸ While tensions still exist, the relationships exhibiting these tendencies seem to be amongst genetic counselors themselves, rather than between counselors and other genetics professionals.

Debates around credentials and gender still abound, although these too seem to be more inwardly-focused on the profession of genetic counseling itself. One counselor who

⁸⁶ Interview with GCS38I10, 5 August, 2010.

⁸⁷ Interview with GCS26I15, 12 August, 2010.

⁸⁸ Interview with GCS00I22, 12 November, 2010.

has been working since 1998 commented explicitly on one of the main concerns surrounding gender in genetic counseling, saying,

There is a salary difference between men and women in genetic counseling that cannot be explained by the setting in which they work. So when I first saw it, I said ‘Well maybe men aren’t in clinical as much, maybe they’re working in more labs and things like that where it’s for-profit so there’s higher salaries.’ But even when they divide it between clinical and non-clinical, there is still a salary difference which infuriates me because, you know, we are a woman-dominated profession, about 90% women...I don’t know, it just pisses me off.⁸⁹

Gender was also discussed as it relates to the need for greater diversity amongst genetic counselors. Since the profession is 95 percent white, middle class women, the NSGC has spearheaded diversity initiatives in an effort to attract more men, as well as people of different ethnic backgrounds and income groups to the field. Genetic counselors have also considered the establishment of PhD level qualifications for their profession. One counselor commented that, “I think there are some individuals who want to look more into possibly having the profession move from a Masters level to a PhD level and I think there’s some tension there, some people who are worried about what it might mean for them personally.”⁹⁰ Ironically, the possibility of a PhD as the new educational standard may jeopardize the profession’s attempt to attract people of more varied socio-economic status. It would appear, then, that many of the issues of gender and credentials that plagued genetic counselors in the 1960s continue to affect them in the 1990s onward.

Perhaps the most pressing contemporary issues facing genetic counselors are licensure, billing, and reimbursement for services. Genetic counselors work within a U.S.

⁸⁹ Interview with GCS94I01, 26 July, 2010.

⁹⁰ Interview with GCS12I08, 4 August, 2010 See also Regina H. Kenen, “Opportunities and Impediments,” 1381.

healthcare system that is attempting to incorporate genetic services despite the fact that health coverage for genetics and genetic testing is quite uneven. Insurance coverage for DNA testing and genetic procedures varies considerably by state and by private insurance providers. While some third-party payer systems reimburse fully for cystic fibrosis testing, prenatal diagnosis, and other diagnostic tests, many reimburse only if testing is “medically indicated”, if there is a physician referral, and if the results of testing will directly impact patient treatment.⁹¹

This paucity in coverage for genetic services, while obviously problematic for patients, is also disadvantageous for genetic counselors. To be properly reimbursed for their services, counselors have often had to attach their billing to that of the MD on their genetics team. Indeed, in 1992, 51 percent of counselors billed under an MD’s name, while just under 6 percent billed independently.⁹² Reimbursement of genetic counseling services is integral to the field’s professional status by demonstrating counselors’ ability to furnish capital within a hospital system and therefore augmenting their value within hospital hierarchies.⁹³ One counselor explained the issues surrounding reimbursement, saying,

⁹¹ United States Department of Health and Human Services, *Coverage and Reimbursement of Genetic Tests and Services*, Report of the Secretary’s Advisory Committee on Genetics, Health, and Society, February 2006, Office of Biotechnology Activities – National Institutes of Health, accessed 14 August, 2013, http://oba.od.nih.gov/oba/sacghs/reports/CR_report.pdf. See also Barbara A. Bernhardt, “A Survey of Reimbursement for Cystic Fibrosis Carrier Testing,” *Journal of Genetic Counseling* 2, no. 2 (1993), 69-76; Dale Halsey Lea, “Client Advocacy and Collaboration with Insurance and Laboratory Testing Agencies: A Case Study Illustrating Genetic Counselors’ Roles,” *Journal of Genetic Counseling* 8, no. 3 (1999), 175-181.

⁹² Uhlmann, “Professional Status Survey,” 10.

⁹³ Lisa Feuchtbaum, “Reimbursement and Credentialing Issues for Genetic Counselors: A Report on a Survey of Genetic Counselors in California,” *Perspectives in Genetic Counseling* 7, no. 2 (June 1985), 1-3; Interview with GCS89I17, 24 August, 2010.

We do have a CPT [current procedural terminology] code now for genetic counseling and that is huge. And I think insurance companies are starting to get better at reimbursing genetic counselors...If we can bring money in, hospitals are going to employ more, and we have more respect I think when we bring money in. But also, at the same time...it seems like it's getting harder and harder to get insurance companies to pay for genetic testing. It really feels like it should be going the other way around...My big thing about the insurance is just trying for genetic counselors to get paid for the work that we do, and have insurance companies reimburse that and realize that we're worth the money.⁹⁴

Genetic counselors continue to advocate for independent reimbursement and recognition of their valuable role within genetic healthcare.

Licensure has been another issue of professional significance to the contemporary field. Counselors discussed licensure in *Perspectives* as early as 1979, but this issue was more prominently featured in the NSGC's agenda by the 1990s.⁹⁵ Licensure for genetic counselors means the acquisition of state legislation that determines which individuals or organizations can provide counseling services.⁹⁶ Counselors discussed some of the major benefits of licensure including the further legitimation of their profession; increasing state revenue through licensing fees; and limiting the numbers of people practicing genetic counseling. This was also related to reimbursement for services as licensing boosts counselors' status when pursuing compensation through third-party payer arrangements within a hospital-based fee-for-service system.⁹⁷ Licensure might also encourage physicians to make referrals to genetic counselors more frequently. The concern

⁹⁴ Interview with GCS12I08, 4 August, 2010.

⁹⁵ Walker, "Asilomar East," 1.

⁹⁶ Janet K. Williams, "Licensure and Genetic Counseling," *Perspectives in Genetic Counseling* 7, no. 1 (March 1985), 1.

⁹⁷ *Ibid.*; Philip Reilly, "Professional Identification: Issues in Licensing and Certification," in *Genetic Counseling: Facts, Values, and Norms*, eds. Alexander M. Capron et al. (New York: Alan R. Liss, 1979), 295.

surrounding licensure and reimbursement has only increased in recent years as although 14 states have achieved licensure, many continue to fight for what they see as a professional necessity.⁹⁸ As these professional concerns all revolve around professional autonomy, genetic counselors are again in the position of having to prove their value to other health professionals, as well as insurers.⁹⁹

The NSGC has certainly played a central role in debates over licensure, reimbursement, and other contemporary issues. Interestingly, it appears that while most people still consider the NSGC an important professional institution, some have come to question its current purpose and direction. One counselor, when asked about the role the NSGC currently plays for the profession, said,

In the beginning it was essential because there weren't that many genetic counselors and individually we weren't well known and we didn't have a very big voice. And so I think the Society was really, really helpful in terms of providing educational opportunities and networking opportunities. I think it was really important in terms of giving us the chance to speak with a unified voice on certain issues like the formation of the American Board of Genetic Counseling....But I'm not personally as sure what it's doing right now and how valuable it is. I kind of feel because the group has become very big...It used to be that there were 1000 genetic counselors in the whole country if you were lucky. Now there's probably 2500 or verging on 3000. It's big and the organization went from being a real grassroots, mom and pop kind of thing where everybody knew everybody and the administration knew everybody by name, to it being run by a professional company with offices and a corporate park kind of thing...I'm just confused about what it's doing right now.¹⁰⁰

Another genetic counselor echoed this sentiment, saying, "I don't consider myself an NSGC cheerleader...I've seen a couple of steps backward, like the exam-splitting, that I

⁹⁸ Four other states are listed by the NSGC as "with bills passed/in rulemaking." See "States Issuing Licenses for Genetic Counselors," National Society of Genetic Counselors, accessed 13 August, 2013, <http://www.nsgc.org/Advocacy/StatesIssuingLicensesforGeneticCounselors/tabid/347/Default.aspx>

⁹⁹ Kenen, "Opportunities and Impediments," 1379, 1382-1383.

¹⁰⁰ Interview with GCS49I18, 20 September, 2010.

sit back and question ‘Where in the world are we going and what are they doing for us?’¹⁰¹ Questioning the role of the NSGC, I would suggest, is part of a larger schema of a profession still very much in transition.

Aside from confronting intra-professional issues, counselors have also been forced to address public perceptions of genetic counseling. In many cases, this has meant engaging in discussions about the social implications of medical genetics and biotechnology arising from the Human Genome Project and highly-publicized genetics initiatives like the 1997 cloning of Dolly the Sheep. Despite working in a range of capacities, genetic counselors reported near-constant struggles in supplanting the common-place association of counselors with prenatal testing and, more damagingly, with abortion and eugenics. A second-generation graduate of the University of California Berkeley program said, “I can’t even remember how many times people have said, either to me directly or I’ve heard people say, ‘I’m not going to genetic counseling because I don’t want to get an abortion’ or, ‘Oh you’re a genetic counselor so you tell people to get abortions.’”¹⁰² Another counselor, reflecting on the purpose of genetic counseling versus allegations of genetic engineering, remarked that, “there are so many genetic diseases that need address. That’s where the interest lies. People are much more interested in trying to solve Duchene Muscular Dystrophy and watching kids die over the course of twenty years, than we are in somebody being two inches taller.”¹⁰³ A third counselor corroborated this testimony, and suggested the need for greater public education “so society understands that no,

¹⁰¹ Interview with GCS26I15, 12 August, 2010.

¹⁰² Interview with GCS94I01, 26 July, 2010.

¹⁰³ Interview with GCS104I13, 10 August, 2010.

we're not going to clone humans. It really will never work, I don't think. We're not going to change their baby. We're not going to guarantee them a blond-haired blue-eyed Adonis."¹⁰⁴ These concerns reference a larger public anxiety about the ethics of genetic research, testing, and counseling amidst the rapid accumulation of scientific knowledge. Genetic counseling, as a young profession, continues to grapple with professional questions that are simultaneously more inwardly and outwardly focused than in previous decades.

Genetic counselors have navigated an ongoing professionalization process shaped by encounters with other genetics healthcare professionals. The profession has made considerable gains in the past sixty years. Nevertheless, counselors are faced with a host of contemporary professional challenges including the struggle for licensure and reimbursement of genetic counseling services, the impact of direct-to-consumer testing, and a growing public awareness about genetic healthcare services.¹⁰⁵ Counselors have developed new professionalization strategies to structure their ever-evolving relationships with other genetics specialists and American society; it seems, however, that much of the contemporary profession's tactics and characteristics harken back to genetic counseling's earliest days, and the professional trajectory carved by predominantly-female, Masters-level genetic counselors.

A study of genetic counseling enhances our understanding of medical professionalization by uncovering an alternative professional trajectory that both challenges and conforms to standard historical narratives. An analysis of the early days of

¹⁰⁴ Interview with GCS38I10, 5 August, 2010.

¹⁰⁵ Kenen, "Opportunities and Impediments," 1377-1386.

genetic counseling is significant for historians of health and medicine by exploring how medical professions have the power to profoundly shape one another's professional trajectories. It also demonstrates the value of analyzing medical professions within Abbott's system of professions with particular attention to how genetic counselors' situation between sympathy and science influenced their encounters with other genetics healthcare workers. The history of genetic counseling complicates understandings of the shifting axes of power and authority within medical hierarchies, and elucidates the process by which relatively new healthcare professions emerge and establish their own professional enclaves.

Genetic counselors capitalized on the fluidity and precariousness of genetics after the Second World War, carving a specialized occupational space for themselves. This group then took advantage of the field's lack of standardization to establish their profession, and gain a certain amount of autonomy and control over their range of expertise and professional evolution. Counselors also availed themselves of the socio-political climate of the 1960s and 70s, during which time genetic counseling became a gendered space for women in science. The profession of genetic counseling became an occupational space characterized by encounters with other allied healthcare professionals. Within this space, Masters-level practitioners are occasionally contested by other genetics specialists while still maintaining a fair amount of self-determination over their professional trajectory. Contests over professional jurisdiction and autonomy will undoubtedly undergo continued revisions and renegotiations into the twenty-first century as greater numbers of

health professionals are absorbed into the system of professions, and as increasing numbers of Americans seek out the services of genetic counselors.

Chapter 4: To Listen, Educate, Support, and Counsel: The Client-Counselor Relationship, 1947-2000.

Sheldon Reed delivered a lecture in 1977 simply titled “Practical Genetic Counseling,” in which he outlined the most important characteristics of a genetic counselor and key features of the genetic counseling session. He advised his audience (likely students in a genetics course) that “your major job is to listen well because only from listening can you find out what motivated the request for counseling.” He critiqued the authoritarian nature of the physician who often failed to “listen well” and adequately address the patient’s concerns because “he didn’t have the time” to research and explain their condition. Reed suggested that the four main steps in an ideal genetic counseling session were 1) establishing the risk for an “abnormal” child; 2) interpreting that risk in a “meaningful way” for clients; 3) helping the client to weigh their risk; and 4) providing follow-up to the counseling session. Reed assured his listeners that no matter the outcome, “your conscience should be clear if you did a conscientious job of counseling. You cannot expect to be clairvoyant, only intelligent, diligent and compassionate.”¹

Reed’s description, although an optimistic vision of the counseling process, highlights the major issues genetic counselors have negotiated in their patient relationships throughout the late-twentieth century. Authoritarian physicians and the paternalism of the traditional doctor-patient relationship provided the model against which Masters-level genetic counselors often situated their own practice. Risk estimates have always been at the core of prenatal genetic counseling as counselors meet with

¹ Sheldon C. Reed lecture, “Practical Genetic Counseling,” 1977. Underline in original.

parents who are faced with difficult reproductive decisions and expected to make choices that will alter the future of their family life. Finally, counselors have been expected to “listen well” and express compassion in their multiple roles as therapists, interpreters, advocates, and educators. Since genetic counseling is based on a philosophy of client-centeredness, performing their jobs conscientiously has meant considering the patient’s concerns, providing appropriate genetic information, and being non-directive by upholding an individual’s autonomy in decision-making.

The history of patients’ interactions with physicians has been well-documented by historians of health and medicine including Edward Shorter, Roy Porter, and E.B. Smith. Shorter analyzed bedside manners from the doctor’s perspective, while Porter and Smith emphasized patients’ understandings of, and participation in, their own diagnosis, treatment, and health outcomes.² Accounts of the patient-nurse encounter, although more sparse, appear in histories of nursing by Barbara Melosh and Susan M. Reverby. Both scholars furnished glimpses of how the patient-practitioner interaction was affected by the characterization of nursing as “women’s work.” Patient interactions were also visible through the field’s professionalization experiences, and nurses’ interactions with physicians in a larger medical division of labor.³ Our historical insight into the patient-

² Much of this scholarship focuses on Britain, or Europe more broadly. See Roy Porter, “The Patient’s View: Doing Medical History from Below,” *Theory and Society* 14, no. 2 (1985), 175-198; Roy Porter, ed., *Patients and Practitioners: Lay Perceptions of Medicine in Preindustrial Society* (Cambridge: Cambridge University Press, 1985); Dorothy Porter and Roy Porter, *The Patient’s Progress: Doctors and Doctoring in Eighteenth-century England* (Oxford: Polity Press, 1989); E.B. Smith, *The People’s Health, 1830-1910* (London: Croom Helm, 1979); Edward Shorter, *Doctors and their Patients: A Social History* (New Brunswick: Transaction Publishers, 1991). Scholarship on doctors and patients in the U.S. has been produced by John Harley Warner. See, for example, *The Therapeutic Perspective: Medical Practice, Knowledge and Identity in America, 1820-1885* (Cambridge: Harvard University Press, 1986).

³ Barbara Melosh, “The Physician’s Hand”; Susan Reverby, *Ordered to Care: The Dilemma of American Nursing, 1850-1945* (Cambridge: Cambridge University, 1987), 2.

practitioner relationship during the era when physician-geneticists dominated genetic counseling comes from Sheldon Reed's *Counseling in Medical Genetics* (1955) and Charles Bosk's *All God's Mistakes* (1992). Reed's manual revealed the counseling philosophies and understandings of genetic risk that informed physician-geneticists' approach to the counseling session, and their techniques for client management. Bosk's study explored similar themes, but also sites of debate amongst MDs about the meanings of risk, the limits of treatment, and the realistic applicability of counseling principles like non-directiveness.⁴

Barbara Katz-Rothman's *The Tentative Pregnancy* (1993) and Rayna Rapp's *Testing Women, Testing the Fetus* (1999) both provided exceptionally valuable data on women's experiences with amniocentesis and changing conceptions of motherhood. They interrogated areas of overlap but also disconnect between counselors and their patients over interpretations of genetic risk and the advisability of prenatal testing. They also problematized notions of autonomy in relation to prenatal diagnosis by exposing the social, political, and technological contexts in which women make reproductive choices.⁵

Alexandra Minna Stern's *Telling Genes* (2012) performed a close historical analysis of risk in genetic counseling. In particular, she explored varieties of risk assessment, the impact of living in a family "at risk" for a genetic condition, and what it means to be classified as high or low risk. She also discussed concepts of autonomy, non-directiveness, and client-centeredness as the central ethics of genetic counseling, and as key influences on the development of modern bioethics. Stern charted the historical

⁴ Reed, *Counseling in Medical Genetics*; Bosk, *All God's Mistakes*.

⁵ Rothman, *The Tentative Pregnancy*; Rapp, *Testing Women, Testing the Fetus*.

progression from Reed’s understanding of client autonomy to the incorporation of Carl Rogers’ principles in Masters-level counseling programs, and then discussed more recent challenges to, or modifications of, these principles.⁶

This chapter explores the patient-counselor relationship from the perspective of genetic counselors. I position counselors as mediators between their patients and genetic reproductive technologies, and as interpreters of complex medico-scientific information and choices during what can be a complex and anxiety-inducing medical encounter. I focus on the philosophies and theories underlying the patient-counselor relationship, as well as the experience of the genetic counseling session. My analysis of the counselor-patient relationship expands upon Stern’s historical examples by interweaving them with more contemporary, interdisciplinary analyses and, in many cases, foregrounding the voices of genetic counselors.

This chapter then elaborates the existing scholarship in three ways: first, I situate the patient-counselor relationship in relation to the larger system of professions. Counselors fought against the old-fashioned paternalism of their physician-geneticist predecessors, and challenged the traditional doctor-patient relationship. Moreover, counselors’ gender and professional credentials, the two factors that most affected their professionalization process, also influenced their relationships with patients. Second, I suggest that counselors situated the client-counselor relationship in opposition to early-twentieth century eugenics. They explicitly decried the coercion, deception, and rather crass social judgements about “good” and “bad” parents inherent in mainline eugenics. Masters-level

⁶ Stern, *Telling Genes*. See Chapter 2: Genetic Risk: An Evolving Calculus, 28-52, and Chapter 6: Ethics: Shades of Gray in Genetic Counseling, 123-145.

genetic counselors in particular distanced themselves from this eugenic model (and physician paternalism and directiveness) through the core ethical values of client-centeredness and non-directiveness. Although ideologically admirable, these values are complicated and often problematic principles in practice.

Third, my analysis of client-counselor relationships draws attention to both changes and continuities in this interaction over time. I argue that genetic counseling has always revolved around concepts of risk. Every counseling interaction, at its most basic level, is about providing people with risk calculations and information about genetic risk management. Genetic counseling has also evolved around a professional ethos of patient autonomy. Physician-geneticists like Sheldon Reed articulated a commitment to client autonomy, but this ethic grew more pronounced and was formalized through Masters-level genetic counseling programs. The language to describe patient's self-determination has varied, and risk estimates have become more precise; nevertheless, these two factors have structured the patient-practitioner relationship in genetic counseling throughout the late-twentieth century.

The role of the genetic counselor certainly became more complex and diverse between 1947 and 2000. Yet, despite their roles in labs, public health departments, and other employment settings, almost all genetic counselors have spent time in clinical practice. Counselors' patient interactions within the counseling session is also the professional forum in which counselors have been most frequently subject to intense social, political, and ethical scrutiny. By the 1980s and 90s, counselors and the women they counseled became mediators of the new genetics and reproductive technologies. The

personal decisions of the counseling session were subject to increased interest and surveillance by an American public both excited and skeptical about the genetic revolution and their transformation into genetic citizens.

Genetic Encounters of the Traditional Kind: The Early Patient-Practitioner Relationship in Genetic Counseling.

The patient-practitioner relationship of the late-1940s to 1970s closely resembled the standard doctor-patient relationship as MDs and PhD geneticists comprised the bulk of professionals performing genetic counseling. According to historian Edward Shorter, the years between 1880 and 1950 witnessed the ascendancy of the scientifically-trained, “modern” doctor whose power rested on his newfound ability to accurately diagnose disease. The doctor-patient relationship was marked by patients’ “confidence in the doctor as a man of science” and “willingness to accept ‘medial authority,’” although physicians understood that a positive relationship built on mutual respect was crucial to patients’ health. Doctors often emphasized a holistic healthcare perspective.⁷ The “postmodern” doctor (to use Shorter’s term) arose in the 1940s from dramatic changes in drug therapy and technology. From this point, physicians concentrated primarily on the diagnosis of specific ailments. These changes occurred as improved understandings of bacteriology, immunology, biochemistry, and other basic medical sciences facilitated their ability to cure in the post-WWII period.⁸

With the increasing authority of biomedicine in the 1950s, the doctor-patient relationship became more technically-specific through a focus on scientific testing for a

⁷ Shorter, *Doctors and their Patients*, 75, 92, 107.

⁸ *Ibid.*, 180-185.

particular disease. The physician's role narrowed considerably to concentrate on lab values and a specific diagnosis rather than a patient's holistic well-being. Infamous historian of medicine Roy Porter described of this transition that, "With effective weapons against organic disease, [physicians] tended to forget the psychological significance and benefits of the doctor-patient relationship. The new generation of physicians was filled with therapeutic self-confidence: a display of humanity had become therapeutically unnecessary and risked being forgotten."⁹ This doctor-patient relationship, characterized by an asymmetrical power balance with expectations of doctor dominance and patient passivity, was decried as paternalistic in the 1960s and 70s. Feminists and others revolted against physician authority, the "medical model," and the over-medicalization of American society by promoting self-help and seeking alternative health practitioners.¹⁰

Physician-geneticists providing genetic counseling services in the field's early days would have engaged in some way with Shorter's postmodern medical paradigm, whether in their educational training, clinical philosophies, or interactions with patients. Individuals or couples seeking the advice of a genetic counselor may have visited one of the few heredity clinics existent in 1950s America, while others discussed concerns related to their genetic health with their family doctors at regularly-scheduled

⁹ Porter, *The Greatest Benefit to Mankind: A Medical History of Humanity* (New York: W.W. Norton and Co., 1997), 686.

¹⁰ Sandra Morgen, *Into Our Own Hands: The Women's Health Movement in the United States, 1969-1990* (New Brunswick: Rutgers University Press, 2002), 72-73. See also Starr, *The Social Transformation of American Medicine*, 391; Barbara Ehrenreich and Deirdre English, *For Her Own Good: 150 Years of Experts' Advice to Women* (Garden City: Anchor Press, 1979); Barbara Ehrenreich and Deirdre English, *Witches, Midwives and Nurses* (New York: The Feminist Press, 1973).

appointments.¹¹ This clinical relationship was based on the doctor-as-medical-authority assessing the patient's health status, and then providing information and a course of treatment. Based on this role, we might label physicians' training and approach as "directive."¹² Indeed, many of the first physician-geneticists to perform genetic counseling subscribed to a directive patient ethos. An example of a physician working in this directive way was Clarence P. Oliver, the first director of the Dight Institute. Alexandra Minna Stern described him as "a brazen advocate of the eugenic role of genetic counseling" who advised that counselors "should give forceful advice in cases where genetic defects were likely in future offspring."¹³ Psychiatrist Franz J. Kallmann also advocated a directive approach, warning that "persons requesting genetic advice cannot always be presumed to be capable of making a realistic decision as to the choice of a mate, or the advisability of parenthood, without support in the form of directive guidance and encouragement."¹⁴

The interests of Shorter's postmodern doctor are clearly evident in the work and priorities of physician-geneticists performing genetic counseling before the 1970s. This cohort was deeply engaged with the scientific underpinnings of the field by performing research in human genetics and studying the hereditary nature of various traits and disorders. The introduction of a symposium volume, *Heredity Counseling* (1959), by John C. Bugher insisted that the counselor's responsibility is "the scientific content of his

¹¹ Reed, *Counseling in Medical Genetics*, iv-v. Reed wrote this book specifically for physicians to give them a basic education in genetics. He suggested that while they may consult geneticists at heredity clinics for assistance, at the "grass-roots" level, counseling will be done by the family physician.

¹² Paul, *The Politics of Heredity*, 138.

¹³ Stern, *Telling Genes*, 130.

¹⁴ Franz J. Kallmann, "Types of Advice Given by Heredity Counselors:I," in *Heredity Counseling*, ed. Helen G. Hammons (New York: Hoeber-Harper, 1959), 82.

special field, the knowledge of genetics,” and that the “chief objective” of genetics research is to “understand more completely the manner of inheritance of human characteristics.”¹⁵ There was little consideration of “counseling” in clinical manuals and textbooks from this period, and the field’s emphasis was firmly on the “genetic” portion of the job title. The foregrounding of information and the genetic basis of disease is also evident in texts on human genetics by James V. Neel and Victor McKusick. As scientists first and counselors second, these individuals were primarily interested in the science of genetics and its role in furnishing a decline in hereditary disease.¹⁶

Physician-geneticists penchant for scientific knowledge was reflected in their counseling style. Their patient interactions centered on the provision of risk estimates and genetic information, and they often marginalized a confirmation of patient understandings and psychological follow-up. Sociologist Charles Bosk noted that even in the late-1970s and early 1980s, physician-geneticists often evaluated their counseling success based on the stories they constructed for patients, focusing on their “telling” rather than the patient’s “hearing,” and on their own counseling procedures rather than patient outcomes.¹⁷ Indeed, a 1978 survey of 447 MDs or PhDs performing genetic counseling indicated that 88 percent saw information giving as their foremost concern. Only 22 percent considered psychosocial counseling a primary goal, while 73 percent described it

¹⁵ John C. Bugher, “Introduction,” in *Heredity Counseling*, ed. Helen G. Hammons (New York: Hoeber-Harper, 1959), 3-4. The symposium was sponsored by the American Eugenics Society.

¹⁶ See James V. Neel and William J. Schull, *Human Heredity* (Chicago: University of Chicago Press, 1954); Victor A. McKusick *Human Genetics* (New Jersey: Prentice Hall, 1964); Victor A. McKusick, *Mendelian Inheritance in Man: Catalogs of Autosomal Dominant, Autosomal Recessive, and X-Linked Phenotypes* (Baltimore: Johns Hopkins UP, 1966). This group of physician-geneticists also believed that while patients should make their own decisions, the goals and interests of their patients and broader society were the same: to bring about a decline of genetic disease.

¹⁷ Sheldon C. Reed, “Types of Advice Given by Heredity Counselors: II,” in *Heredity Counseling*, ed. Helen G. Hammons (New York: Hoeber-Harper, 1954), 91; Bosk, *All God’s Mistakes*, 123.

as a secondary professional duty. 5 percent classified it as entirely “not a professional obligation.”¹⁸

Even Sheldon Reed, who was more invested in genetic counseling than many other physician-geneticists, could adhere to this patient model. In *Counseling in Medical Genetics* (1955), Reed briefly outlined the history of genetic counseling and his counseling philosophy before devoting the rest of his treatise to a discussion of select health concerns, their potential genetic origins, and summaries of the latest scientific studies. He included discussions of schizophrenia, diabetes, seizures, congenital dislocation of the hip, mental retardation and clubfoot, amongst other disorders.¹⁹ Reed ended each chapter with an “illustrative example” of the counseling issues inherent in each condition, many of which demonstrate a strong emphasis on scientific explanations. In one case, Reed considered whether or not a baby boy should be put up for adoption since he was born to a “mentally retarded cretin,” who was a “high grade moron” and “completely lacking in social graces.” Reed suggested, “There is no general agreement whether cretinism is hereditary or not. However, it is a clearly delimited glandular dysfunction and could well depend upon some complicated type of recessive heredity.”²⁰ This emphasis on diagnosis and information-giving is reflective of a postmodern doctor-patient relationship. Reed’s response was also based on his belief that people, as rational actors, needed information to make objective decisions about their reproductive and familial futures.

¹⁸ James Sorenson and Arthur J. Culbert, “Professional Orientations to Contemporary Genetic Counseling,” *Genetic Counseling: Facts, Values, and Norms*, eds. Alexander M. Capron et al., (New York: Alan R. Liss, 1979), 91-92.

¹⁹ Sheldon Reed, *Counseling in Medical Genetics*, vii-viii.

²⁰ *Ibid.*, 98.

At the same time, Reed (ever the complex and contradictory figure) and a few other physician-geneticists still expressed interest in patients' emotional and psychological well-being. As his lecture on "Practical Genetic Counseling" demonstrated, Reed believed it was crucial that the counselor "listen well" to the client's concerns and express compassion.²¹ In this way, he foreshadowed the client-centered paradigm that became central to genetic counseling as it developed in the 1960s and 70s. Reed also demonstrated a commitment to an individual or couple's autonomy in reproductive decision-making. Alexandra Minna Stern suggested that Reed's concern for patient autonomy is evident through his use of the term "client" rather than "patient" to denote the individuals seeking his services. This was reflective of his view that the counseling session was "much more one of helping than of healing."²² A newspaper article in St. Paul *Pioneer Press* from March 16, 1958 explained that, "Dr. Reed does not tell any patient whether she should or should not have another child. That is up to the couple. His job is only to give the mathematical chances, as accurately as they are known, of a defect occurring again."²³ Genetic counselor Robert Resta suggested that although Reed did not use the terms non-directiveness or client-centeredness, it is clear that "the emotional well-being of his patients formed the philosophical core of his concern for patients and their families."²⁴

What differentiated Reed and his contemporaries from their Masters-level successors was their logic that a patient's sound decision-making and emotional well-being would

²¹ Sheldon C. Reed Lecture, "Practical Genetic Counseling," 1977.

²² Stern, *Telling Genes*, 131-132.

²³ "Heredity Explained: U Team Calls Toss on Genetic Gamble," St. Paul *Pioneer Press*, 16 March, 1958, Sheldon Reed Info File, DI.

²⁴ Resta, "In Memoriam," 283-285.

come from a solid understanding of their genetic risk rather than in-depth psychological counseling.²⁵ Reed's published case studies effectively demonstrate his finesse for numbers and their centrality to his counseling philosophy. In response to a request about the hereditary transmission of mental illness, Reed explained that,

Manic depressive psychosis seems to be inherited as a dominant character in the large mass of pedigree material available...While we expect half the children of a manic-depressive to develop this psychosis at some time during their lives, in theory, fortunately only one third of the offspring actually appear at medical centers for treatment. Using this new figure of one third, the chances that neither child will ever develop the disease are 45 in 100; the chances that one, but not the other, will develop the psychosis are also 45 in 100; the chances that both will develop the disease are only 10 out of 100. The chances are 55 out of 100 that that one or both will develop the disease at the same time. To what extent does the state wish to protect foster parents from possible future discomfort? This question is not my problem, but it is clear that the future foster parents must be warned of this misfortune which might develop.²⁶

This counseling perspective was corroborated by James V. Neel who, like Reed, was more interested in counseling than the average physician-geneticist. He explained that, "it is our policy to inform a responsible family member of any family with a counseling problem of all the facts at our disposal bearing on the issue. However, with rare exceptions, we do *not* attempt to pass judgment as to the advisability of parenthood. This is a decision to be reached by the family concerned."²⁷ It seems, then, that a client's holistic well-being and autonomy in decision-making was important to the counseling session as conducted by Reed in particular. In this period, however, promoting patient

²⁵ Franz J. Kallmann, "Psychiatric Aspects of Genetic Counseling," *American Journal of Human Genetics* 8, no. 2 (1956), 97. Kallmann explained that genetic counseling assumed that "intelligent people, who are morally entitled to truthful information regarding the prospects of their own health and that of their children, are capable of dealing with their family problems realistically and without special guidance."

²⁶ Reed, "Counseling in Human Genetics," 11. This particular question, like many others, was about whether to place children in foster care.

²⁷ Neel and Schull, *Human Heredity*, 308. Italics in original.

health was tied less to the counselor's ability to offer thorough emotional counseling than to the provision of scientific risk estimates and medical information on which to base rational reproductive decisions.

“Decisions That Are Best for Themselves”: Client-Centeredness and Non-Directiveness in Genetic Counseling.

The principles of autonomy in genetic decision-making valued by Sheldon Reed and James V. Neel contrast quite sharply with coercive mainline eugenic policies outlined earlier in this study. The newer values were formally articulated, however, as client-centered and non-directive approaches by Dr. Carl Rogers, a professor of clinical psychology, counselor, and psychotherapist.²⁸ Psychotherapy generally, and psychoanalysis in particular, achieved prominence in the United States between the late-1940s and 1960s, a period termed “the golden age of psychoanalysis.”²⁹ The 380,000 psychiatric casualties amongst America's WWII soldiers raised awareness about the potential of psychological counseling and the need for better mental health services.³⁰ Psychotherapeutic techniques also triumphed during this era due to the arrival in the United States of European analysts who were fleeing political persecution at home.³¹

Psychotherapy and psychoanalysis became the therapy of choice for middle class Americans who sought self-insight. This counseling model was enthusiastically adopted by many psychiatrists to expand their professional duties beyond the confines of the

²⁸ Rogers, *Counseling and Psychotherapy*, v, 115-126; Rogers, *Client-Centered Therapy*, Part I: A Current View of Client-Centered Therapy.

²⁹ Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*, 171. The “golden age of psychoanalysis” is Shorter quoting from Lewis Coser.

³⁰ Jonathan Engel, *American Therapy: The Rise of Psychotherapy in the United States* (New York: Gotham Books, 2008), 45-47.

³¹ Shorter, *A History of Psychiatry*, 166-170.

asylum to the general American public.³² Psychotherapy filled a gap in the doctor-patient that had fallen by the wayside with the postmodern physician's ability to cure disease. This group of MDs addressed psychiatric illness through surgery, painkillers, antidepressants, and psychoactive drugs as they entered "the era of psychopharmacology" beginning in the 1950s.³³ Psychologists like Rogers, then, took over this vacancy in psychotherapeutic counseling by providing patients with a venue for exploring their thoughts, feelings, and experiences.

Rogers espoused a counseling model that stressed helping the client obtain insight into his personal problems, and tuning him into his ability to change his feelings, behaviours, and attitudes.³⁴ He believed that "*Effective counseling consists of a definitely structured permissive relationship [between counselor and client] which allows the client to gain an understanding of himself to a degree which enables him to take positive steps in the light of his new orientation.*"³⁵ Rogers eschewed the view that "The counselor knows best," which was profoundly entrenched in earlier psychotherapeutic models. Instead, he advocated a counseling paradigm that put the individuals' emotions, character, and personal situation at the center of the therapeutic paradigm. The counseling session was meant to act as a forum for clients to work through their own problems with professional guidance, rather than an opportunity for the counselor to impart answers as the expert.³⁶

³² Ibid., 153, 163-165.

³³ Ibid., 255; Shorter, *Doctors and their Patients*, 244-251.

³⁴ Rogers, *Counseling and Psychotherapy*, v, 3.

³⁵ Ibid., 18. Italics in original.

³⁶ Ibid., 27, 29, 33.

Rogers first defined this type of counseling as a non-directive approach. This label emphasized the agency of the individual seeking counseling, and distanced Roger's methods from Freud's brand of psychoanalysis.³⁷ Much like Reed, Rogers argued that, "it is not his [the counselor's] function to urge a certain course of action or to give advice."³⁸ Rogers first discussed his non-directive approach in *Counseling and Psychotherapy* in 1942, in which he outlined that,

Non-directive counseling is based on the assumption that the client has the right to select his own life goals, even though these may be at variance with the goals that the counselor might choose for him. There is also the belief that if the individual has a modicum of insight into himself and his problems, he will be likely to make this choice wisely...The non-directive viewpoint places a high value on the right of every individual to be psychologically independent and to maintain his psychological integrity.³⁹

The guidelines around non-directiveness delineated that the interviewer should not give moral admonition or foreground his authority. In fact, he should only intervene in order to rid clients of fears or feelings of guilt, guide the conversation to a topic that has been neglected, or mention implicit assumptions in the counselee's rationale.⁴⁰

Rogers replaced his "non-directive" model with "client-centered therapy" in 1951 to address aspects of non-directiveness he felt were lacking.⁴¹ Mainly, he believed that although a non-directive approach described his therapeutic paradigm, client-centeredness

³⁷ Stern, *Telling Genes*, 127.

³⁸ Rogers, *Counseling and Psychotherapy*, 41.

³⁹ *Ibid.*, 126-127. He contrasted a non-directive counseling paradigm against a directive approach that placed a premium on social conformity, in which the counselor determined the session's goals, and in which the counselor was tacitly acknowledged as superior to the client.

⁴⁰ *Ibid.*, 125.

⁴¹ Beth A. Fine, "The Evolution of Nondirectiveness in Genetic Counseling and Implications of the Human Genome Project," in *Prescribing our Future: Ethical Challenges in Genetic Counseling*, eds. Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan (New York: Aldine de Gruyter, 1993), 108.

more accurately captured the pivotal role of the counselee in the counseling session.⁴² The three central elements to client-centeredness included the element of “genuineness” on the part of the counselor in trying to place himself within the client’s worldview; a commitment to “empathic understanding”; and “unconditional positive regard” and acceptance for the client.⁴³ In this model, the counselor’s role was to facilitate an open and receptive environment in which the client felt at liberty to express themselves and discuss the therapeutic options available. Importantly, the session’s outcome was the shared responsibility of the client and counselor.⁴⁴ Non-directiveness and client-centeredness worked together to place the client and their experiences at the center of a counseling session in which the counselor provided information and available options, but ultimately respected the autonomous decision-making of the client.

Non-directiveness and client-centeredness became the watchwords of the day in the 1960s and 70s as new professionals were educated in Masters-level genetic counseling programs. A non-directive ethos and promotion of autonomy reflected scientific values of objectivity and empiricism, and a boundary between researcher and subject, all of which likely helped counselors boost their claims to expertise in the realm of science.⁴⁵ One counselor remembered that, “when I started [in 1983] everything was non-directive, non-directive, non-directive.”⁴⁶ Another counselor who attended the Sarah Lawrence program

⁴² Stern, *Telling Genes*, 127-128.

⁴³ Rogers, *Client-Centered Therapy*, 29, 36; Carl Rogers, “A Client-Centered/Person-Centered Approach to Therapy,” in *The Carl Rogers Reader: Selections from the Lifetime Work of America’s Preeminent Psychologist, Author of On Becoming a Person and A Way of Being*, eds. Howard Herschenbaum and Valerie Land Hendeson (New York: Houghton Mifflin, 1989), 135-152.

⁴⁴ Rogers, *Counseling and Psychotherapy*, 87-96.

⁴⁵ Petersen and Bunton, *The New Genetics and the Public’s Health*, 146.

⁴⁶ Interview with GCS59I11, 6 August, 2010.

in the mid-1970s explained that the “psychosocial training was framed in Carl Rogers’ principles, and the key words were ‘autonomy,’ and ‘non-directiveness,’ and ‘genuineness.’”⁴⁷ Indeed, in 1976 Sarah Lawrence introduced a program specifically called “Client Centered Counseling.”⁴⁸ Several counselors built their careers around a fundamental belief in this ethical model. One counselor praised this counseling method, saying,

When I was in training [in the 1980s] we were taught that concept of non-directive and client-centered counseling, and I totally buy it...the phrase I love is that we’re supposed to ‘create an atmosphere where the client can make decisions that are best for themselves.’ And I love that phrase because I think it’s so true. And I think what a lot of people don’t realize is it’s so liberating because if I’m directive or paternalistic, then when I go home I have some weight on my shoulders of having influenced the decision. But if I’m non-directive and client-centered, then I don’t have to feel responsible if the outcome is such and such. I haven’t pushed for a particular outcome.⁴⁹

Genetic counselor Robert Resta reminds us that Rogers did not develop client-centeredness specifically as a reaction against eugenics. Resta also emphasized that many physician-geneticists like Reed, who professed a prototypical non-directive philosophy, also supported the eugenic potential of medical genetics.⁵⁰ Nevertheless, Masters-level counselors seemingly adopted non-directive and client-centered approaches to distance themselves from the paternalism of earlier modes of heredity and marriage counseling, and to infuse their burgeoning profession with an ethic centered on autonomy. This approach also stood, at least in principle, against

⁴⁷ Interview with GCS00I21, 12 November, 2010.

⁴⁸ Marks, “The Training of Genetic Counselors,” 20.

⁴⁹ Interview with GCS42I05, 28 July, 2010.

⁵⁰ Resta, “Eugenics and Non-Directiveness,” 255-58.

early-twentieth century eugenic coercion. A pioneering genetic counselor explained that,

Early on in genetic counseling, the [Second World] war was recent and eugenics was still fresh in people's minds, and most genetics was related to prenatal diagnosis. So non-directiveness was really appropriate for those times when you didn't want to be telling people 'have a baby, don't have a baby.' This was especially so because disability rights was coming of age, as were civil rights in terms of recognizing the impact of race, abilities, and class. You have no idea the fine line you had to walk to raise our own awareness in order to provide ethical and inclusive genetic counseling.⁵¹

Seymour Kessler, a well-known and prolific genetic counselor, took up Rogers' emphasis on the psychological and client-centered aspects of counseling. In *Genetic Counseling: Psychological Dimensions* (1979), Kessler situated a psychosocial approach in contrast to earlier models of counseling that emphasized the scientific, technological and diagnostic components of genetic counseling. Instead, he highlighted the commonalities between genetic counseling and other fields of personal counseling, and argued that at its core, genetic counseling meant "dealing with human actions, attitudes, behaviour, beliefs, fantasies, values, and wishes concerning health, procreation, and parenthood."⁵² Kessler believed in the need to move beyond the conveyance of facts, and suggested that counselees come to genetic counseling less for technical genetic information than for "help in finding meaning in their experiences with genetic disease."⁵³ In opposition to a medical model, he saw counselor-patient dynamic as more of a teacher-student relationship characterized by mutual participation. He argued that,

⁵¹ Interview with GCS00I24, 19 November, 2010. Stern provides interesting examples of how GCs came to reject directiveness through training and personal experiences (*Telling Genes*, 136).

⁵² Seymour Kessler, ed, *Genetic Counseling: Psychological Dimensions* (New York: Academic Press, 1979), xi.

⁵³ *Ibid.*, 12.

“Perhaps the most cogent reason for moving toward a model of mutual participation is that the traditional model of physician-patient interaction, like other relationships based on a power differential, often is a self-defeating one.”⁵⁴ Interestingly, Kessler’s advocacy for a teacher-student relationship, while based on an idealized collaboration between counselor and patient, demonstrates one of the fissures in a client-centered and non-directive approach: namely, the differential in knowledge between counselor and patient that can create, however unwittingly, a power imbalance. Kessler was ultimately committed, however, to an emphasis on communication, coping processes, and emotional aspects of counseling within a larger framework of client-centeredness.

The psychosocial and client-centered models outlined by Rogers and elaborated by Kessler became the dominant paradigms in the field of genetic counseling through the 1980s. As such, many counselors sought to enhance the counseling aspect of their practice so as to better serve their patients’ psychological needs. One pioneering counselor became a psychotherapist to augment her genetic counseling training. She recounted that, “I eventually found that I needed and wanted more counseling training. So I, like many, returned to graduate school. As a result, I broadened and deepened the psychological perspective that I could bring to genetic counseling practice and research. To this day, our profession still borrows heavily from psychotherapy.”⁵⁵

Another pioneering counselor explained that she sought to join a psychological supervision group that met on a weekly basis and included various kinds of psychological

⁵⁴ Ibid., 57. The mutual participation model was also discussed by Kenen and Smith in “Genetic Counseling for the Next 25 Years,” 119-120.

⁵⁵ Interview with GCS00I24, 19 November, 2010.

therapists. She attended the group for seven years, and even tried to enrol in a family therapy program. She explained her reasoning for seeking out these programs, saying, “I realized that there was this huge body of literature about counseling, therapy, psychology that I knew nothing about. And it was a little alarming that I had this word ‘counselor’ after my name, and I really didn’t know what I was supposed to know.”⁵⁶ Interestingly, when she first attempted to gain access to psychologically-oriented discussion groups, she was told that most people in the group actively saw patients for psychological issues and that “you’re more medical.”⁵⁷ This offhand comment speaks to the somewhat liminal position of genetic counselors. Despite the profession’s focus on psychotherapy, and counselors’ identification with the roles played by other brands of therapists, they were still sometimes classified by other healthcare personnel as operating more firmly in the medical realm.

Genetic counselors have maintained a commitment to a client-centered approach into the modern day; non-directiveness, however, came under scrutiny within the profession. In a 1989 issue of *Perspectives in Genetic Counseling*, genetic counselor Karen Copeland asked “Can Non-Directiveness be Non-Helpful?” When questioned by a woman with an ambiguous CVS (chorionic villus sampling) finding as to what she would do in the same situation, Copeland refused to shut down the discussion by a standard non-directive response. She found that attempts at a neutral answer like there is “no right decision or action, and that each couple must decide what is best based on their own personal social, religious and economic needs,” only irritated the patient further. Convinced that the

⁵⁶ Interview with GCS00I21, 12 November, 2010.

⁵⁷ Ibid.

woman truly wanted her opinion, she explained her own decision and decision-making process, and justified this course of action by arguing that, “There is a fine line between discussing and persuading.”⁵⁸ In *All God’s Mistakes*, Charles Bosk argued that counselors “at times use the goal of patient autonomy as a ground for patient abandonment” by highlighting their own value-neutrality and the patient’s need for self-determination in decision-making. Bosk suggested that, “the most ironic result of genetic counseling is that a process designed to support couples in their reproductive decision making, to insure their autonomy, leaves them isolated and overwhelmed with the burden of decision making.”⁵⁹

Counselors also questioned the applied practicality of a non-directive stance in the *Journal of Genetic Counseling*. In 1992, Seymour Kessler suggested that non-directiveness and directiveness are not in complete conflict with one another as both are a form of persuasion. While non-directiveness may pledge value neutrality, it is based on persuading clients that they have the ability to make their own choices. He explored the arguments in favour of a directive approach to counseling including the perspective that patients in a medical setting facing an emotionally-charged life decision want professional advice, and that a non-directive approach can leave them “hanging out on a limb.”⁶⁰ Throughout the 1990s, genetic counselors proposed various modifications or alternatives to a strict non-directive approach including “value-based directiveness,” in

⁵⁸ Karen Copeland, “Can Non-Directiveness Be Non-Helpful?” *Perspectives in Genetic Counseling* 11, no. 3 (Fall 1989), 3, 9. The following year, Copeland’s question sparked a debate about the usefulness of non-directive counseling.

⁵⁹ Bosk, *All God’s Mistakes*, 10, 40, 55.

⁶⁰ Seymour Kessler, “Psychological Aspects of Genetic Counseling: VII. Thoughts on Directiveness,” *Journal of Genetic Counseling* 1, no. 1 (1992), 11, 14.

which the congruence or incongruence in values between counselor and patient determines whether directiveness is appropriate. Counselors also explored the possibility of weighing autonomy versus beneficence in relation to the patient's ethical system, and the potential of an "experience-oriented approach" to genetic counseling in which "the point of departure for all activities is the experience of the patient/client."⁶¹

Many of the genetic counselors I interviewed in this study spoke of the initial necessity and value of non-directiveness during the field's early days. As a group, however, they were increasingly critical of strict adherence to this model in contemporary counseling practice. A counselor who has been working since 1983 explained that, "I'm a big critic of non-directiveness. It's not a particularly helpful philosophy or counseling technique. Not that I would necessarily tell a patient what to do, but I have no problem with telling a patient when I think they're not making a good choice, one that's not consistent with their values, with their understanding of the information."⁶² Arguing against a stringent policy of non-directiveness, this counselor simultaneously (and perhaps paradoxically) reinforced his commitment to client-centeredness by aspiring to help patients make decisions in line with their particular values. A contemporary counselor voiced a similar dissatisfaction with non-directiveness, saying,

I also don't think there's necessarily anything true about non-directiveness because anytime a doctor tells you something, you automatically attach importance to it. Anytime someone in a skirt and pumps sits down across from you in a very scary situation, they're going to be seen as a person with

⁶¹Sarina M. Kopinsky, "'Value-Based Directiveness' in Genetic Counseling," *Journal of Genetic Counseling* 1 no. 4 (1992), 345-348; Michael L. Begleiter and Jill Cellars Rogers, "Genetic Counseling for a Family with Two Distinct Anomalies," *Journal of Genetic Counseling* 3, no. 2 (1994), 91-92; Gerhard Wolf and Christine Jung, "Nondirectiveness and Genetic Counseling," *Journal of Genetic Counseling* 4, no. 1 (1995), 13-14.

⁶² Interview with GCS50I03, 27 July, 2010.

some information that I apparently need or else I wouldn't be there. So I think to sit down in that position, to hold that power and say, 'but I shouldn't sway you at all,' just your presence in the room is attaching an importance to the decision and an importance to the risk.⁶³

Charles Bosk demonstrated that despite attempts at neutrality, counselors can shape patient choices through the way they frame risk statements, so that the patients either understand their chances as serious or trivial. Counselors also affect client decisions through the conviction and genuineness with which they present available choices.⁶⁴ Indeed, in the late-twentieth century, counselors frequently discussed the implicit power dynamics that influence the counseling session despite an explicit commitment to a non-directive ethic.

In 1991, the NSGC introduced their Code of Ethics. Not surprisingly, genetic counselors began discussing the development of formal ethical guidelines in the late-1980s, just as the profession's commitment to non-directiveness wavered.⁶⁵ The Code was intended to guide counselors in their encounters with colleagues and society, as well as with their clients. The Code explicitly stated that, "The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare, and freedom." Within this framework, counselors were to respect their client's personal beliefs, and facilitate their informed decision-making in an environment free of

⁶³ Interview with GCS26I15, 12 August, 2010.

⁶⁴ Bosk, *All God's Mistakes*, 29. Bosk noted that while counselors were required to introduce all possible options in a prenatal context, they also made it evident that some options were open for discussion while others could possibly be brought up at a later date or with a different healthcare professional (128).

⁶⁵ "A Report from the Ad Hoc Committee on Codes of Ethics and Ethical Principles," *Perspectives in Genetic Counseling* 11, no. 3 (Fall 1989), 1, 4.

coercion.⁶⁶ In many ways, the National Society of Genetic Counselors' ethical code encapsulates the basic tenets of non-directiveness. That such a formalized code did not appear until the early 1990s is a testament to counselors' confidence in non-directiveness as a valuable professional ethic for more than twenty years. The Code of Ethics also signalled professional maturation, or the supplanting of a simplistic, rigid, and perhaps unrealistic ethic for something slightly more complex.

The critique of non-directiveness received an additional boost as genetic counseling moved out of strictly prenatal or pediatric contexts. This was particularly the case with cancer counseling in the 1990s where the field's eugenic potential is perhaps less pertinent. A University of Minnesota graduate articulated a commitment to leaving the ultimate decision in the hands of the patient, but also urged that "if somebody needs a mammogram...can you really be non-directive about it?"⁶⁷ Importantly, while non-directiveness has been questioned in recent years, counselors remain committed to a "non-judgmental" stance with regards to patients' wishes and choices. Though the philosophies that guide the client-counselor relationship have evolved, they have always signalled an obvious rejection of old-fashioned eugenics and coercion. Counselors' ethics also pushed back against the traditional, asymmetrical doctor-patient power dynamic through a paradigm that places the client and their autonomous decision-making at the center of the counseling session.

⁶⁶ "Code of Ethics," 1991, National Society of Genetic Counselors, accessed 25 April, 2013, <http://www.nsgc.org/Advocacy/NSGCCCodeofEthics/tabid/155/Default.aspx>. See also Judith L. Benkendorf et al., "An Explication of the National Society of Genetic Counselors (NSGC) Code of Ethics," *Journal of Genetic Counseling* 1, no. 1 (1992), 31-39.

⁶⁷ Interview with GCS12I08, 4 August, 2010.

Both Different and the Same: Change and Continuity in the Work of Counselors, Structure of the Counseling Session, and Patient Options.

The history of genetic counseling can, in many ways, be characterized as a story of swift, continuous change. Such a portrayal holds well due to the field's close relationship with human genetics and reproductive technologies, both of which accelerated dramatically in the last four decades of the twentieth century. Several components of the counseling session have evolved considerably. First, most genetic counseling done in Sheldon Reed's era was done individually, meaning the physician or geneticist saw one couple at a time. Today, however, there are multiple counseling formats such as group sessions, where a number of couples or individuals take part in at least the educational part of genetic counseling together.⁶⁸ Contemporary genetic counselors also often work in teams with oncologists, pediatricians, and other specialists whereas physician-geneticists seem to have worked relatively independently. Second, the type of counseling performed has shifted from focusing predominantly on prenatal and pediatric conditions to include cancer and other specialized disease areas like Huntington's disease or cystic fibrosis counseling. This shift has been the result of dramatic changes in genetic science, which in turn means that many more genetic conditions can be identified, treated, and counseled for. In the 1970s, Down syndrome was the only major condition detected prenatally; by the 1990s, dozens of fetal anomalies could be detected *in utero*, and predictive tests could

⁶⁸ Robert S. Young, Ronald J. Jorgenson, and Steven D. Shapiro, "An Evaluation of Three Commonly-Used Counseling Formats," *Perspectives in Genetic Counseling* 7, no. 4 (December 1985), 1. This study suggested that by the mid-1980s even, a variety of counseling formats existed including individual, group and audiovisual counseling.

identify carriers of genetic diseases including late-onset disorders, polycystic kidney disease, Tay-Sachs, sickle-cell anemia, and certain cancers.⁶⁹

Third, the counseling session has been modified by the various options available to patients. In the 1960s, amniocentesis was the only available prenatal testing option; by the 1990s, patients could request amniocentesis but also chorionic villus sampling, AFP screening, ultrasounds, *in vitro* fertilization, and pre-implantation genetic diagnosis.⁷⁰ Fourth, there has been a noticeable change in the demographic groups that present for genetic counseling. While white, middle-class women made up the majority of counselors and counseling patients in the 1960s and 70s, today a somewhat more diverse population seeks genetic counseling. Indeed, into the 1990s, counselors became increasingly concerned with reaching African American, Latina, and Native American women. NSGC diversity initiatives have also addressed the pervasive whiteness of the profession itself.⁷¹ Finally, there is now a wide array of support groups available for families of children with a variety of hereditary diseases. The internet has revolutionized the ways in which families can communicate to share experiences with their specific genetic diagnosis.⁷²

⁶⁹ Paul, *Controlling Human Heredity*, 131.

⁷⁰ Harper, *A Short History of Medical Genetics*, 355.

⁷¹ Ellen Simpson et al., “A Spanish Language Prenatal Family Health Evaluation Questionnaire,” *Journal of Genetic Counseling* 3, no. 1 (1995), 39-62. The need for Spanish-language counseling materials is the result of increasing numbers of Latina women coming for genetic counseling. By the 1990s, the greater numbers of Native American and African American women are also reflected in the literature which discusses how to accommodate these demographics at length. See, for example, B. Meredith Burke and Aliza Kolker, “Variations in Content of Prenatal Genetic Counseling Interviews,” *Journal of Genetic Counseling* 3, no. 1 (1995), 23-38, and Patricia N. Olney and Richard S. Olney, “Harlequin Ichtyosis among the Navajo,” *Journal of Genetic Counseling* 2, no. 1 (1993), 3-8.

⁷² Carolyn Bay, “Parent Groups: A Mechanism to Facilitate Parental Adjustment, and a Useful Addition to the Counseling Team,” *Perspectives in Genetic Counseling* 1, no. 2 (1979), 1. This volume discussed REACH OUT, a support group for parents with children with multiple impairments.

Despite changes in the social context, technology, and options surrounding genetic counseling, the core of the patient-counselor relationship exhibited remarkable continuity throughout the late-twentieth century.⁷³ In many ways, the contemporary counseling encounter bears a strong resemblance to Sheldon Reed's counseling sessions in both the underlying rationale and basic counseling format. Like modern counselors, Reed approached counseling from the philosophy that people have a "right to know" their hereditary composition, and that this should be explored in a friendly, welcoming environment.⁷⁴ The counselor needed to listen to the patient's experiences and questions, and treat them as an important contributor to the counseling session. The genetic counselor provided patients with genetic information based on a family history or pedigree in an accessible way. Their role was to then give risk estimates and predictive outcomes while allowing the patient to voice their concerns and make their own choices.⁷⁵

Similarly, the contemporary counseling session includes the initial "contact phase," where the counselor would "contract" with the patient, "so why are they there, what are they hoping to get from the session."⁷⁶ As Seymour Kessler described, this portion also includes going over the family and medical history, and establishing trust. The session's middle or "encounter" phase then focuses on giving genetic information, discussing the medical implications, and counseling for emotional issues. One counselor described this

⁷³ Charles Bosk similarly described the counseling process as "static" in *All God's Mistakes* (xx), and suggested that information communication and issues considered, amongst other factors, have remained similar over time.

⁷⁴ Sheldon Reed to Dr. Elizabeth M. Boggs, 20 April, 1961, Correspondence B, 1965-83, Box 1, Correspondence and Administrative Files, DI.

⁷⁵ Sheldon C. Reed lecture, "Genetics, 1969," Box 5, Dight Lectures, DI.

⁷⁶ Interview with GCS12I08, 4 August, 2010.

segment as focusing on “educating the patient on whatever condition you’re looking at or information you can provide for them, and then kind of helping them make the decision of where to go next.”⁷⁷ Decision-making about how to proceed with this new medical information forms the “summary” phase of the session, where the counselor and patient plan for the next step.⁷⁸ In addition to the basic structure and content of the counseling session, the counselor-patient relationship has also consistently turned on the multiple meanings of risk.

What are the Chances?: Genetic Counseling and Elements of Risk.

According to sociologist Ulrich Beck, we are now entering a new modernity, an age of “reflexive modernization,” characterized by the production of a “risk society.”⁷⁹ Anthony Giddens described this type of social order as “a society increasingly preoccupied with the future (and also with safety),” and one in which “we increasingly live on a high technological frontier.”⁸⁰ Genetic risk calculations have become increasingly sophisticated. Clinical evaluation and family pedigrees in the 1940s and 50s gave way to biochemical tests for enzyme disorders and advances in cytological analysis by the 1960s.⁸¹ Genetic risk and the provision of risk calculations has, however, always been central to the counseling session and the profession’s overall purpose. The American Society of Human Genetics defined genetic counseling in 1974 as a “communication

⁷⁷ Ibid. See also Rothman, *The Tentative Pregnancy*, 36-37 for the basic components of the counseling session.

⁷⁸ Seymour Kessler laid out the basic components of the counseling session quite well in *Genetic Counseling: Psychological Dimensions*, 67. These are also the steps described by most of the counselors I interviewed.

⁷⁹ Ulrich Beck, *Risk Society: Towards a New Modernity* (London: Sage Publications, 1992), 9-16.

⁸⁰ Anthony Giddens, “Risk and Responsibility,” *Modern Law Review* 62, no. 1 (1999), 3.

⁸¹ Stern, *Telling Genes*, 47.

process” that explored “the occurrence, or risk of occurrence, of a genetic disorder in a family.”⁸² The most recent definition of genetic counseling by the National Society of Genetic Counselors (2005) defined it as “the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. This process integrates...[the] interpretation of family and medical histories to assess the chance of disease occurrence or recurrence...[and] counseling to promote informed choices and adaptation to the risk or condition,” as well as an educational component.⁸³

One of the central messages of Sheldon Reed’s classic text *Counseling in Medical Genetics* (1955) was that risk is universal, meaning we all carry some genetic risk.⁸⁴ Indeed, the significance of risk to the counseling session is evident in other genetic counseling manuals. The first line of the introduction for a manual from 1970 read, “Genetic counselling is concerned mainly with advising people about the risk that a member of a family will suffer from a congenital or hereditary disorder.” The manual then proceeded to discuss various conditions with a focus on explaining single figure risk estimates and other statistics of genetic probability.⁸⁵ Peterson and Bunton summarized the relationship between risk and genetic counseling, explaining that, “estimations of risk are considered to be crucial in the process of decision-making, in planning for, and if necessary insuring against, future eventualities...In genetic counseling, risk information is

⁸²Ad Hoc Committee on Genetic Counseling, “Genetic Counseling,” *American Journal of Human Genetics* 27, no. 2 (1975), 240.

⁸³ Resta et al., “A New Definition of Genetic Counseling,” 79.

⁸⁴ Stern, *Telling Genes*, 45.

⁸⁵ Alan Carruth Stevenson and B.C. Clare Davison, *Genetic Counselling* (Philadelphia: J.B. Lippincott, 1970), 1. Chapter 3: Principles of Derivation of Risk Estimates focused entirely on types of risk estimates and varying modes of genetic transmission, 46-61.

seen by counsellors as crucial in assisting people to make decisions about their family planning, employment choices, and the like.”⁸⁶

Many genetic counselors spoke of the importance of risk to their profession and their interactions with their patients. A University of California Irvine graduate explained that, “the overarching [purpose] in any setting is to educate individuals about the genetic conditions that may run in their families or that they may be at risk to develop themselves.” She elaborated that, “Some of that is also recurrence risk, sometimes about what are the chances for other people in the family to have that condition again, whether it’s a subsequent child or children of other relatives.”⁸⁷ Another counselor commented that,

basically, if I had to say what a genetic counselor does, is you’re trying to help people understand and adapt to things that are happening in their lives as a result of having or being at risk for a genetic disease or birth defect. And that’s probably true whether you’re facilitating a support group, or working with an individual or a family. In both cases, people are really trying to incorporate this diagnosis or potential diagnosis into their family schema and see what changes they need to make, what choices and decisions they need to make, what kinds of strategies they have for coping with the changes that are going on.⁸⁸

In a 1993 article in the *Journal of Genetic Counseling*, Palmer and Sainfort described the importance of risk and risk recurrence as “stem[ming] from the impact it is believed to have on decision making.”⁸⁹ Importantly, there was a shift away from the strict provision of risk estimates in the last two decades of the twentieth century as counselors emphasized

⁸⁶ Petersen Bunton, *The New Genetics and the Public’s Health*, 8.

⁸⁷ Interview with GCS94I01, 26 July, 2010.

⁸⁸ Interview with GCS49I18, 20 September, 2010.

⁸⁹ Christina G.S. Palmer and François Sainfort, “Towards a New Conceptualization of and Operationalization of Risk Perception in the Genetic Counseling Domain,” *Journal of Genetic Counseling* 2, no. 4 (1993), 276.

psychosocial counseling as the basis of client-centeredness. Risk calculations, however, remained integral to the client-counselor interaction and the counseling session.

Genetic counselors often spoke of statistical odds for inheritance using the term “risk,” and the terminology of “risk” was similarly employed in most of the genetic counseling literature for professional practice between 1947 and 2000. Indeed, patients were often classified as “high risk” or “low risk,” a naming that could greatly affect their perceived health status. In many cases, however, counselors chose to articulate the genetic likelihood of expressing a particular disorder through an alternate, more patient-friendly vocabulary. One contemporary genetic counselor, who now works in a laboratory setting, commented that, “I think ‘risk’ is a big scary word, and I don’t know that I’ve ever used ‘risk’ with a patient. I use ‘chance,’ ‘the probability that...,’ ‘the chance that...’”⁹⁰ Another counselor expressed a similar commitment to a particular patient vocabulary, saying, “Terminology is important. Instead of ‘risk,’ I’m always talking about ‘chances’ or ‘likelihoods’ when I discuss risk with patients.” She continued, “I will often use phrasing like ‘genetic changes,’ ‘spelling differences in genes,’ or ‘problems/abnormalities in the genes that keeps them from working properly’ rather than ‘mutations’ because of the connotations people hear with the term ‘mutations.’”⁹¹

Part of this modification of language is the result of the counselors’ propensity for “code-switching.” Anthropologist Rayna Rapp described “code-switching” as counselors’ ability to “move from one language framework— statistical, biomedical, familial, colloquial— to another, adjusting the message to the speaker’s perception of who the

⁹⁰ Interview with GCS26I15, 12 August, 2010.

⁹¹ Interview with GCS19I14, 11 August, 2010.

listener might be.”⁹² In this case, “code-switching” might refer to the ability of counselors to switch between medical notions of risk with more patient-friendly and less emotionally-charged terminology of “chance” so as to lessen patient anxiety. It remains clear, however, that whether described as “risk,” “chance,” or “likelihoods,” risk remains at the core of patient-practitioner consultations about genetic health.

Genetic counselors learned to convey risk estimates or genetic chances in a variety of ways through their formal training and subsequent years of clinical practice. Patients needed to understand their probability for developing a given hereditary disorder before the counseling portion of the interaction could be truly effective. One counselor, who currently works in pediatrics but who counseled in a prenatal context for almost ten years, explained the varying methods traditionally used by genetic counselors:

When I was doing prenatal and you’re talking about the chance to have a baby with Down syndrome, for example, and let’s say your risk is 1 in 100. I would always communicate that in 4 different ways and that is the chance of your baby having Down syndrome is 1 in 100, that means there’s 99 chances out of 100 that your baby doesn’t have Down syndrome. Then I’d also convert it into a ratio. I always do percents and ratios. So if I was saying there’s a 1% chance, that’s 1 out of 100, or that’s a 99% chance the baby doesn’t have it, or 99 out of 100...[If] you’re saying a 4% risk, then I would convert that to 1 out of 25, 24 out of 25 that it’s ok, or a 96% chance that it’s ok. So I would say it always in 4 different ways. Kind of the positive and the negative, the percent and the ratio, in the hope that one of those is going to get through to them and is going to make sense to them in a meaningful and accurate kind of way.⁹³

Other counselors relied on visual aids to help their risk conveyance. One contemporary counselor explained that she used pie charts to demonstrate a patient’s genetic probability.

Another counselor visually demonstrated a given patient’s risk for a particular disease

⁹² Rapp, *Testing Women, Testing the Fetus*, 63.

⁹³ Interview with GCS94I01, 26 July, 2010.

with a jar of marbles in which a sea of white marbles was punctuated with a few darker units.⁹⁴

One counselor used charts, often a “pros” and “cons” list to discuss risk and the testing options available should that be desirable to the patient.⁹⁵ Another counselor, who completed her Masters degree in 1984, also relied on analogies such as, “I always imagine I’m out on a balcony and there’s a courtyard. There are forty women below and I’m going to throw an egg down and I’m going to hit one of you. It’s very random, it’s just going to be one of you by chance. I’m not aiming or anything, I’m just going to throw it. If twenty more people came into the courtyard, those are better odds because now I’m less likely to hit you.”⁹⁶ These different tactics are another example of code-switching, and the multitude of ways in which counselors adapted complex risk figures into comprehensible, meaningful scenarios patients could understand.

Genetic counselors described a number of factors that affected how perceptions of risk were discussed with clients. The way a counselor approached risk with a client might depend on the patient’s education level, socioeconomic status, how well genetic counseling had been explained by the referring physician, and prior experiences with (or knowledge of) genetic diseases and reproductive technology. Many white, middle-class women who came in for concerns related to advanced maternal age (over thirty-five years) were already well-informed about genetic counseling. Some patients reportedly said, “I know all about this. My girlfriends have all done it. I’m perfectly calm and

⁹⁴ Interview with GCS64I09, 4 August, 2010.

⁹⁵ Interview with GCS34I04, 27 July, 2010.

⁹⁶ Interview with GCS104I13, 10 August, 2010.

comfortable with this.” In this case, the genetic counselor would simply fill any gaps in the patients’ knowledge.⁹⁷ In many cases, a prior understanding of genetic counseling greatly facilitated the client-counselor relationship as patients were more prepared and less anxious about their medical encounter.

In other cases, previous experiences with a genetic condition could hamper patient-counselor communication and skew understandings of risk estimates. Often, genetic counselors were forced to address misunderstandings regarding the purpose of genetic counseling, or the risks people actually carried versus overinflated and often fatalistic assumptions. One counselor who is a director of a genetic counseling program explained that, “You need to dispel some myths, so for the person whose brother died of CF (cystic fibrosis) 20 years ago, the treatment and life expectancy are very different today for CF...[and] I think with those patients, you have a different approach.” She described that, alternatively, “you get a new couple who’ve never heard anything about CF, and you just start talking to them about general population carrier screening and they wind up to both be carriers. They’re both coming into it with a clean slate. So you’re working with them at a different level.”⁹⁸ It seems that prior knowledge of, or encounters with, genetics could cut both ways, acting in different cases as a help or a hindrance to the counselor-patient dynamic.

Counselors also commented on the ways in which issues of race and class influenced discussions of risk, as well as the particular risks under examination. One counselor explained that in cancer counseling, “[the patients] are usually more upper-middle class,

⁹⁷ Interview with GCS49I18, 20 September, 2010.

⁹⁸ Interview with GCS64I09, 4 August, 2010.

educated. I think there's a lot more give and take with those because they're actually interested and I think they understand the information better. Then we deal with a lot of patients with lower income who didn't even graduate high school, and have a lot of other issues going on in their lives."⁹⁹ Another counselor, who worked in clinics in the north-eastern United States, discussed a similar gap based on socio-economic status. Her comments betray some of the stereotypes about the lifestyles and choices of women with lower educational and class status versus more educated, professional women. She explained that,

There are a lot of times that people come in and say, 'I have a degree in biology,' and you start going into your education about inheritance or whatever it may be. And I might say something like, 'If you feel comfortable with this, tell me and I will move forward'...I think the differences, though, are maybe in how you provide the information, so in certain groups you may really need to take time to show pictures because some of the lower-income literacy is still a factor...The big difference would be why the person was there, and in the lower-income there's much, much more discussion of teratogens. So people are there because of alcohol or drug use. That's why they've been referred to the counselor. It's maybe different from the suburbs where, for that clinic at least, it was just a lot of AMA [advanced maternal age] cases, older women who are pregnant.¹⁰⁰

Another counselor who worked in New York City counseled teenage pregnancies, upper-middle class older women, recent immigrants, and African American and Hispanic populations. She recalled that the interaction with each of those patient populations was quite different since "upper-middle class patients read every pamphlet," while "immigrant patients really didn't understand at all."¹⁰¹ This assessment speaks to the enormous disparities in wealth, education, and advantage in the U.S., but also the privilege of

⁹⁹ Interview with GCS12I08, 4 August, 2010.

¹⁰⁰ Interview with GCS8I116, 16 August, 2010.

¹⁰¹ Interview with GCS64I09, 4 August, 2010.

counselors. It is perhaps likely that being predominantly white, middle class, and well-educated themselves, genetic counselors tended to identify with thirty-five year old women attending counseling for advanced maternal age. They were more generous in their characterization of this group's understanding and interest in genetic counseling, and more disparaging of women who do not share their background.

Discussions of risk were usually accompanied by an assessment of the limits and potentials of genetic testing, an examination of available options, and counseling for feelings of anxiety and especially guilt. One counselor explained that,

If it's just a risk that we're talking about, I do remind people that everybody has certain risks, certain genetic conditions that occur sporadically, and risk is evenly distributed. All women of each age group are at risk for having a baby with a chromosome abnormality, and we all carry recessive genes for something or other. It's just a matter of whether the testing is available to detect what we carry. I like to remind patients that they have no control to cause or prevent the genetic conditions we're talking about, and try to reduce the guilt that they may feel or shame they may feel associated with being at risk.¹⁰²

In the *Journal of Genetic Counseling*, Olney and Olney considered Harlequin Ichthyosis (a congenital skin condition) amongst the Navajo. The counselor in this case study reported having to assuage feelings of guilt for a child's birth defects resulting from a cultural belief that paternal behaviours can alter a woman's pregnancy and the characteristics of the child.¹⁰³ Contemporary counselors have attempted to relieve parental guilt by altering their terminology to exclude anxiety-inducing terms like "defect,"

¹⁰² Interview with GCS61I06, 30 July, 2012.

¹⁰³ Olney and Olney, "Harlequin Ichthyosis among the Navajo," 3-8. Harlequin Ichthyosis is the most severe kind of congenital ichthyosis, a skin condition in which the epidermis looks like scales. It can also include facial deformities and contracted limbs.

“problem,” and “abnormality.”¹⁰⁴ A renewed emphasis on genetic causation in the late-twentieth century has often helped to alleviate parental guilt and anxiety by focusing responsibility for birth defects on genetic mutations, something we all have, instead of on parental behaviours recognized by Western science to have no bearing on one’s pregnancy. Counselors’ ability to contextualize genetic risk and reduce patient anxiety is a crucial component of the client-counselor encounter. Indeed, Sheldon Reed was well-liked by his clients in part because of his ability to alleviate parental guilt by explaining genetic principles and how abnormalities come about.¹⁰⁵

While counselors approached risk conveyance through a host of different philosophies, tones and methods, it was their impression that some patients left the session with an incomplete understanding of their risk. As Alexandra Minna Stern demonstrated, increasingly precise measurements of risk have often failed to align with how patients understand their personal risk assessments. Indeed, patients’ evaluations of their own genetic lottery, and willingness to play that lottery, do not necessarily reflect their categorization by the counselor as high or low risk.¹⁰⁶ A second-generation counselor commented that,

the bottom line is that for some people, those numbers just aren’t going to make sense. What I’ve learned through this process is that for some people, all they’re thinking is binary. It’s on or off, it’s yes or no. So all they see is there’s a chance that it’s yes, and there’s a chance that it’s no...For some people, that’s an educational piece, it’s because they just don’t have the education about ratios and percentages and statistics. And for some people that’s an emotional piece, and it’s because you’re talking about my baby.¹⁰⁷

¹⁰⁴ Dianne M. Bartels, “Maternal Anxiety,” *Journal of Genetic Counseling* 3, no. 1 (March 1994), 77-78.

¹⁰⁵ Stern, *Telling Genes*, 83.

¹⁰⁶ *Ibid.*, 31, 46-47.

¹⁰⁷ Interview with GCS94I01, 26 July, 2010.

This comment reveals some of the underlying fissures of non-directiveness and counselors' attempts to be non-judgemental. There is still a power dynamic based on education and genetic literacy, and an expectation of an effort on the patient's part to rationally internalize risk figures. Client's attitudes towards genetic chance have, however, been structured according to a complex array of social, religious, and cultural values in which risk estimates are just one relevant piece of information. A counselor who practiced predominantly in the American South described that, "the thing about the patients in Arkansas, God love 'em, [is that] you could tell them something devastating was going to happen and they would smile and say 'Thank you very much.' Nobody really wanted to do anything proactive about it." She explained that, "It was very conservative, for the most part, in the poor and rural sections [people figured] 'This is what God gave me so that's what I'll deal with.' So we really didn't have a lot of people pursue their own individual risks."¹⁰⁸

Counselors were responsible for calculating the patient's genetic risk but also for discussing a variety of other risk factors. If a patient in a prenatal setting chose to move forward with further testing, the counselor was obligated to discuss procedural complications, that is, the hazards associated with amniocentesis or other prenatal screening technologies. The World Health Organization published a report in 1968 warning of the risk amniocentesis posed to the fetus.¹⁰⁹ Barbara Katz Rothman described patient perceptions of this risk, saying, "Over and over and over, from almost every woman, there is a constant refrain: amniocentesis poses a risk - a risk to the continuation

¹⁰⁸ Interview with GCS26I15, 12 August, 2010.

¹⁰⁹ Stern, *Telling Genes*, 155.

of the pregnancy, a risk to the baby, a risk of hurting the very thing one is trying to achieve: a healthy baby.”¹¹⁰ A Hastings Center Report emphasized that both amniocentesis and CVS “are invasive and carry some risk to the fetus” and “are only recommended for women considered to be at high risk of having a child with a birth anomaly.”¹¹¹ One counselor tempered views of pervasive prenatal risk, explaining that, “There’s a physical risk doing amniocentesis...though the risk of miscarriage is small.”¹¹² Regardless, procedural risk was an important discussion between counselor and patient.

Another counselor emphasized that after speaking with patients about their family history and hereditary risks for various disorders, he presented “what procedures are open to them if they want to pursue them, the risks and advantages of the procedures,” and sought to “explore really, hopefully, the emotional impact of all that.”¹¹³ Especially important for counselors was weighing the risk of the procedure against the risk of developing a disorder, and against other personal factors affecting patient decision-making. A second-generation counselor explained that it’s crucial to encourage patients to think about,

What would you do if you got bad news? Is it important for you to know things in advance? How hard was it for you to get pregnant? Even the weight of the miscarriage is different from person to person. If we have a woman who had 15 years of infertility and she’s finally pregnant after spending \$30,000 on fertility treatments and that’s her last dime, she’s going to weigh a 1 in 1000 risk to have a miscarriage after amnio differently than somebody who’s pregnant by accident and has 5 kids at home. Some people are just very

¹¹⁰ Rothman, *The Tentative Pregnancy*, 77; Hubbard, *The Politics of Women’s Biology*, 153-155.

¹¹¹ Nancy Press and C.H. Browner, “Risk, Autonomy and Responsibility: Informed Consent for Prenatal Testing,” *Hastings Center Report, Special Supplement* 25, no. 3 (May-Jun., 1995), S9.

¹¹² Interview with GCS62I02, 26 July, 2010.

¹¹³ Interview with GCS50I03, 27 July, 2010.

matter-of-fact. ‘If I miscarry, I’m meant to. Let’s just do the test.’ Other folks interpret 1 in 1000 as 50/50.¹¹⁴

Some counselors used their session to weigh the risks of amniocentesis versus chorionic villus sampling (CVS). Risks associated with CVS include pregnancy complications, the failure to extract a useable sample, and placental mosaicism (when the chromosome sample extracted from the placenta does not match the baby’s cells). Procedural risks affiliated with amniocentesis include dry amniotic taps, needle stabs, the need to repeat the procedure, and miscarriage.¹¹⁵ Counselors also helped their patients weigh the invasiveness of each procedure, the timing of testing (since CVS can be performed much earlier than amniocentesis), and a host of other factors. Essentially, deciding whether to use physically-invasive procedures like amniocentesis or CVS has come down to whether or not “the information you’re going to gain is worth some risk.”¹¹⁶

Anthony Giddens suggested that a positive aspect of the new “risk society” the promotion of choice, although he admits that individuals’ choices are largely conditioned by race, class, and other social determinants. He argued that, “Technological innovation usually expands the domain of choice” and used the example of reproductive technologies.¹¹⁷ Nevertheless, it would seem that many women are facing increasing pressures brought about by the genetic revolution to know their own risks and curb the appearance of “abnormalities” in their children. In *The Tentative Pregnancy* (1993), Barbara Katz Rothman argued that women are faced with the “illusion of choice” when it

¹¹⁴ Interview with GCS104I13, 10 August, 2010.

¹¹⁵ Carla B. Golden, “Case Reports in Genetic Counseling,” *Perspectives in Genetic Counseling* 9, no. 1 (March 1987), 4-5; Barbara Thayer, “Strategies and Risk of Early Amniocentesis,” *Perspectives in Genetic Counseling* 10, no. 4 (Winter 1988), 2, 7; Rothman, *The Tentative Pregnancy*, 91-93.

¹¹⁶ Interview with GCS38I10, 5 August, 2010.

¹¹⁷ Giddens, “Rights and Responsibilities,” 5.

comes to genetic testing and prenatal diagnosis. They are told they have multiple reproductive options but, when diagnosed with an “abnormal” child, they are expected to pick those that are socially endorsed. With technology that conjures the prospect of “the perfect baby,” women and their counselors have become social gatekeepers of discourses about genetic citizenship, personhood, responsible parenthood, and what counts as an acceptable genetic risk. The routinization of reproductive technologies has made it so that those “who choose not to have amniocentesis more often have to justify their decision.”¹¹⁸

Rayna Rapp, who echoed Rothman’s criticism of the “illusion of choice,” called women “moral philosophers of the private,” individuals who have been forced to negotiate society’s anxieties about new prenatal technologies.¹¹⁹ Ruth Hubbard suggested that, “New choices all too readily become obligations to make the ‘right’ choice by ‘choosing’ the socially approved alternative.” In many cases, medical, social, and legal pressures have colluded to endorse prenatal diagnosis and, in the case of an “abnormal” finding, either push for fetal therapy or (more often) pregnancy termination.¹²⁰ Indeed, parents who choose to deliver a baby with birth defects may encounter hostility for “perpetuating disability” and draining social resources.¹²¹

In the early days of genetic counseling before *Roe v. Wade*, choosing to terminate a pregnancy may have been the option most vulnerable to social condemnation. While the heavy cultural loading and moral denunciation of abortion has certainly not disappeared

¹¹⁸ Rothman, *The Tentative Pregnancy*, 14, 63, 180.

¹¹⁹ Rapp, *Testing Women, Testing the Fetus*, 167, 306

¹²⁰ Hubbard, *The Politics of Women’s Biology*, 143, 156-157, and Chapter 13: Prenatal Technologies and the Experience of Childbearing, 161-178.

¹²¹ Allison C. Carey, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth Century America* (Philadelphia: Temple University, 2009), 211.

(and may be on the rise again), the growing arsenal of genetic technologies signals to women the desirability of genetic testing. When coupled with a general lack of social support for people with disabilities, this arsenal can also imply the undesirability of children with birth defects.¹²² Indeed, refusing genetic testing or failing to act on genetic information in the expected manner now carries social risks in an age of increasing geneticization.

Many genetic counselors spoke of the social and technological pressures to undergo genetic testing. A second-generation graduate of the Sarah Lawrence program explained that, “I think what has happened, because genetic testing is so readily available, everything is pushed towards the testing.” She explained that she has consistently fought against this with the students in her training program, telling them, “Just because testing is available doesn’t mean people have to have it or want to have it.” In her opinion, “if somebody walks away and doesn’t have the test, I’ve done my job equally well, maybe even better.”¹²³ Another counselor explained that occasionally patients assumed the counselor was “trying to sell me something,” to which she responded, “You know, I’m not working on commission. We don’t care if you do an amnio or not, we just want you to have the information so that you know what you could do, what’s out there, what’s an option.”¹²⁴

There seems to be a sort of “technological imperative” that convinces people that if the testing is available, they should make use of it. In these cases, the role of the counselor

¹²² Tom Shakespeare, *Disability Rights and Wrongs* (London: Routledge, 2000), 101. The implications of prenatal technologies for people with disabilities is a major strand of disability rights activism. See Chapter 5 for a thorough analysis of disability and genetic reproductive technologies.

¹²³ Interview with GCS64I09, 4 August, 2010

¹²⁴ Interview with GCS104I13, 10 August, 2010.

has been to backtrack in order to carefully consider the choices that lead to testing. A pioneering counselor explained that,

it happens that people go into a genetic counseling encounter knowing that a specific technology is available, thinking ‘Gee whiz, there’s a test for Huntington’s now. If I have Huntington’s in my family, I should take it’...When you really sit down with them and say ‘have you thought about this, have you thought about that, what would you do, how do you think this would change your relationship with your sister if your sister tested positive and you tested negative?’ There are a lot of things that people really haven’t thought through and part of the art of genetic counseling is to really help people not only understand what the technology can do but what the impact of utilizing it may be on their family.¹²⁵

At times, the role of the counselor has therefore centered on mitigating social pressures surrounding genetic testing and the “technological imperative.” This counseling function is particularly intriguing given public and patient perceptions of counselors as deeply imbedded in, and facilitators of, the new reproductive technologies. Nevertheless, genetic counselors have helped their patients explore their genetic, procedural and, sometimes, social risks by framing clients’ options within their own value system. They perceive this role as part of their ongoing commitment to client-centeredness which, alongside other factors, differentiated counselors from other genetics health professionals.

The Patient-Counselor Relationship and the System of Professions.

The patient-counselor relationship developed in relation to the larger system of genetics professions in which counselors’ gender and professional credentials influenced their client interactions. Genetic counselors often situated their patient relationships against those of other healthcare professionals, specifically MDs and PhD geneticists.

¹²⁵ Interview with GCS00I22, 12 November, 2010.

Counselors asserted that their practice was “non-paternalistic,” and chastised approaches or philosophies that smacked of old-fashioned directiveness or the traditional doctor-patient relationship. A second-generation male counselor described non-directiveness as “liberating” since directiveness and paternalism had the ability to influence patient choices, thereby reducing autonomy in decision-making and rendering the counselor liable in the session’s outcome.¹²⁶ In a letter to the editor in the *Journal of Genetic Counseling*, Susan E. Hodge attacked the “paternalistic and protective tone” of an article on Huntington’s disease testing for monozygotic twins published in an earlier volume. She argued that, “For decades, medical professionals, particularly physicians, have been prone to this kind of arrogance, but genetic counselors are supposed to exemplify a different attitude.”¹²⁷ Paternalism, particularly as associated with a traditional medical model, has remained very much a watchword for genetic counselors and a concept against which to define their own patient ethics.

Counselors have frequently discussed the effects of the practitioner’s gender on ethical decision-making and patient-counselor trust. In the first issue of the *Journal of Genetic Counseling* in 1992, Pencarinha et al. compared the perspectives of Masters-level counselors and medical geneticists on ethical issues in genetic counseling. Their study revealed that Masters-level genetic counselors were more willing than medical geneticists to uphold patient confidentiality. A larger number were also willing to counsel a patient pursuing prenatal testing for sex selection (a controversial precedent for abortion) based

¹²⁶ Interview with GCS42I05, 28 July, 2010. See also Petersen and Bunton, *The New Genetics and the Public’s Health*, 141.

¹²⁷ Susan E. Hodge, “Paternalistic and Protective?” *Journal of Genetic Counseling* 4, no. 4 (1995), 351-352.

on respect for patient autonomy. The authors attributed divergent responses in part to Masters-level counselors' gender, but also their greater training and daily practice in counseling patients.¹²⁸

Dorothy Wertz revealed that gender was the most important factor in ethical decision-making in her 1994 article, "Provider Gender and Moral Reasoning." In a survey of 682 geneticists in nineteen countries, she found that women were 13.2 times more likely than men to help patients understand their options and 2.7 times more likely to support patients in their choices. She concluded that women were more respectful of patient autonomy than men, and less likely to give directive advice.¹²⁹ She drew on feminist psychologist and ethicist Carol Gilligan's work on the ethics of care, and suggested that women bring a different approach to moral problems. Gilligan argued that women evaluate themselves based on their ability to care, and define themselves according to their relationships with others. She suggested that women's "greater orientation toward relationships and interdependence implies a more contextual mode of judgement and a different moral understanding." This brand of ethics has often been devalued in a society that emphasizes competition and individuation (or more "masculine" characteristics) as the standard model of psychological development.¹³⁰

Wertz also suggested that counselors' approach to ethical issues is structured by their position in a hierarchy of power. She used Susan Sherwin's work to describe that in many

¹²⁸ Deborah F. Pencarinha, et al., "Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspectives," *Journal of Genetic Counseling* 1, no. 1 (1992), 27-29.

¹²⁹ Dorothy C. Wertz, "Provider Gender and Moral Reasoning: The Politics of an 'Ethics of Care,'" *Journal of Genetic Counseling* 3, no. 2 (June 1994), 95-112.

¹³⁰ Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Cambridge: Harvard University Press, 1982), 14, 16-17, 22.

cases, the ethics of care is also “the ethics of the powerless.” Women who work within a predominantly-male system of genetics professions are perhaps more likely to identify with their largely-female patient base. As such, they may focus on developing a relationship characterized by strong moral support and the promotion of autonomous decision-making.¹³¹ Indeed, in an earlier survey from 1988, Dorothy Wertz and John Fletcher suggested that women with an MD or PhD responsible for “administering genetic services” were 2.68 times more likely than men to be non-directive, while men were 6.9 times more likely than women to advise a patient on an appropriate course of action.¹³² Articles on these themes suggest, then, that like their professionalization process, counselors’ gender and credentials affected their interactions with patients.

Many genetic counselors reflected on how their gender shaped the counselor-patient relationship and the dynamics of the counseling session. Several female counselors spoke of how the experience of having their own families affected their client interactions. One pioneering counselor explained that,

I’ve always been drawn to working with women. I went to a women’s college, I’ve always had feminist leanings in a non-strident kind of way, and I think that the work I did around reproductive medicine certainly augmented that... I think that being a parent, having had kids, adds to your credibility in a pediatrics clinic. I tend to work with a patient population particularly in prenatal that is largely Latina and I think there are issues of trust and confidence that are easier to establish with women from certain cultural backgrounds when one has had these experiences. First of all, it’s easier for them to talk to those women about reproductive issues, and secondly, I think there are commonalities in terms of you do have a family, have you experienced this, etc...¹³³

¹³¹ Wertz, “Provider Gender and Moral Reasoning,” 95-112. See also Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press, 1992).

¹³² Dorothy C. Wertz and John C. Fletcher, “Attitudes of Genetic Counselors: A Multinational Survey,” *American Journal of Human Genetics* 42, no. 4 (1988), 597.

¹³³ Interview with GCS00I22, 12 November, 2010.

Female counselors articulated a connection between womanhood, their choice of profession, the decision to work in reproductive health, and their bonds with female patients in a prenatal or pediatric setting based on shared female experiences.

Counselors in a cancer setting similarly expressed bonds based around a shared experience of womanhood. One pioneering counselor described that she found commonalities with her female patients in cancer counseling due to the fact that, “so many of us are going to get cancer, even if we don’t have a mutation. 1 in 8 of your friends is going to get breast cancer, and 1 in 3 of your friends is going to get some kind of cancer when they get old enough.”¹³⁴ Women’s participation in a collective category of cancer risk was also, then, a source of mutual understanding and an experience over which counselors and patients could bond. Interestingly, several male genetic counselors emphasized that their gender allowed them to identify with husbands who presented for counseling with their wives. In these situations, the counselors encouraged the men to be involved in their wife’s reproductive decision-making.¹³⁵

Genetic counselors set themselves against physician-geneticists in a variety of ways other than their gender, credentials, and counseling philosophies. Many counselors stressed that they were able to spend more time with their patients and could provide an additional level of care. Edward Shorter suggested that in the mid-1980s, the average physician-patient consultation was eleven minutes, while a patient’s interaction with a

¹³⁴ Interview with GCS00I24, 19 November, 2010.

¹³⁵ Interview with GCS38I10, 5 August, 2010.

medical resident might be eighteen minutes.¹³⁶ An NSGC survey from 2010 demonstrated that while most physicians spent less than fifteen minutes per patient, counselors spent between thirty-one and sixty minutes.¹³⁷ One counselor described that, “doctors aren’t able to spend the time explaining the procedures, or diagnosis, or future things to consider with their patients,” whereas genetic counselors “care that [the patients] really understand, we want to make sure that they’re taking in the information, relating it to their life, and making the best possible decision for them. And not necessarily that other providers don’t care, but it’s our job to have the time to do so.”¹³⁸ Another counselor who has worked in both pediatrics and cancer settings echoed this sentiment saying,

I think from what I hear from them [the patients], we are rare in that we can spend so much time to sit down and listen. They often just start asking all kinds of medical questions because they know that I’ll listen...I think unfortunately the difference between us and other practitioners is that they see 70 patients in one day and don’t have time to answer their questions. In fact, one of my patients said to me this morning, ‘When I went to my doctor and was asking him these same questions about my pathology report and my diagnosis for cancer, I could tell he was getting impatient with me. And finally he told me to go look on the internet.’¹³⁹

Having time as a professional commodity made counselors valuable to their patients and set them apart from other genetics healthcare professionals. Indeed, counselors saw their interactions with patients as different than physicians’ encounters on account of being more “therapeutic” than just “medical.”¹⁴⁰ Establishing the time to care more thoroughly as an important part of their interactions with patients, however, does seem to reinforce

¹³⁶ Shorter, *Doctors and their Patients*, 208.

¹³⁷ Stern, *Telling Genes*, 10.

¹³⁸ Interviews with GCS 81I16, 16 August, 2010 and GCS61I06, 30 July, 2010.

¹³⁹ Interview with GCS62I02, 26 July, 2010.

¹⁴⁰ Interview with GCS00I24, 19 November, 2010.

their situation between sympathy and science, and what one counselor described as a duty to “tak[e] care of the emotions.”¹⁴¹

Counselors have undoubtedly seen themselves as distinct from physician-geneticists in both ideology and training. Yet, despite their emphasis on their unique and valuable skill set, genetic counselors remained necessarily connected to physician-geneticists and the doctor-patient relationship. This is due in part to the fact that often, counselor and physician duties converged. One counselor explained that, “in a lot of ways, there’s a lot of overlap in what we do, so a lot of what the physicians I work with do is they do genetic counseling and they pretty much do exactly what I do for my patients.”¹⁴² Due to the frequent sharing of responsibilities between physicians and genetic counselors, patients often confused their respective duties. This was especially the case with regards to prescribing medications and directive treatments, which had typically been the preserve of physicians. One counselor described that when a couple came in for a potentially “abnormal” ultrasound finding, the husband sought a prescription from the counselor, saying, “Well, you have to give her something because she’s just going to the bathroom all the time and it’s just awful, and she just hurts, and you have to give her something,” to which the counselor thought, “Even if I wanted to address it, I couldn’t” and suggested that, “Maybe the doctor might be able to help you out.”¹⁴³ The same counselor explained that these types of patient demands stemmed from the fact that they are,

used to physicians in a very patriarchal way saying, ‘You need to do this, ok?’...The medical model says the doctor will tell you. So here I am, and I

¹⁴¹ Interview with GCS50I03, 27 July, 2010.

¹⁴² Interview with GCS42I05, 28 July, 2010.

¹⁴³ Interview with GCS26I15, 12 August, 2010.

was wearing a white coat, so I might as well have been a doctor or something close, or at least someone who knew something about genetics.¹⁴⁴

A recent graduate of the University of Michigan described that, “Most of the time when you go to the doctor, they tell you, ‘this is the problem,’ and they tell you how to fix it.”¹⁴⁵

A third counselor explained that, “when you’re a kid, you grow up and you go to a doctor’s office, and you sort of get an idea of how it’s going to work. But I think in genetic counseling, people are a bit more anxious...they’re still not sure exactly what’s going to happen.”¹⁴⁶ It seems that despite their attempts to carve their own patient skill set and relationship within a system of professions, patients often saw genetic counselors as part of a larger medical hierarchy in which they are ranked similarly to physicians. This is quite a strange reversal in genetic counselors’ attempts to garner professional recognition separate from MDs and PhD geneticists.

The overlap between counselors and physicians in patient interactions is further evidenced in the language genetic counselors used to describe the individuals or couples they counseled. Many counselors oscillated between the terminology of client and patient, usually depending on the context in which they worked. Counselors used “patients” primarily in hospital settings, while “clients” was used more in laboratory, administrative, or teaching capacities. Significantly, genetic counselors’ choice of nomenclature often followed physician terminology which seemed to dictate the dominant discourses used in genetic healthcare. A counselor who started working in 1986 explained that individuals seeking her professional services were often called patients “because they’re usually

¹⁴⁴ Interview with GCS26I15, 12 August, 2010.

¹⁴⁵ Interview with GCS34I04, 27 July, 2010.

¹⁴⁶ Interviews with GCS64I09, 4 August, 2010.

referred to us by physicians who are referring to them as patients, and I do feel like I'm a healthcare provider seeing a patient more so than a client."¹⁴⁷ Other counselors shared a similar preference, saying that, "We write letters to referring doctors and doctors very, very commonly use the word 'patient,' so because I'm writing letters to the doctors, I will use the word patient because that's what they're pretty much expecting to hear."¹⁴⁸ Sharing a common vocabulary with physicians around the patient-practitioner relationship tied genetic counselors to the doctor-patient relationship. And while utilizing the language employed by physicians could suggest physician dominance, it also demonstrates counselors' integral participation in patient encounters with genetic healthcare.

The counselor-patient dynamic was also structured by physicians' attitudes towards genetic counseling, and the way they made the referral to a genetic counselor. Some physicians' lack of experience with genetic counseling was a hindrance to counselors' successful acquisition of new patients. A male graduate of the Sarah Lawrence program explained that, "most physicians who I worked with who referred patients to us had never met a genetic counselor. They didn't run into any in their training. They knew somewhere in a guideline that they were supposed to send this patient for genetic counseling but they really didn't know what that was." The same counselor explained that as he bonded with the physicians, they became more comfortable in referring patients. Physician support and a confident referral were important since having patients actually show up for counseling

¹⁴⁷ Interview with GCS12I08, 4 August, 2010

¹⁴⁸ Interviews with GCS42I05, 28 July, 2010.

services was “all in the way the physician makes that referral, and if they really believe there’s some benefit for their patient.”¹⁴⁹

In many cases, it seems patients were referred to a counselor without being told anything about genetic counseling or why they were advised to seek the advice of a genetic specialist. One counselor remembered having to spend a great deal of time just talking about what genetic counseling is because patients did not know why they were there beyond “my doctor wants me to do this.”¹⁵⁰ Another counselor explained that, “I think there’s a lot of worry – why am I here? We have a lot of people who feel like they’re coming and they haven’t been told the full story about why their doctor wants them to come, what their child’s being referred for.” An obscure referral could lead anxious patients to wonder, “Is there something on the ultrasound that they’re not telling me?”¹⁵¹ Feeling uninformed and ill-prepared to see a genetic counselor could foster distrust since patients had little background knowledge about what genetic counselors did.

Issues of professional jurisdiction and the amount of physician-counselor interaction also affected the dynamics of the counseling session. A second-generation Sarah Lawrence graduate explained that in pediatrics “it’s more physician-driven,” whereas in prenatal, “genetic counselors work pretty autonomously with patients.” She elaborated, describing that,

We usually see patients without a physician in the room at all times. In cancer settings we usually see patients almost autonomously. Physicians come in for part of the session, but they’re not there for the entire session. In pediatrics, in many settings, the genetic counselor might go in and do the contracting, take

¹⁴⁹ Interview with GCS38I10, 5 August, 2010.

¹⁵⁰ Interview with GCS104I13, 10 August, 2010.

¹⁵¹ Interview with GCS34I04, 27 July, 2010.

the family history. But then a lot of the session is physician driven because there's a physical exam. There's much more that the physician drives in terms of making diagnoses. So in those settings, there might be a bit of a power dynamic because the physician is sort of in charge.¹⁵²

Again, a distinction was drawn here between being therapeutic versus being purely medical, which is the more highly-valued status.

The counselor-patient relationship was also affected by what counselors perceived to be patients' greater bond with physicians due to the frequency with which they were seen by their doctors. One counselor explained that, "There are bonds that form because this is the one time in your life, during a pregnancy, where you're seeing the same doctor over, and over, and over again. Towards the end, you're seeing them once a week and I think that's a natural precursor to having that bond because it's almost friend-like" whereas "most of the time, I saw them 30 minutes."¹⁵³ Counselors felt that having thirty minutes to an hour with a patient endowed them with the advantage of being able to spend more time on that individual's health issues; at the same time, they also felt that only seeing most patients once, compared to doctors' more frequent encounters, was much to their detriment. Even Sheldon Reed noted that in most cases, his clients made only one visit to the Dight Institute.¹⁵⁴

The patient-counselor relationship has therefore been shaped by issues of professional jurisdiction, and has remained intimately tied to a larger system of genetics professions in the late-twentieth century. Genetic counselors have been very aware of their practice in relation to other professions in genetic healthcare, and have pushed back against older

¹⁵² Interview with GCS64I09, 4 August, 2010.

¹⁵³ Interview with GCS26I15, 12 August, 2010.

¹⁵⁴ Sheldon Reed, *Parenthood and Heredity* (New York: John Wiley & Sons, 1964), 81.

medical models characterized by an asymmetrical power dynamic and a paternalistic physician attitude. They have also consciously situated their professional ethos within an anti-eugenic framework and against the coercion of the early-twentieth century eugenics movement through the principles of client-centeredness and non-directiveness. The history of medical genetics has been characterized by profound change over the course of the late-twentieth century as genetic knowledge increased to such a degree that our abilities to diagnose often far surpassed our abilities to treat. Interesting, then, is the fact that the basic components and concerns of the genetic counseling session have remained relatively stable. The basic patient-counselor relationship has, at its core, retained a consistent focus on concepts of risk and the maintenance of patient autonomy. As one counselor explained, the profession still centers on the values that “we’ve talked about since the first definitions of what genetic counseling is...support for the individual, support for decision-making, comfort if possible, emotional support, education.”¹⁵⁵

The patient-practitioner relationship in genetic counseling will likely undergo an evolution in coming decades. These changes will occur courtesy of the greater numbers of professionals working in genetic healthcare, the increasing precision of risk estimates and diagnostics, and counselors’ carving out of new occupational niches as they adapt to a rapidly-evolving field. The foundational tenet of patient autonomy could also become contested as Americans consider the duties, privileges inherent in the new genetic citizenship, and assess the multiple meanings and implications of genetic risk. These deliberations significantly blur the boundaries between patients’ personal counseling

¹⁵⁵ Interview with GCS00I19, 4 October, 2010.

session, and public perspectives on the value of life and freedom of choice in an age of enhanced geneticization.

Chapter 5: Debating the New Genetics: Reproductive Rights, Disability Advocacy, and the Rights and Responsibilities of Genetic Citizens, 1960-2000.

In the Fall of 1994, *Perspectives in Genetic Counseling* published an article considering the role of the genetic counselor in the case of a “mentally impaired” woman who presented for counseling nine weeks pregnant. The woman suffered from untreated maternal PKU (phenylketonuria), a genetic metabolic disorder that can be managed by restricting phenylalanine in one’s diet. If a woman consumes phenylalanine while pregnant, fetal brain development is impaired leading to mental retardation.¹ The author, Fiona Field, outlined the ethical concerns posed by this case, including the counselor’s responsibilities to both the patient and the fetus. She then considered the “*feasibility of hospitalizing the patient for dietary control, the possible intervention of Child Protective Services on the part of the fetus and defining who has follow-up responsibility.*”² Other counselors weighed in on the case, reminding their readership that there were no legal grounds on which to intervene, and that they must respect the patient’s right to privacy. Though counselors concluded that they were not liable for this patient’s decisions, they nevertheless mentioned her violation of the NSGC’s Prenatal Substance Abuse resolution and suggested that she might benefit from greater contraceptive knowledge.³

The patient-counselor relationship described in the previous chapter is often conceptualized as a private medical encounter through which Americans have confronted genetics in very personal, and potentially life-altering, ways. Patients have certainly been

¹ PKU was the first disease for which state-sanctioned mass screening programs were established in the U.S. in the 1960s.

² Fiona Field, “When Intellect and Instinct Don’t Agree: Untreated Maternal PKU,” *Perspectives in Genetic Counseling* 16, no. 3 (Fall 1994), 5. Italics in original.

³ Ibid.

primary negotiators of concepts of risk and notions of autonomy in decision-making related to genetic reproductive technologies. As this case demonstrates, genetic counseling has also been a key site for the public and highly-politicized loading of women's individual and private reproductive decisions. It also elucidates how the complex and very public crossovers between reproductive rights and disability advocacy played out in and around genetic counseling sessions. That is, counselors and patients negotiate risk, but have also worked through a complex matrix of competing rights and responsibilities that are of both a private and public nature within their encounter. At the same time, concerns over rights, responsibilities, and autonomy have bled into the public realm through vociferous debates about the duties and privileges of the new genetic citizenship.

Deborah Heath, Rayna Rapp, and Karen-Sue Taussig proposed the concept of genetic citizenship in their 2004 article of the same title. These scholars suggested that, "With extensive new areas of everyday life now open to both personalized eugenics and official regulation, these emergent networks have also given rise to new forms of democratic participation, blurring the boundaries between state and society, and between public and private interests." They depicted this new type of citizenship as a novel point of interaction between knowledge, power and "embodied discipline," characterized by new duties and privileges.⁴

People have been increasingly encouraged to think genetically, to "see themselves in terms of genetic attributes and limits." Geneticized thinking has been promoted through

⁴ Heath, Rapp, and Taussig, "Genetic Citizenship," 152.

the late-twentieth century with greater visibility of, and emphasis on, health activism and research, as well as heavy investment in biotechnology.⁵ Alan Petersen and Robin Bunton suggested that the values of the new genetics are socially endorsed because they coalesce well with those of advanced neoliberal societies. Both emphasize individual potential and empowerment through the language of rights and freedoms; in the case of genetics, this translates to the “right to know” and “freedom of choice.” The new genetics, however, is also based on expectations of “active citizenship” characterized by citizens’ pursuit of genetic literacy and knowledge of their own genetic risks, as well as the responsibility to limit one’s own role in perpetuating genetic disease. Since the 1970s, when genetic explanations of human behaviours and diseases began to wield renewed scientific and social influence, many groups were forced to renegotiate their identities as patients, healthcare professionals, and activists to align themselves with the new expectations of genetic citizenship.⁶

My study of the private and public dimensions of the rights and responsibilities of genetic citizens in relation to genetic counseling and reproductive technologies expands upon these works. My analysis moves beyond traditional political and legal meanings of citizenship to explore the politicization of personal genetic encounters and the negotiation of a scientifically-based social contract. This chapter continues to draw on the historical,

⁵ Ibid., 159. In the 2000s, a literature has developed on “scientific citizenship” that interrogates the relationship between individuals, science, and the state. See Alan Irwin, “Constructing the Scientific Citizen: Science and Democracy in the Biosciences,” *Public Understanding of Science* 10, no. 1 (2001), 1-28; Mark Elam and Margareta Bertilsson, “Consuming, Engaging, and Confronting Science: The Emerging Dimensions of Scientific Citizenship,” *European Journal of Social Theory* 6, no. 2 (2003), 233-251; and Maja Horst, “Public Expectations of Gene Therapy: Scientific Futures and Their Performative Effects on Scientific Citizenship,” *Science, Technology, & Human Values* 31, 5 (2006), 565-598.

⁶ Petersen and Bunton, *The New Genetics and the Public’s Health*, 4-5, 57-58, 65.

sociological, anthropological, and other literatures which informed my prior examination of the patient-counselor relationship and concepts of risk. I draw on Ruth Schwartz Cowan's *Heredity and Hope* (2008) to explore the feminist perspective that genetic screening has been medically-beneficial and of great value to families burdened by genetic disease. Her work is a valuable counterpoint to criticisms of genetic reproductive technologies voiced by the National Women's Health Network and FINRRAGE.⁷ Erik Parens and Adrienne Asch's *Prenatal Testing and Disability Rights* (2000) examined the disability critique of the new genetics, and provides the necessary context through which to analyze the activism of The Arc and National Down Syndrome Congress.⁸ In *Telling Genes* (2012), Alexandra Minna Stern explored autonomy as "something of a mantra in genetic counseling," and devoted a chapter to the interactions between disability and genetics. She analyzed Sheldon Reed's engagement with "mental retardation," the origins and growth of disability rights, and the efforts of genetic counselors to incorporate disability perspectives into their practice.⁹ I elaborate on her work by layering on a reproductive rights perspective, and by drawing on historical but also contemporary examples.

This chapter continues to explore the patient-counselor relationship, and emphasizes that both parties have been frontline mediators of the new genetic citizenship characterized by a host of (sometimes competing) rights and responsibilities. Counselor responsibilities, many of which were included in the NSGC Code of Ethics (1991), have

⁷ Cowan, *Heredity and Hope*; FINRRAGE stands for the Feminist International Network of Resistance to Reproductive and Genetic Engineering.

⁸ Parens and Asch, eds. *Prenatal Testing and Disability Rights*.

⁹ Stern, *Telling Genes*, 124. See Chapter 4, Disability: The Dynamics of Difference, 75-101.

included the maintenance of patient confidentiality, the presentation of all available options, and a commitment to nonmaleficence and beneficence.¹⁰ Patients have been expected to carefully weight their options and live up to certain expectations of responsible parenthood; they have also had the “right to know” about their genetic heritage, and the right to autonomy in reproductive decision-making. Moreover, I suggest that discourses of rights and responsibilities have, since the 1960s, been extrapolated outward to the public sphere and taken up by reproductive rights and disability advocates.

I explore the arguments of these two groups within public debates about genetic reproductive technologies. While reproductive and disability rights activists pursued their own agendas, both factions expressed concern about the preservation of autonomy, respect, and freedom of choice; they also championed informed decision-making. These principles were then juxtaposed against fears of a new eugenics and the geneticization of embodied difference.¹¹ For feminists, the right to self-determination in reproductive choices was central to their advocacy agenda, especially for those anxious about the over-medicalization of women’s bodies. Women as mothers were also expected to carefully weigh the risks and benefits of prenatal technologies in their pursuit of healthy pregnancies. Disability rights advocates were concerned about the rights of people with cognitive and physical impairments, and urged social responsibility in the form of more balanced public education about the lives of people living with disabilities. These debates

¹⁰ “Code of Ethics,” 1991, National Society of Genetic Counselors, accessed 25 April, 2013, <http://www.nsgc.org/Advocacy/NSGCCCodeofEthics/tabid/155/Default.aspx>

¹¹ Discussions of a “new eugenics” emerged with the development of genetic reproductive technologies in the late-twentieth century. The term is used by critics to denote their discomfort with techniques of genetic engineering and the routinization of prenatal technologies. Despite the language of choice that accompanies the new genetics, critics see these technologies as tools of a eugenic enterprise rather than beneficial medical therapies.

occurred against other criticisms of reproductive technologies, and with input from genetic counselors as professionals responsible in part for furnishing social discussions of the new genetic citizenship. In this role, genetic counselors served as intermediaries between private and public negotiations of the genetic revolution.

On the Frontlines of Genetic Citizenship: The Responsibilities and Duties of Patients and Counselors.

Genetic counselors' interactions with their patients within a personal counseling session have been structured around a complex set of professional responsibilities. On a very basic level, counselors, along with "scientists, researchers and doctors have professional responsibilities to ensure that the knowledge they obtain is wisely used to benefit their patients and society."¹² Interviews with genetic counselors revealed that they felt a responsibility to "wear many hats," acting as educators, patient advocates, and interpreters of medical information. Counselors also felt a responsibility to treat patients with respect from an ethical and client-centered approach. A second-generation counselor emphasized that his primary responsibility or goal was "that the patient make a decision that works for them."¹³

Patricia Ward discussed counselor responsibilities in a 1989 article in *Perspectives in Genetic Counseling* entitled "Professional Responsibilities and Counseling Issues," in which the basic equation for a respectful patient ethos was laid out as "knowledge + options = responsible counseling."¹⁴ Under this general rubric, the major components

¹² British Medical Association, *Human Genetics*, 8.

¹³ Interview with GCS38I10, 5 August, 2010.

¹⁴ Patricia A. Ward, "Professional Responsibilities and Counseling Issues," *Perspectives in Genetic Counseling* 11, no. 2 (Summer 1989), 1.

necessary for a responsible counseling session included an up-to-date knowledge of testing options and costs, and the potential uses of testing as applied to specific counseling cases. Counselors also had a duty to communicate risk factors to patients in an understandable and meaningful way, and to maintain patient confidentiality. In short, counselors were expected to “accept the challenging responsibility of maintaining current information about the availability of testing, providing education about this new technology to families and other professionals and facilitating provision of these services through coordination efforts and counseling support.”¹⁵

Over the last three decades, genetic counselors have confronted two complicated questions as a greater number of testing options became available, as diagnostic accuracy improved, and as the number of genetic diseases that could be tested for increased: “Where does genetic responsibility lie?” and “To whom is the genetic counselor responsible?”¹⁶ In a 1986 issue of *Perspectives in Genetic Counseling*, counselor Carla B. Golden reported a case study in which thirty-six year old pregnant woman hid a family history of haemophilia from her husband. Golden asked, “Is it the responsibility of the genetic counselor to be sure the patient is aware of all the ramifications of the situation, particularly if there are implications for other family members?...Was it my responsibility to inform this husband and father-to-be that his son had a 25 percent risk of having haemophilia?”¹⁷ This question of potential responsibility to multiple patients was

¹⁵ *Ibid.*, 7.

¹⁶ Jessica G. Davis, “A Counselor’s Viewpoint,” *Genetic Counseling: Facts, Values, and Norms*, eds. Alexander M. Capron et al. (New York: Alan R. Liss, 1979), 121; Carla B. Golden, “Case Reports in Genetic Counseling,” *Perspectives in Genetic Counseling* 8, no. 1 (March 1986), 1.

¹⁷ Golden, “Case Reports in Genetic Counseling,” 1.

addressed again in the newsletter's following issue, in which counselor Seth Marcus responded to Golden's case study. He asked,

Who is the patient? The science of genetics challenges our long-standing assumptions about that question. Genetics means that a patient's constitution is not only his or her own, but is shared with family members. In a health-care system knowledgeable of genetics, one can state that an individual's health and predisposition to disease are not individual phenomena but familial ones. As our knowledge of genetics evolves, society will have to redefine how we are to determine who the patient is.¹⁸

Potential responsibility to numerous family members affected by a given disease plagued many genetic counselors. They found it difficult to balance their client-centered and neutral stance against their hope that family members would disclose their disease or carrier status to others since genetic disorders are inherently intergenerational. Counselors saw their professional responsibilities and the repercussions of the counseling session as often extending beyond the individual to affect a host of other people.

The duty to avert harm has been one of genetic counselors' primary responsibilities. In 1959, Franz J. Kallmann suggested that counselors "will always be mindful of the fact that as members of a health service team, they are expected to understand the age-old principle of *nil nocere*."¹⁹ Their commitment to "do no harm" dovetails well with physicians' Hippocratic Oath, which outlines this most foundational of duties, as well as the ethics of other healthcare professionals. A 1990 article titled "Patient Confidentiality and the Duty to Avert Harm" explored the case study of a woman with a 13/14

¹⁸ Seth Marcus, "Case Reports in Genetic Counseling: Response to Case No. 5," *Perspectives in Genetic Counseling* 8, no. 2 (June 1986), 3.

¹⁹ Franz J. Kallmann, "Types of Advice Given by Heredity Counselors: I," in *Heredity Counseling*, ed. Helen G. Hammons (New York: Hoeber-Harper, 1959), 81. Italics in original.

translocation carrier status who refused to inform family members, and the ethical conflict between one patient's "right to confidentiality" versus another patient's "right to know."²⁰

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1990), established by the U.S. Congress, stated that "a profession's primary obligation (to the patient) is in some circumstances subsumed by the need to prevent harm to others." Counselors may have a "moral obligation" to inform other family members.²¹ Another counselor, however, refuted this claim on the grounds that the counselor-patient relationship depends on trust, and that "The obligations of the counselor to the patient are primary and stronger than those to any other parties...Doing no harm to the patient is a stronger obligation than doing something possibly beneficial for someone else."²² By 1998, counselors considered a position on multiple patient responsibilities that supported a duty to warn third parties if the third party at risk could be identified; if harm to the third party was predictable and avoidable; and if the counselor had a special relationship with the patient that put them at risk.²³ Articles in the *Journal of Genetic Counseling* also discussed conflicting responsibilities. "Genetic Counseling for a Family with Two Distinct Anomalies" contrasted the "duty to respect a client's freedom vs. duty to care for the client's welfare," or, otherwise stated, "Autonomy vs.

²⁰ Lorraine Suslack, "Patient Confidentiality and the Duty to Avert Harm," *Perspectives in Genetic Counseling* 12, no. 1 (Spring 1990), 3.

²¹ Ibid.

²² Susan Schmerler, "Responses to Case Report #20: Patient Confidentiality and the Duty to Avert Harm," *Perspectives in Genetic Counseling* 12, no. 2 (Summer 1990), 2. See also British Medical Association, *Human Genetics*, 19, on the duty to benefit patients and avoid harm.

²³ Chantelle Wolpert, "Duty to Warn Third Parties: Practical Consideration," *Perspectives in Genetic Counseling* 20, no. 2 (Summer 1998), 11.

Beneficence.”²⁴ Attempts to balance the multiple harms facing one patient may pose problems for counselors’ attempts at non-directiveness, while a sense of duty to avert harm to third parties may compromise the client-centeredness and confidentiality of the patient directly under the counselor’s care.

The oldest and most consistent duty of genetic counselors has been to help patients weigh risks, offer support in the decision-making process, and facilitate patient choices. The NSGC Code of Ethics outlined some of the most basic patient responsibilities, particularly enabling them to “make informed decisions, free of coercion” by supplying genetic information and discussing available options.²⁵ Some genetic counselors described this task as the shared responsibility of both counselor and patient with one counselor, who graduated from Sarah Lawrence in 1986, suggesting, “it’s a partnership.”²⁶ A second generation counselor who attended the University of California Berkeley program explained that,

the most successful interactions have to do with shared responsibility...you value them [the patient] as a teacher about their family, about their set of values, about what their experience has been up to this point. And then you share with them your expertise about the condition or about the reason they came in or the disease in question. And then together you work collaboratively to figure out what’s a good decision for them.²⁷

For genetic counselors who continued to adhere to the value of non-directiveness amidst growing professional skepticism, the counselor has been responsible for remaining neutral

²⁴ Begleiter and Rogers, “Genetic Counseling for a family with Two Distinct Anomalies,” 89, 91. Italics in original. See also Lynn E. Bernard et al., “Duty to Re-Contact: A Study of Families at Risk for Fragile X,” *Journal of Genetic Counseling* 8, no. 1 (1999), 3-15.

“Code of Ethics,” 1991, National Society of Genetic Counselors, accessed 25 April, 2013, <http://www.nsgc.org/Advocacy/NSGCCCodeofEthics/tabid/155/Default.aspx>

²⁶ Interview with GCS64I09, 4 August, 2010.

²⁷ Interview with GCS49I18, 20 September, 2010.

when helping patients to assess risks and make choices about their genetic health. Indeed, they looked to non-directiveness to ensure that they bear no responsibility for a patient's negative counseling experience.²⁸ The value of non-directiveness coalesced nicely with social and bioethical values of the post-WWII era including patient autonomy and reproductive rights. More recently, this ethos also dovetailed with neoliberalist principles and the scaling back of the welfare state by emphasizing individual responsibility as a key component of social citizenship.²⁹

Finally, genetic counselors have been responsible for presenting all available options to their patients including further testing and the possibility of terminating the pregnancy; they have also introduced patients to the available services should they continue the pregnancy and become parents of a child with a disability. A recent graduate of the counseling program at the University of California Irvine described that,

[Abortion] is something that I definitely do bring up if we get back early results showing a high risk for an abnormality and the patients are sort of on the fence about whether to pursue diagnostic testing. I'll let them know that you can pursue that testing anytime after sixteen weeks. It's not a 'hurry up to do it at sixteen weeks' in terms of delivering the baby, but if ending the pregnancy is something that you would consider should a diagnosis be made, then it becomes important to do it earlier rather than later. I try to explain why I'm bringing it up too. I certainly don't push it on anybody, but I do feel it's our responsibility to make them aware of all their options.³⁰

Counselors felt it was their ethical duty to bring up prospects for further testing. They also thought it was important to consider whether a patient would or would not terminate a pregnancy based on testing results. A second-generation male counselor explained that in

²⁸ Scott Polzin, "Directiveness: 0% Professional: 100% Trap," *Perspectives in Genetic Counseling* 12, no. 3 (Fall 1990), 1, 6.

²⁹ Petersen and Bunton, *The New Genetics and the Public's Health*, 138.

³⁰ Interview with GCS61I06, 30 July, 2010.

a prenatal setting, “Whether or not somebody is going to terminate a pregnancy is a key issue as to whether one should or shouldn’t have an amniocentesis. So not bringing it up, to me, seems to be avoiding the most critical reason why they’re in the room.”³¹ Another counselor echoed this sentiment, noting that they “would be remiss not to bring it up,” while a third counselor explained to her patients that, “I’m going to tell you about these procedures. It doesn’t mean you have to have one, but it’s part of your complete knowledge set we think you should have.”³² Counselors also considered it their responsibility to inform patients of adoption procedures and existing support groups.³³

In *The New Genetics and the Public’s Health* (2002), Petersen and Bunton discussed patient responsibilities vis-à-vis the new genetics. They explored assumptions about the character of patients within the context of genetic health, specifically “a view of the subject as an independent rational decision-maker who weighs all available information on risks and arrives at a rational decision.”³⁴ Sheldon Reed’s genetic counseling also rested on the assumption that once informed of their genetic makeup, his (largely middle class) patients would make responsible decisions that suited their personal family situation, and preferably also conformed to dominant societal values.³⁵ What this has meant for the genetic counseling session and the counselor-patient relationship is that while counselors have certainly had a set of responsibilities, patients also have duties that come with their participation in genetic healthcare. They have the duty to listen to the

³¹ Interview with GCS50I03, 27 July, 2010.

³² Interviews with GCS59I11, 6 August, 2010 and GCS104I13, 10 August, 2010.

³³ Interviews with GCS94I01, 26 July, 2010 and GCS62I02, 26 July, 2010; Barbara Lerner, “Using Genetic Support Groups Wisely,” *Perspectives in Genetic Counseling* 15, no. 3 (1993), 1,6.

³⁴ Petersen and Bunton, *The New Genetics and the Public’s Health*, 138.

³⁵ Reed, “Counseling in Human Genetics, Part II,” 6-7.

counselor, to consider all available options, and to choose the best option for themselves, meaning one that is consistent with their values. The seriousness and gravity of the patient's responsibility to make "good choices" is signalled by the counselor at various junctures, including their refusal to answer the question "What would you do?" (at which time the burden of choice is deflected back to the patient), or by even telling patients they think they're making a "bad" decision, one that is at odds with their personal morals or vision of family life.³⁶

Genetic counselors' clients have also been pressured to live up to certain expectations and responsibilities of parenthood. Assumptions about the duty of parents (especially women as mothers) to protect their children from harm have led to discussions about the parental responsibility to pursue genetic testing, and termination of a "defective" fetus as an act of parental devotion. The British Medical Association's *Human Genetics: Choice and Responsibility* (1998) explained that, "Some people have argued that parents may have a moral obligation to protect their future child from a life of suffering by avoiding, where possible, the birth of a severely disabled child."³⁷

Sociologist Barbara Katz Rothman described the responsibility women felt when having to make difficult choices. One genetic counseling patient described "the inescapable sense of deep responsibility" she felt, saying, "There are times that I really curse modern technology. No one should have to make these kinds of decisions." This was especially the case with women who terminated their pregnancies because the fetus

³⁶ Interviews with GCS50I03, 27 July, 2010 and GCS49I18, 20 September, 2010.

³⁷ British Medical Association, *Human Genetics*, 47. See also Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon*, 2nd ed. (Ann Arbor: University of Michigan, 2004), 146-147.

had Tay-Sachs or other disorders which result in the child having a short and often painful life. In these cases, abortion was seen as “a painful obligation the mother has toward her fetus, toward her baby.” Rothman explained that, “The responsibility when the diagnosis is a fatal condition is the responsibility for determining the timing and the mode of the baby’s death.”³⁸ Anthropologist Rayna Rapp further elaborated this expectation of “female accountability,” the “gendered notion of maternal responsibility,” and the idea that women are responsible for the “quality control” of their offspring. She suggested that society holds women responsible for things like smoking and drinking during their pregnancy, but it also seems to hold them responsible for “mysterious events over which individuals have no control,” as well as chromosomal disorders.³⁹

Patients have also borne responsibilities to other family members, as well as to posterity. Sidney Callahan, a member of bioethical institute The Hastings Center, suggested in 1978 that parents are “three-way agents...Responsible to and for themselves, to and for society, and to and for their child.” They hold a “temporary mandate” over a “future adult citizen [who] must be adequately socialized.”⁴⁰ Petersen and Bunton described how in the new social schema presented by available risk management for genetic health, the silent assumption is that,

not only do people have a right to genetic information, but they also have a *duty* to minimize or manage their own contribution to disease...The expectation is that the individual will inform themselves about their genetic risk, and take whatever steps are deemed necessary to reduce the risk to themselves and to others, especially if they are found to be a ‘carrier’ and

³⁸ Rothman, *The Tentative Pregnancy*, 182-184.

³⁹ Rapp, *Testing Women, Testing the Fetus*, 86-89.

⁴⁰ Sidney Callahan, “An Ethical Analysis of Responsible Parenthood,” *Genetic Counseling: Facts, Values, and Norms*, eds. Alexander M. Capron et al. (New York: Alan R. Liss, 1979), 234.

prospective parent. Clearly, obligations associated with genetic risk management always have an intergenerational dimension.⁴¹

The British Medical Association also discussed patient responsibilities towards others, suggesting that, “all patients have duties of some sort, which may include voluntarily disclosing information to other people who may be affected.” Historically, one of the most common genetic duties to posterity was to abstain from marriage and remain childless if one and/or one’s partner possessed “undesirable” traits.⁴² Genetic counselors’ ethics prevent them from informing a patient’s family members of their genetic findings due to confidentiality restrictions, but they strongly advise known carriers to disclose their genetic disorder to their families as to avert unnecessary future harms. A second-generation counselor who currently specializes in cancer counseling described how a kind of familial responsibility, or group responsibility, has sometimes worked. He explained that, “[When] pursuing genetic testing with breast cancer, it’s usually a little bit more straight forward. Women are often driven not by themselves but by their sisters, their daughters, their nieces. They take themselves in a secondary role and say, ‘I already have cancer. This is less important to me but it does matter for my 23 year old daughter, my 45 year old sister.’”⁴³

The patient-counselor relationship, and being a genetic citizen, has therefore been structured according to numerous responsibilities. The counselor has had professional duties to be knowledgeable, value-neutral, prevent harm, and protect patient confidentiality. For their part, patients have incurred responsibilities to be active

⁴¹ Petersen and Bunton, *The New Genetics and the Public’s Health*, 57-58.

⁴² British Medical Association, *Human Genetics*, 11-12.

⁴³ Interview with GCS50I03, 27 July, 2010.

participants in the counseling session but they have also had duties to others, particularly family members, since genetic health is intergenerational. In some cases, these competing rights and responsibilities meant that patient values of client-centeredness and non-directiveness were somewhat compromised as even in their personal genetic counseling session, patients were implicitly asked to consider the larger consequences of their choices and the uses of genetic knowledge.

The New Social Contract: Patient Rights in the Age of Bioconstitutionalism.

The genetic revolution prompted new debates over the rights of individuals increasingly defined by their genetic composition. Indeed, Sheila Jasanoff, a scholar of Science and Technology Studies, suggested that “periods of significant change in the life sciences and technologies should be seen as constitutional or, more precisely, *bioconstitutional* in their consequences.” A new concept of bioconstitutionalism and “reorderings in our imagination of the state’s life-preserving and life-enhancing functions” has arisen from discussions about the rights and responsibilities of living beings and the very re-conceptualization of human life.⁴⁴ Genetic counseling has also been affected by an individual concept of rights, and the notion of patients’ rights in particular has been central to the profession since its early days.⁴⁵ In fact, the field’s early commitment to non-directiveness and enduring dedication to client-centeredness is a direct reflection of genetic counselors’ investment in patient rights of autonomy and

⁴⁴ Sheila Jasanoff, ed. *Reframing Rights: Bioconstitutionalism in the Genetic Age* (Cambridge: MIT Press, 2011), 3-4. Italics in original.

⁴⁵ George J. Annas has written prolifically on patients’ rights, including his classic text, *The Rights of Patients* (Totowa: Humana Press, 1989). See also George J. Annas, “A National Bill of Patients’ Rights,” *New England Journal of Medicine* 338, no. 10 (1998), 695-700.

freedom of choice. The purpose of non-directive counseling was to “enable clients to make informed and independent decisions with minimal risk of coercion.”⁴⁶ Though counselors have questioned and criticized non-directiveness since the 1990s, the patient’s right to self-determination and decision-making free of manipulation has remained a cornerstone of the genetic counseling session. The British Medical Association delineated the patient’s “individual rights” and explained that “showing respect for patient decisions is seen as central to good practice.” Nevertheless, a tension over rights exists as “Individual rights are not absolute” since “It is desirable for people to be aware of the implications their own decisions have for other people close to them.”⁴⁷

Second only to this most foundational right to self-determination and the right to make individual choices in genetic counseling has been the “right to know.” Petersen and Bunton argued that, “the assumption that ‘knowledge is a good thing,’ and ‘the more knowledge the better,’ remains largely undisputed in the new genetics.”⁴⁸ Indeed, advocacy for greater knowledge of genetics has been infused by the “language of rights and freedoms – ‘right to know’ and ‘freedom of choice.’”⁴⁹ A foundational tenet of the new genetics has been that patients deserve to benefit from genetic knowledge and need to be informed so as to make the best possible decisions for themselves and their families. By the 1990s, however, counselors discussed the “right not to know” about your genetic health. In cases of adult-onset disorders like Huntington’s disease and various cancers, some patients have chosen to remain unaware of their genetic risk due to feelings of

⁴⁶ Mary Terrell White, “‘Respect for Autonomy’ in Genetic Counseling: An Analysis and a Proposal,” *Journal of Genetic Counseling* 6, no. 3 (1997), 297-313.

⁴⁷ British Medical Association, *Human Genetics*, 23-25.

⁴⁸ Petersen and Bunton, *The New Genetics and the Public’s Health*, 58.

⁴⁹ *Ibid.*, 58.

helplessness or fears of adopting a fatalistic attitude towards their future. A 1992 case report in *Perspectives in Genetic Counseling*, in which a woman only wanted to be informed of certain amniocentesis findings, discussed the “patient’s right not to receive information.” In this case, it was the responsibility of the counselor to comply with the patient’s wishes, and document that she decided on this course of action through informed consent.⁵⁰ In the case of cancer counseling, where there are many measures families can take to curb their risk of developing cancer, counselors have tried to balance the right not to know with the perceived benefits of genetic knowledge for oneself and family members who may be susceptible to similar cancers.⁵¹

Private issues of patient rights and their implications beyond the individual counseling session became overtly public in the 1960s, and continue today, through public debates about genetics. Genetic counselors, through their professional and personal encounters, have been active participants in these discussions. Disability and feminist activists have, however, been perhaps the most dominant voices in public negotiations of the new genetic citizenship. Though some feminists have praised genetic reproductive technologies, most reproductive rights and disability advocates have challenged the new genetics, often using the language of rights and duties. Genetic criticisms also centered on a rejection of old-fashioned and paternalistic medical models that pathologized the bodies of women and people with disabilities. Activists situated their platforms within an anti-

⁵⁰ Denise M. Greene Simonsen, “When the Patient Doesn’t Want to Know,” *Perspectives in Genetic Counseling* 14, no. 2 (Summer 1992), 4.

⁵¹ Katherine A. Schneider et al., “Complexities in Cancer Risk Counseling: Presentation of Three Cases,” *Journal of Genetic Counseling* 6, no.2 (June 1997), 149-152.

eugenic framework, both explicitly and implicitly, through concerns about the preservation of autonomy, informed decision-making, and freedom of choice.

The Centrality of Choice and Autonomy: Reproductive Rights Encounter Genetic Technologies.

Reproductive rights activists have been some of the most conspicuous voices in debates over genetic counseling, prenatal testing, and genetic technologies. They have also been integral to thinking through the rights, responsibilities, and choices of the new genetic citizenry. The reproductive rights movement emerged from Second Wave feminism in the 1960s and 70s. According to historian Rickie Solinger, women vehemently insisted on “reproductive autonomy as a core requirement of full citizenship status for women” and argued that all other rights were meaningless unless women could control when, and when not, to bear children.⁵² Reproductive rights proponents were most famously involved in the lower court challenges that led to *Roe v. Wade* in 1973 and, indeed, the Supreme Court decision on abortion is the most recognized landmark of the group’s advocacy.

Activists also worked on a range of issues including women’s sexuality, access to a wider range of contraceptive devices, and women’s right to safe reproductive health care.⁵³ Reproductive rights advocates often participated in the women’s health movement of the 1960s and 70s, and were involved in famous initiatives like the Boston Women’s Health Book Collective’s *Our Bodies, Ourselves* and the Jane Collective for abortion

⁵² Solinger, *Pregnancy and Power*, 165-166.

⁵³ *Ibid.*, 2.

services.⁵⁴ African American and Latina activists also focused on issues specifically affecting women of color including freedom from coerced sterilization and the right to bear children out of poverty.⁵⁵ The movement's African American activists were often involved in Billye Avery's National Black Women's Health Project, which focused specifically on reproductive and health issues relevant to black women in the U.S.⁵⁶ Since the 1980s, reproductive rights campaigners have championed the rights of women in relation to technological imperatives such as amniocentesis, *in vitro* fertilization, and artificial insemination. They have consistently focused on protecting and enhancing women's status and autonomy. Although there are several strands of the reproductive rights position on genetic reproductive technologies and prenatal testing, I will highlight two.

The first reproductive rights perspective revolved around a belief that reproductive technologies have, and will continue to, enhance women's rights and autonomy. According to sociologist Judy Wajcman, some feminists of the 1970s considered reproductive technologies to be progressive as they "opened up the potential for finally severing the link between sexuality and reproduction."⁵⁷ For radical feminists like Shulamith Firestone, the foundation of patriarchy was men's control of women's fertility and reproduction. Through birth technologies, artificial wombs, and what she called

⁵⁴ Morgen, *Into Our Own Hands*, 19-22, 30-35.

⁵⁵ Nelson, *Women of Color and the Reproductive Rights Movement*, 2. See Chapter 5, "Race, Class, and Sexuality: Reproductive Rights and the Campaign for an Inclusive Feminism," which focuses on the work of CARASA, the Committee for Abortion Rights and Against Sterilization Abuse, 133-177.

⁵⁶ *Ibid*, 44-45.

⁵⁷ Judy Wajcman, *Feminism Confronts Technology* (University Park: Pennsylvania State University Press, 1991), 56.

“cybernetics,” women could free themselves from the tethers of pregnancy and childbearing, and finally escape their biologically-sanctioned subservience.⁵⁸

By the 1990s and 2000s, it seemed that genetic reproductive technologies had more feminist critics than supporters. There remains, however, a cadre of women who support such innovations. Donna Haraway suggested that human evolution entails the integration of new technologies and posited a utopian future society in which humans and machines are thoroughly enmeshed. These “cyborgs,” which are “self-replicating” and “asexual,” could create a post-gender world in which the binaries of female-male and private-public no longer matter.⁵⁹ Additionally, many women have supported reproductive technologies from a more moderate standpoint. They perceive these technologies as resources that greatly enhance women’s bodily integrity and autonomy by providing them with greater information on which to base their reproductive decisions. That American women continue to request amniocentesis, utilize *in vitro* fertilization, and enter into surrogacy arrangements suggests that many view these technologies as beneficial.⁶⁰

Historian Ruth Schwartz Cowan pursued this argument in her work *Heredity and Hope* (2008). She acknowledged that women undoubtedly make reproductive decisions within a larger socio-political matrix where the personal is intensely political, but maintained that genetic screening and prenatal testing “increases choice, and choice, as so

⁵⁸ Ibid.; Shulamith Firestone, *The Dialectic of Sex: The Case for Feminist Revolution* (New York: William Morrow and Co., 1970).

⁵⁹ Nancy Lublin, *Pandora’s Box: Feminism Confronts Reproductive Technology* (Lanham: Rowman & Littlefield, 1998), 32-33, 36; Donna J. Haraway, *Simians, Cyborgs and Women: The Reinvention of Nature*, Donna J. Haraway (New York: Routledge, 1991), 149-181.

⁶⁰ Tom Shakespeare described of prenatal diagnosis that, “consumer demand plays a significant role in the adoption of testing in pregnancy,” a fact the disability critique (and, I would argue, the feminist critique) has often ignored (*Disability Rights and Wrongs*, 87).

many feminists have argued for so many years, is the *sine qua non* of freedom.”⁶¹ Cowan argued against the critiques levelled by disability rights advocates that genetic testing will bring about a new era of eugenics and coercive medical genetics, or that the communities targeted by genetic testing will experience discrimination. She suggested, rather, that in choosing prenatal diagnosis and the potential for abortion, women are simply asserting their right to choose the life they want, a life that may be incompatible with raising a child with a serious disability.⁶²

She argued against the common criticism of genetics as eugenics in disguise by addressing what she called the “genealogical fallacy” of eugenics and the influence of this fallacy on current concerns about medical genetics. She characterized the charge by genetics opponents that the field has been tainted by its eugenic past as “roughly akin to punishing the grandchildren for the beliefs of the grandparents, or, in this case, visiting the sins of the second cousins once removed upon their relatives, fifty years later, who had made a considerable effort to repudiate the original stain on the family name.” She explained that, “Yes, these people are connected to one another, but their fundamental beliefs are not the connection.”⁶³ Cowan’s research convinced her that that the people who developed genetic screening worked from motives that she respected, and were “good people who were acting ethically.”⁶⁴

⁶¹ Cowan, *Heredity and Hope*, 244. Italics mine.

⁶² Mary Ann Baily made an argument similar to Cowan’s in, “Why I Had Amniocentesis,” in *Prenatal Testing and Disability Rights*, eds. Erik Parens and Adrienne Asch (Washington: Georgetown University Press, 2000), 64-71.

⁶³ Cowan, *Heredity and Hope*, 67. Cowan also used an analogy of a tree with different trunks representing the different branches or uses of genetics to try to explain how small eugenics was to the overall field of genetics historically.

⁶⁴ *Ibid.*, 9.

Genetic counselors have been important contributors to this strand of reproductive rights activism from their position as women publicly involved in the genetics enterprise. Counselors have supported a positive and empowering relationship between feminist activism and the new genetics through genetic counseling since the profession's early days. One counselor described many of her fellow pioneering counselors as "applied feminists...[who brought] a holistic approach to our work"; indeed, many counselors were acutely aware of, and often participated directly in, the reproductive rights and abortion debates of the early 1970s from an intensely women's rights and pro-choice perspective.⁶⁵

A 1978 Sarah Lawrence graduate recalled,

I was pretty active in the pro-choice movement in New York State, and definitely in my own community, and was involved in actually bringing the pieces together and to support the beginnings of an abortion service that still exists today. That abortion service is a first-trimester service but, I'm not kidding you, we did bake sales for that. We did bake sales to raise money so we could help women who needed to end their pregnancies, to go places in New York State, for a bus ticket there and back.⁶⁶

For many early counselors, a pro-choice position in their workplace was essential to their feminist values; it was also central to the maintenance of a responsible counseling philosophy and a necessary piece of a genetics encounter meant to augment women's reproductive choices. One counselor who graduated from the training program at the University of California Irvine in 1975 remembered that,

I toyed for a while with taking a job I was offered in Texas, but when I learned that Medicaid did not pay for abortions there, I rapidly lost interest. This inequity in access would make genetic counseling very frustrating--- which is not to say that all untoward prenatal diagnoses lead to abortion. But pregnancy termination *is* part of the armamentarium of options we have to

⁶⁵ Interview with GCS00I24, 19 November, 2010.

⁶⁶ Interview with GCS00I21, 12 November, 2010.

discuss, and it needs to be realistically available to the client. As a counselor, it's very difficult to have to qualify discussion of this option by saying, 'You could go to Colorado to have an abortion, but you can't get it done here in Louisiana.'⁶⁷

For genetic counselors, endorsement of a pro-choice position was essential to maximizing their client's options. There are certainly genetic counselors who, in their personal lives, might have pro-life leanings. In their professional capacities, however, counselors encourage patients to make sound reproductive decisions based on information gleaned from increasingly-sophisticated prenatal diagnostics.

Genetic counselors, particularly the pioneering cohort, also promoted a positive relationship between genetics and feminist activism through work at Planned Parenthood clinics across the United States. This employment situation reflected the women's feminist inclinations, as well as the broader socio-political climate of the age. One counselor, who had "always sort of had feminist leanings in a non-strident kind of way," performed reproductive and sexuality counseling for Planned Parenthood in California in the early 1970s. Her responsibilities, which included running sex-education sessions with women before they obtained birth control, heightened her awareness of women's health and reproductive issues.⁶⁸ A second counselor recalled that,

I had this very crazy idea and a naive notion...I thought well why not try to introduce genetic counseling into Planned Parenthood...I went to the director and said 'Here's what I'm thinking. I think there's a real role for family health history, and expanding the whole family health history and concerns about birth defects. That is, if the mission of Planned Parenthood is that every child should be a wanted child, and that's why Planned Parenthood offers contraceptive services, that when individuals are ready to have a family there

⁶⁷ Interview with GCS00I22, 12 November, 2010.

⁶⁸ Ibid.

is some responsibility within the Planned Parenthood community to help them have the family they want.’⁶⁹

Her interest in family planning led her to create a questionnaire on family health history and risk perception. Interestingly, this same counselor worked simultaneously on “the flipside of family planning” at an infertility clinic, where she continued her work with family health questionnaires. This counselor, and many others, worked to expand reproductive rights by championing women’s self-determination in matters of fertility and childbearing from their position as frontline genetic healthcare workers.

The contrasting strand of the reproductive rights position is exhibited by such scholars as Barbara Katz Rothman and Gena Corea, who have challenged reproductive technologies as harmful to women’s rights because they decrease their reproductive autonomy. In *The Tentative Pregnancy* (1993), Rothman argued that amniocentesis has changed the experience of motherhood so that women’s commitment to their pregnancy is tentative or in a state of suspended animation, contingent upon medical knowledge gleaned from prenatal diagnosis. She argued that the routinization of this technology and the medicalization of pregnancy have exerted social pressures on women’s ability to exercise reproductive choice. Rothman suggested that services like prenatal testing and genetic counseling serve to promote quality control, and situate women as gatekeepers of a society burdened by vast genetic knowledge without increased social responsibility.⁷⁰

In *Man-Made Women* (1987), Gena Corea and others also argued that reproductive technologies are oppressive to women. The collection focused on issues of femicide, sex

⁶⁹ Interview with GCS00I21, 12 November, 2010.

⁷⁰ Rothman, *The Tentative Pregnancy*, xii, 2, 11-14, 100-101.

predetermination, and surrogate motherhood. The authors suggested that while reproductive technologies have been presented to women as gifts that will enhance their choices, what such technologies actually facilitate is increased (male) medical control over women's lives, thereby decreasing their right to choose.⁷¹ The arguments presented by Rothman and Corea reflect the larger concerns of this school of thought, specifically the worry that with the increasing routinization of services like genetic counseling, amniocentesis, and genetic testing, women will lose autonomy in the face of a new dominant norm of practice.

A critical feminist perspective on reproductive technologies took perhaps its most extreme form in the organization FINRRAGE, the Feminist International Network of Resistance to Reproductive and Genetic Engineering. Reproductive rights activists began meeting in the mid-1970s and formed the organization FINRRAGE in 1984 as an international feminist network. The group (in which Gena Corea was a key activist) established linkages between women in the first and third worlds, and developed position statements on genetic engineering and reproductive technologies.⁷² In 1989 the group, which included doctors, lawyers, social scientists, teachers, community organizers, and others from thirty different countries, issued the Declaration of Comilla. This statement emanated from a conference by the same name in which the participants advocated for the

⁷¹ Gena Corea et al., *Man-Made Women: How New Reproductive Technologies Affect Women* (Bloomington: Indiana University Press, 1987), 12. See also Gena Corea, *The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs* (New York: Harper & Row, 1985).

⁷² Gena Corea et al., "FINRRAGE: The Struggle Over New Reproductive Technology," 1, reprinted from the prologue of *Made to Order: The Myth of Genetic and Reproductive Progress*, eds. Patricia Spallone and Deborah Lynn Steinberg (Oxford: Pergamon Press, 1987), 1-12, accessed 23 April, 2013, http://www.finrrage.org/pdf_files/History%20of%20Finrrage/FINRRAGE.pdf

“need to halt the political decisions which are leading to the rapid development and increasing application” of reproductive and genetic technologies.⁷³ They argued that these technologies were “aggravating the deteriorating position of women in society and intensifying the existing differences among people in terms of race, class, caste, sex, and religion.” They also decried these technologies as inherently eugenic, particularly through the classification of human beings into “superior” and “inferior” categories. Moreover, the group railed against the use of eugenics as a political strategy to “divide and rule” and its use, when combined with racism, to justify policies of population control. The Declaration also expressed concerns that “tinkering with genetic codes opens up a truly uncontrollable situation of ‘runaway designer genes.’” Conference participants called for increased recognition and concern about the rights of women to better health education, to control over their fertility, and to determine the conditions under which they will bear children.⁷⁴

FINRRAGE worked on a range of topics including population control, unsafe contraceptive methods, and cervical cancer vaccines. Much of their work in the late-1980s and 90s focused explicitly on the damages many of the bedfellows of genetic counseling (such as reproductive technologies, genetic testing, and genetic engineering) caused to women. In 1988, the group protested women’s use of *in vitro* fertilization and called for a moratorium on all such fertilization initiatives, arguing that, “the IVF

⁷³FINRRAGE, ed., *Declaration of Comilla*, FINRRAGE-UBINIG International Conference 1989 Proceedings (Dhaka: UBINIG, 1989), vii.

⁷⁴ *Ibid.*, vii-xi.

procedure amounts to experimentation on women's bodies."⁷⁵ The group also fought against surrogacy, which was described on their website as an "assault" on women's dignity, "a risk to their health, and a modern form of slavery."⁷⁶ They argued that surrogacy was dangerous in that it commodified women and children, and turned pregnancy into an economic venture or contest over property and ownership.⁷⁷ The group also challenged prenatal screening for sex determination, women's legal prosecution for giving birth to drug-exposed infants, and the safety of prenatal diagnostic tests like CVS.⁷⁸ Given the breadth of their work, the initiatives pursued by the organization are a useful example of the anti-technology strand of the reproductive rights argument on prenatal and genetic testing in action. In particular, they demonstrate the ways in which women organized collective resistance in the late-twentieth century against what they perceived as the erosion of their rights, the medicalization and geneticization of their bodies, and the potential eugenic coercion involved in the new genetics.

In the United States, the National Women's Health Network (NWHN) was a key player in the Women's Health and Reproductive Rights movements of the late-twentieth

⁷⁵ Dr. R. Klein, "Healthy Women are Victims of IVF Fiddling," *FINRRAGE Newsletter*, Australia, May 1988, 10, accessed 23 April, 2013,

http://www.finrrage.org/pdf_files/Newsletters/Newsletter_May_1988.pdf. See also Renate Klein, "New Reproductive Technologies: Who Profits? Who Pays the Price?," in *Declaration of Comilla*, 50-58.

⁷⁶ FINRRAGE.org, Home Page, accessed 23 April, 2013, <http://www.finrrage.org/>

⁷⁷ "Finrrage Responds to Surrogacy Report 1989," Draft Report on Surrogacy Issued by the Australian National Bioethics Consultative Committee – The Debate on Surrogacy Continues, accessed 23 April, 2013,

http://www.finrrage.org/pdf_files/RepTech%20General/Aust_National_Bioethics_Consultative_Committee_Report_on_Surrogacy_Debate_in_Australia.pdf

⁷⁸ Gena Corea and Cynthia De Wit, "Current Developments and Issues: A Summary," *Reproductive and Genetic Engineering: Journal of International Feminist Analysis* 1, no. 3 (1988), under Developments and Issues 3, accessed 23 April, 2013, <http://www.finrrage.org/reptechgeneral.html>; Cynthia De Wit and Gena Corea, "Current Developments and Issues: A Summary," *Reproductive and Genetic Engineering: Journal of International Feminist Analysis* 1, no. 3 (1990), 51-69, under Developments and Issues 1, accessed 23 April, 2013, <http://finrrage.org/reptechgeneral.html>.

century. Feminists Barbara Seaman, Belita Cowan, Alice Wolfson, Phyllis Chesler, and Mary Howell formed the NWHN in 1975.⁷⁹ Based in Washington D.C., the Network acts as a non-profit watchdog organization devoted “To mak[ing] the nation’s health policies and community health services responsive to the needs of women and their families.” To this end, the Network devoted itself to advocating for the Women’s Health movement in Congress and to federal agencies; evaluating medical and health research to determine their impact on women’s health; and providing a national network that links health professionals, public interests, and consumer advocates.⁸⁰

Much of the organizations’ work focused intently on issues of reproductive rights as related to the impact of genetic technologies on women and their families. In a 1979 press release, the Network asserted that, “abortion on demand is the cornerstone of women’s reproductive freedom” but the group was similarly committed to women’s rights in overall maternal health and care in childbirth.⁸¹ They argued that, “Every woman has the right to control decisions about the method of getting pregnant (including the use of artificial or self insemination), about the continuation of a pregnancy, and about the person(s) she chooses to live with once the child is born.” The NWHN advocated for prenatal care, which often meant self-care and preventive measures including good nutrition and vitamins supervised by a choice of birthing attendants as opposed to solely physicians; MDs, they charged, “are not trained to give high quality preventive prenatal

⁷⁹ Morgen, *Into Our Own Hands*, 29.

⁸⁰ “National Women’s Health Network,” NWHN Internal History 1975-1983 folder, National Women’s Health Network records (hereafter NWHN), Washington, D.C.

⁸¹. “National Women’s Health Network Press Release,” 15 February 1979, Network Position Papers and Press Releases, NWHN. The group also supported active pro-choice advocacy in their newsletter, *Network News*, April/May 1979, NWHN Network News, NWHN.

care” and rather “rely on prescribing drugs and on childbirth technology to improve outcomes.”⁸² Genetic counseling, although rarely addressed in specifics by the NWHN, was included in the range of services a woman-centered health system should offer related to pregnancy in addition to prenatal care, postpartum care, newborn care, nutrition counseling, and genetic testing.⁸³

The Network’s concerns about reproductive rights typically centered on the over-medicalization of women’s bodies and the excessive use of technologies in women’s pregnancies and birthing experiences. The group interrogated the safety and necessity of tools for monitoring women’s pregnancies and “visualizing” the fetus, and questioned the physical impact of ultrasounds on women and their babies.⁸⁴ They also worried about the impact of genetic screening tests like AFP (alpha fetoprotein), particularly the implications of commonly-occurring false positives in what are only screening tests and not definitive diagnostic tools. They explained that,

the possibility exists that, upon notification of a positive AFP result, a woman may choose to have an abortion without opting for additional follow-up screening. Thus on the one hand, if the results were a ‘false positive,’ a normal fetus might be aborted. On the other hand, with abortion services

⁸² “National Women’s Health Network Working Position Paper on Maternal Health and Childbirth,” 1981, 1-2, Network Position Papers and Press Releases, NWHN.

⁸³ “National Health Plan Principles,” c.1978, NWHN Internal History 1975-1983, NWHN.

⁸⁴ “National Women’s Health Network, List of Yearly Accomplishments,” 20 June, 1985, NWHN Yearly Achievements, NWHN; “News from Around the Country,” in *Network News* 4, no. 6 (November/December 1979), 9, NWHN Network News, NWHN. Another issue addressed by the Network was electronic fetal monitoring. Cheryl Krasnick Warsh described the controversy over this diagnostic tool, particularly questions of whether staff were overly-inclined to interfere in natural childbirth processes. There were also questions about the long-term results of ultrasounds and the monitor’s electrodes on the fetus. See Warsh, *Prescribed Norms: Women and Health In Canada and the United States since 1800* (Toronto: University of Toronto Press, 2010), 125-126.

becoming more and more scarce, women with a defective fetus may be forced to carry the pregnancy to term against their will.⁸⁵

The Network's position on AFP centered on a concept of women's right to abortion, but also the necessity of accurate diagnostic information on which to base a responsible, fully-informed reproductive decision.

The NWHN, much like FINRRAGE, also took a hard line on surrogacy. In a statement presented at the National Conference of Women Legislators, the group proposed that commercial surrogacy "disregard[s] the value of human life, exploit[s] women and should be prohibited by law"; that these laws should enable the prosecution of any man, woman, or medical professional involved in commercial surrogacy; and that surrogacy contracts should be void "because no women should be forced to give up a child based on a surrender signed prior to conception or birth."⁸⁶ This statement not only reaffirmed women's rights over their bodies as mothers, but it sought to institutionalize these fundamental freedoms through legal responsibilities.

The National Women's Health Network addressed disability issues through a concern with birth defects, although this occurred within a larger commitment to promoting women's health. As prenatal technologies rapidly expanded through the 1980s, the group raised awareness about the causes of birth defects, specifically the role of drugs, alcohol, contraceptives, and environmental factors as opposed to genetic determinants. Leading member of the NWHN Doris Haire made significant contributions to a bill introduced to

⁸⁵ "National Women's Health Network Washington Update," *Network News* 6, no. 1 (January/February 1981), 3, NWHN Network News, NWHN. See also "National Women's Health Network Washington Update," *National Women's Health Network News* 5, no. 2 (March/April 1980), 9.

⁸⁶ "National Women's Health Network position statement on surrogacy", c. 1987, Network Position Papers and Press Releases, NWHN; "National Women's Health Network 1987 Program Highlights," NWHN Yearly Achievements, NWHN.

the House of Representatives in 1980 that would “insure that women will be able to make a more informed decision about the use of drugs and procedures during pregnancy and delivery, hence helping to prevent possible injury to millions of American newborns.” The bill also made a provision for an investigation into the effects of obstetrical procedures and drugs on pregnant women, and required the circulation of information detailing such risks.⁸⁷ The group campaigned against pregnant women’s consumption of alcohol, which could result in a child with Fetal Alcohol Syndrome, arguing that, “Alcohol abuse is not only harmful to the fetus, but to the mother as well.”⁸⁸ Since the 1970s, the Network raised concerns about contraceptives like Depo-Provera, which was associated with congenital birth malformations, and DES (diethylstilbestrol), which caused increased risk for rare forms of vaginal and cervical cancers in the daughters of women who took the drug.⁸⁹ In addressing birth defects and disability, the Network articulated a concern not only with women’s rights but also with their responsibilities as mothers for their health and that of their baby. Thus, despite their stance against the geneticization of women’s bodies and commercialization of pregnancy, the NWHN suggested ways in which certain biological duties were still expected of women as mothers.

Contrasting feminist perspectives on genetic reproductive technologies often clashed in the late-twentieth century. Nevertheless, their central concern with autonomy and

⁸⁷ “Congress Could Help Prevent Birth Defects,” *Network News* 5, no. 2 (March/April 1980), 10, NWHN Network News, NWHN.

⁸⁸ “Network News-Alert: Proposed Warning Label on Alcoholic Beverages for Pregnant Women,” 1978, NWHN Internal History 1975-1983, NWHN.

⁸⁹ “National News Alert on Depo-Provera,” 1978, NWHN Internal History 1975-1983, NWHN; “National Women’s Health Network case statement,” c. 1980, NWHN Internal History 1975-1983, NWHN.

informed decision-making overlapped considerably with disability rights discourses as both groups continually re-negotiated their rights, responsibilities, and choices as new genetic citizens.

Arriving in a “Different Place”: Disability Advocacy and the New Genetics.

The disability rights movement in the United States emerged from activist spirit of the 1960s and was influenced by the Women’s and Civil Rights movements in particular. During this period, people with physical and intellectual disabilities organized a movement to reconceptualise perceptions of disability, and fight stigma and social isolation through political and legal means. Many activists have fought against a “medical” or “individual” model of disability that pathologizes their impairment and blames their condition for their exclusion from social and civic activities.⁹⁰ As sociologist Richard K. Scotch has noted, the disability rights movement rather “promoted the idea that prejudiced attitudes and exclusionary practices are far greater barriers to social participation for many disabled people than are their physical or mental impairments.”⁹¹

Disability advocates were successful in drawing attention to the physical barriers facing people with disabilities, one result of which was the ANSI Barrier Free Standard aimed at making buildings more accessible. The late-twentieth century also witnessed the emergence of the Independent Living movement which emphasized that people with

⁹⁰ Jackie Leach Scully, *Disability Bioethics: Moral Bodies, Moral Difference* (Lanham: Rowman and Littlefield, 2008), 22-25. See Tom Shakespeare, *Disability Rights and Wrongs*, for a thorough discussion of various models of conceptualizing disability. Shakespeare advocated a relational or interactional understanding of disability. This model suggests the experience of disability is structured by the interplay of one’s impairment and existing social conditions in Chapter 3: Disability: A Complex Interaction, 54-67.

⁹¹ Richard K. Scotch, “Politics and Policy in the History of the Disability Rights Movement,” *The Milbank Quarterly* 67, supplement 2 (Part 2). *Disability Policy: Restoring Socioeconomic Independence* (1989), 380.

disabilities are in the best position to know their needs and experiences, and a shift away from institutionalization to community living for people with cognitive impairments. In 1973, the Rehabilitation Act was established to prohibit discrimination based on ability in all programs receiving Federal monies. This was the most important disability legislation in the United States until the Americans with Disabilities Act (ADA) of 1990. The ADA intended to prohibit discrimination based on ability/disability in a wide range of civil rights including employment, public accommodations and transportation, and telecommunications.⁹² Despite certain gains, however, people with physical and intellectual disabilities have often remained “on the margins of citizenship,” negotiating shifting and often contradictory discourses about their access to basic civil rights extended to other Americans.⁹³

Disability rights advocates entered debates about prenatal and reproductive technologies from a concern about the lived application of these innovations to human beings, and the message they send to people with disabilities about their value and quality of life. Skepticism about the new genetics from the disability community is historically warranted. People with disabilities were subject to many atrocities throughout the early-

⁹² Paul K. Longmore and Lauri Umansky, *The New Disability History: American Perspectives* (New York: New York University Press, 2001), 1-29; Paul Longmore, *Why I Burned My Book, and Other Essays on Disability* (Philadelphia: Temple University Press, 2003), Chapter 5, The Disability Rights Moment: Activism in the 1970s and Beyond, 102-115. See also Noll and Trent., eds., *Mental Retardation in America: A Historical Reader*; Catherine J. Kudlick, “Why We Need Another ‘Other’,” *The American Historical Review* 108, no. 3 (June 2003), 763-793; Doris Zames Fleischer and Freida Zames, *The Disability Rights Movement: From Charity to Confrontation*, updated ed. (Philadelphia: Temple University Press, 2011); Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Random House, 1993).

⁹³ Carey, *On the Margins of Citizenship*. Carey analyzed “rights restrictions” like early-twentieth century surgical sterilization, the use of a rights discourse by parent groups advocating for their “mentally retarded” children, and disability advocacy of the late-twentieth century aimed at achieving social justice and equal rights in education, employment, and marriage.

twentieth century including surgical sterilization or segregation of the American eugenics era, and the euthanasia of approximately 200,000 physically or mentally handicapped individuals under the Nazi regime.⁹⁴ In *Prenatal Testing and Disability Rights* (2000), Erik Parens and Adrienne Asch outlined the three-pronged critique levelled by some disability rights activists against prenatal diagnosis and selective abortion.⁹⁵ Disability advocates charge that “prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.” They also argue that by aborting a desired child who has become “undesirable” based on a “defect,” parents are suggesting that they are disinclined to compromise on their original parental aspirations. Finally, by selecting against a fetus with a disability, parents are signalling that a disabled child could never fulfill their ideal parent-child relationship.⁹⁶

These ideas were further elaborated by Adrienne Asch and David Wasserman in their 2005 chapter, “Where is the Sin in Synecdoche?” They argued against prenatal testing and the decision to abort based on such testing, suggesting that it is morally problematic to allow “a single known characteristic of the future child to so overwhelm and negate all other hoped-for attributes that the prospective parents no longer desire the coming-into-

⁹⁴ Ian Dowbiggin, *A Concise History of Euthanasia: Life, Death, God, and Medicine* (Landham: Rowman & Littlefield, 2005), 92.

⁹⁵ The perspectives expressed in this volume range considerably, and by no means encompass all the nuances of disability activists’ concerns with prenatal testing. Many of these perspectives have, however, dominated discussions of disability and reproductive technologies.

⁹⁶ Erik Parens and Adrienne Asch, “The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations,” in *Prenatal Testing and Disability Rights*, eds. Erik Parens and Adrienne Asch (Washington: Georgetown University Press, 2000), 12-13.

being of that child.”⁹⁷ Asch and Wasserman suggested that parents are insufficiently informed about the lived experience of caring for a disabled child, and that contrary to popular belief, having a child with an impairment does not preclude a fulfilling parent-child relationship. They also suggested that choosing to abort based on synecdoche (allowing one characteristic to define the child’s entire life) sends a negative message about the value and quality of life of persons with disabilities and, as such, gives the disability community grounds for a moral grievance.⁹⁸ Based on this rationale, the central thrust of the disability rights argument against prenatal testing has emphasized respecting the rights and lives of those with disabilities. Toward this end, activists have advocated for the American public to become better educated about the experiences of disabled people. Such a perspective is crucial to making more responsible, informed reproductive decisions free from inaccurate and stigmatizing perceptions of disability.

Genetic counseling of the 1940s was built around what Alexandra Minna Stern described as “a code of prevention,” and Reed in particular had faith that his clients would rationally choose to avoid the birth of a “mentally retarded” child. In an age when bearing a disabled child was thought to bring a lifelong burden characterized by grief and sorrow, Reed was an avid proponent of institutionalization and even voluntary sterilization of the intellectually disabled. At the same time, he “planted the seeds” for a disability rights movement through his commitment to helping parents cope with their

⁹⁷ Adrienne Asch and David Wasserman, “Where is the Sin in Synecdoche?” in *Quality of Life and Human Difference: Genetic Testing, Healthcare and Disability*, eds. David Wasserman, Jerome Bickenback, and Robert Wachbroit (Cambridge: Cambridge University Press, 2005), 182.

⁹⁸ *Ibid*, 183, 202-203, 208.

affected child.⁹⁹ He acknowledged that “it is certainly not easy to have a retarded child in the family,” but “it need not all be a grim experience, and it is a rigorous test of one’s character.”¹⁰⁰

By the 1950s, even as Reed sought to alleviate his clients of their shame and guilt at having produced a “mentally retarded” child, parents of affected children were writing about, and celebrating, the happiness within their families. Most famously, Eunice Kennedy Shriver wrote “Hope for Retarded Children,” which was published in a 1962 edition of the *Saturday Evening Post*. Shriver, who founded the Special Olympics in 1968, discussed the daily successes and challenges experienced by her sister Rosemary while emphasizing that “mental retardation” can occur in any family. Shriver’s work continually reaffirmed the worth and important contributions of the developmentally delayed.¹⁰¹ Author Pearl Buck, who won the Pulitzer Prize in 1932 and the Nobel Prize for literature in 1938, also wrote a best-selling memoir, *The Child Who Never Grew* (1950) about her daughter Carol.¹⁰² Buck was one of the first prominent American cultural figures to publicly recognize their mentally-impaired child at a time when most were quietly kept out of the public eye. She detailed her initial despair, her struggles with institutionalizing her daughter, and the thoughts and questions that plagued her about life with a “mentally-retarded” child. She counseled parents that “there is alchemy in sorrow.

⁹⁹ Stern, *Telling Genes*, 83, 97. In a case study in *Parenthood and Heredity* (pg. 70) Reed suggested institutionalization for a girl with congenital microphthalmos and mental deficiency since the staff would be able to take better care of her than her parents. He believed that she would get more attention in an institution than if she remained at home in a family with other children, and would not have to endure the taunts of “normal” children.

¹⁰⁰ Reed, *Parenthood and Heredity*, 59. In a misguided attempt at humour, Reed followed this statement by then suggesting that “Fortunate are the parents who have a sense of humor because it can change situation from one that is awful to one that is awfully funny.”

¹⁰¹ Eunice Kennedy Shriver, “Hope for Retarded Children,” *Saturday Evening Post*, 22 September, 1962.

¹⁰² *The Child Who Never Grew* was first published in *Ladies Home Journal* in May 1950.

It can be transmuted into wisdom, which, if it does not bring joy, can yet bring happiness.”¹⁰³

Several organization in the United States have championed the rights of individuals with disabilities, one of the oldest being The Arc. The group was organized in 1950 as the National Association for Retarded Citizens (NARC) at a time when institutionalization for intellectual and developmental disabilities was the norm. According to historian Kathleen W. Jones, “the groups voiced a spirit of entitlement that was decidedly new and grounded in the family ideology of togetherness. Their children were a part of the family and deserved the same degree of care, concern, and, ultimately, services that the family (and community) offered its ‘normal’ children.”¹⁰⁴ In addition to advocating for home care and better social infrastructure for their children, Arc parents also aimed to educate the American public about the lives of children with cognitive impairments, and fought for better access to, and equality in, education and employment.¹⁰⁵ They emphasized that “mental retardation” could happen in any family regardless of socio-economic status, race, or religion in an attempt to lessen the social isolation felt by these children and their families. NARC had 62,000 members and more than 680 local affiliate organizations by 1960.¹⁰⁶

¹⁰³ Pearl Buck, *The Child Who Never Grew* (New York: The John Day Company, 1950), 5.

¹⁰⁴ Kathleen W. Jones, “Education for Children with Mental Retardation: Parent Activism, Public Policy, and Family Ideology in the 1950s,” in *Mental Retardation in America: A Historical Reader*, eds. Steven Noll and James W. Trent (New York: New York University Press, 2004), 329.

¹⁰⁵ Robert Segal, “The National Association for Retarded Citizens,” Historical Accounts, The Arc, accessed 2 April, 2013, <http://www.thearc.org/page.aspx?pid=2342>

¹⁰⁶ Katherine Castles, “‘Nice, Average Americans’: Postwar Parents’ Groups and the Defense of the Normal Family,” in *Mental Retardation in America: A Historical Reader*, eds. Steven Noll and James W. Trent (New York: New York University Press, 2004), 351, 355.

More recently, in 2010, The Arc took up issues related directly to prenatal diagnosis and genetic counseling in a position statement on the prevention of developmental and intellectual disabilities. Interestingly, they advocated for the use of genetic screening and asserted that, “the nation must continue to investigate the causes, reduce the incidence and limit the consequences of intellectual and/or developmental disabilities through education, clinical and applied research, advocacy, and appropriate supports.” The Arc actively supported research on the origins and prevention of birth defects; in fact, NARC had funded the development of Guthrie’s PKU test as part of their commitment to preventing mental impairment.¹⁰⁷ Echoing Tom Shakespeare’s perspective on disability and prenatal testing, they maintained that, “Prevention activities do not diminish the value of any individual, but rather strive to maximize independence or enhance quality of life for people with intellectual and/or developmental disabilities.”¹⁰⁸

The Arc’s prevention initiatives included research into the causes of cognitive impairments; education and care before birth including genetic counseling; and the expansion of newborn screening programs to identify conditions that require immediate postnatal attention. Noticeably absent, however, was any discussion of abortion for fetal indications. It seems that while the organization generally supported the prevention of birth defects and postnatal screening programs, the implicit suggestion was that once conceived, babies with disabilities should be born.¹⁰⁹ There is an overlapping, and perhaps contradictory, set of duties inherent in this position. While the Arc recognized

¹⁰⁷ The Arc, “Prevention,” Position Statements on Systems, The Arc, accessed 2 April, 2013, <http://www.thearc.org/page.aspx?pid=2384>; Cowan, *Heredity and Hope*, 126.

¹⁰⁸ The Arc, “Prevention”; Shakespeare, *Disability Rights and Wrongs*, 90-98.

¹⁰⁹ *Ibid.*

that research and prevention of disabilities are a necessary part of responsible genetic citizenship, parents also have a duty to bear and accept children with disabilities once past the preventive stage.

The National Down Syndrome Congress (NSDC) has also been a major actor in disability advocacy. The NDSC was founded in 1973 by the parents and families of people with Down syndrome to advocate for their greater respect and rights. The organization has worked to influence public policy affecting people with Downs; to educate the public about the condition; to promote the participation of people with Down syndrome in community life; and to foster communication with other groups in the disability community.¹¹⁰ Down syndrome (Trisomy-21) has been central to public discussions of genetic reproductive technologies since, as David Wright has noted, it is a common chromosomal conditions and readily-identifiable form of mental disability.¹¹¹ Down syndrome has been a fulcrum for debates about the ethics of prenatal testing and selective abortion. The great range of capabilities exhibited by individuals with Down syndrome has been highlighted by disability rights advocates to argue against attempts to generalize the experience of disability.¹¹² Providing information on Trisomy 21, including how this chromosomal abnormality occurs, the prenatal tests capable of detecting the condition, and some insight into living with this syndrome, is also “the major workload of genetic counselors in prenatal settings.”¹¹³ The NDSC’s position on genetic services was

¹¹⁰ National Down Syndrome Congress, “History and Services,” NDSC, accessed 2 April, 2013 http://www.ndscenter.org/?page_id=43

¹¹¹ David Wright, *Downs: The History of a Disability* (Oxford: Oxford University Press, 2011), 7-8.

¹¹² *Ibid.*, 8, 154-158.

¹¹³ Dagmar Tapon, “Prenatal Testing for Down Syndrome: Comparison of Screening Practices in the UK and USA,” *Journal of Genetic Counseling* 19, no. 2 (April 2010), 112.

that “genetic counseling may be helpful once your child is born or if you have a prenatal diagnosis” in subsequent pregnancies so you can “prepare for their new baby’s arrival.”¹¹⁴

The NDSC fought to correct older disability perspectives that cast people with Down syndrome as a burden on parents and siblings, and as individuals doomed to experience a low and unfulfilling quality of life, by publishing educational materials promoting the rewards of having a child with Downs. The group authored “Light at the End of the Tunnel” for parents faced with prenatal diagnosis results indicating a fetus with Down syndrome. The brochure included reflections from parents in the 1990s who “have already journeyed down the intense road of pre-natal diagnosis - and chose life.” The NDSC hoped for reader that “as you read their comments, may their struggles and experiences resonate with your own...generating direction, options, and hope.”¹¹⁵ Most stories followed a similar pattern of detailing parents’ initial hopes; their experiences with prenatal testing; their feelings of grief upon learning of their child’s condition; and their subsequent acceptance and eventual joy of having a child with Down syndrome.¹¹⁶

The group also drew on a 1987 article by Emily Perl Kingsley called “Welcome to Holland,” a travel-based analogy for ending up with a child other than that which was planned. Kingsley described someone who planned a vacation in Italy but ended up in Holland, and the experience of being in a “different place.” Because of this, you must,

buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It’s just a

¹¹⁴ National Down Syndrome Congress, “Down Syndrome” brochure, Resources, Facts about Down Syndrome, NDSC, accessed 2 April, 2013, <http://ndscenter.org/resources/general-information/facts-about-down-syndrome/>

¹¹⁵ National Down Syndrome Congress, “Light at the End of the Tunnel,” Resources, New and Expectant Parents, NDSC, <http://ndscenter.org/resources/new-and-expectant-parents/>, accessed 2 April, 2013.

¹¹⁶ Ibid.

difference place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while you catch your breath, you look around...and you begin to notice that Holland has windmills...Holland has tulips. Holland even has Rembrandts.

Kingsley noted that while the grief of not having arrived in Italy may never fully disappear, if you spend your life dwelling on this fact, “you may never be free to enjoy the very special, the very lovely, things...about Holland.”¹¹⁷ Several genetic counselors in my study used this article to help parents better grasp the experience of having a child with Down syndrome. One counselor described that Kingsley's article helped her field parents' questions of “What does [Down syndrome] mean for me?,” “What is my life going to be like,” and “What's life going to be like for this baby?”¹¹⁸ Kingsley's narrative can be understood as part of a larger disability rights agenda to promote the responsibility of parents in carefully considering their reproductive choices. It has also acted as a plea to the American public to educate themselves about the lives of people with disabilities.

Genetics healthcare professionals are sometimes thought by critics to be firmly entrenched in the medical model of disability. They are viewed as proponents of the new eugenics aimed at eradicating embodied differences (or what Jackie Leach Scully emphasized as merely “phenotypic variation”).¹¹⁹ A contemporary counselor who herself has a disability described that she has “the disability community on one half of me, and the genetics community on the other half.” This comment highlights the perceived disparities between the medical model of genetics, and the disability community's lived

¹¹⁷ Emily Perl Kingsley, “Welcome to Holland,” Resources, New and Expectant Parents, NDSC, accessed 2 April, 2013, <http://ndscenter.org/resources/new-and-expectant-parents/welcome-to-holland/> Kingsley is a Down syndrome activist. She founded the Adoption Committee of the National Down Syndrome Congress in 1979 (Rapp, *Testing Women, Testing the Fetus*, 270).

¹¹⁸ Interviews with GCS64I09, 4 August, 2010 and GCS19I14, 11 August, 2010.

¹¹⁹ Scully, *Disability Bioethics*, 30.

experience.¹²⁰ Many counselors, however, claim to have a profound respect for disability activism with one pioneering counselor commenting that, “My practice of genetic counseling deepened because of disability advocacy” and work directly with individuals from various disability communities.¹²¹

In an interesting juxtaposition, a second generation genetic counselor who worked primarily in a prenatal context also worked in a clinic for children with Down syndrome. She articulated the need for a more even assessment of life with a genetic disorder, and explained that,

[The focus on Down syndrome] really is disturbing to me because, yes, Down syndrome can happen in a pregnancy but so can a hundred other things...So much time in the prenatal setting is spent talking about Down syndrome. And so, if I were a parent of a child with Down syndrome, I would probably feel a little bit concerned about that and insulted by that too...[But] I think there’s a lot of movement towards trying to be more balanced, especially around Down syndrome. There’s a group of us, of about 12 genetic counselors, who are writing practice guidelines for the NSGC of pre- and post-natal counseling for Down syndrome and what needs to be included. It’s about being balanced and not just giving a laundry list of problems, but also talking about all the things that people with Down syndrome *can* do, and *do* do, and giving kind of a more realistic perspective.¹²²

Another counselor addressed misconceptions that the genetic counselor’s professional responsibility is to “talk people into aborting babies with problems.” He explained that, “My abortion rate for severe abnormalities is about 50%, and the 50% that continued, I really worked to make sure they got the best care possible, their child got the best medical

¹²⁰ Interview with GCS89I17, 24 August, 2010.

¹²¹ Interview with GCS00I24, 19 November, 2010.

¹²² Interview with GCS94I01, 26 July, 2010.

care...they had all the support in place and they were ready. How much that helped, I don't know. But I was as dedicated to both sets of families.”¹²³

Indeed, in the last quarter of the twentieth century, genetic counseling training programs included the disability critique of prenatal testing in their curricula, and encouraged students to seek placements in clinics or schools for disabled children or adults.¹²⁴ Disability perspectives have encouraged counselors to reassess the assumptions inherent in counseling philosophies and what medical terms like “risk,” “defect,” “normal,” and “healthy” convey about the value of human lives. For genetic counselors, providing a well-rounded account of the experience of disability has been increasingly central to a responsible counseling ethos, and to the rights of their patients in making fully-informed reproductive decisions.

The disability community has generally been critical of the medicalization of disability. Activists have challenged the judgements inherent in reproductive genetic technologies about which human characteristics are desirable, and criticized the use of these technologies to prevent the existence of people with disabilities. Their criticisms have, in many ways, been reflected by other factions of American society.

Voices of Dissent: Right to Life, Biological Determinism, and Other Criticisms of Genetic Counseling and Prenatal Testing.

Other perspectives on the new genetics aside from those of reproductive and disability rights activists have shaped public debates and the ways Americans conceive of

¹²³ Interview with GCS38I10, 5 August, 2010.

¹²⁴ Stern, *Telling Genes*, 94. Barbara Bowles Biesecker and Lori Hamby, “What Difference the Disability Community Arguments Should Make for the Delivery of Prenatal Genetic Information,” in *Prenatal Testing and Disability Rights*, eds. Erik Parens and Adrienne Asch (Washington: Georgetown University Press, 2000), 349.

prenatal testing and genetic technologies. Several groups have actively resisted genetic counseling and testing, often using a similar discourse of rights and freedoms, and sometimes in relation to an anti-eugenic framework. Perhaps the most ardent opponents of genetic reproductive technologies have been pro-life advocates whose argument, in its most basic form, runs that prenatal testing is undesirable because it leads towards abortion and the devaluation of human life. In many cases, it seems that genetic science has been delineated as anathema to religious values, a logic which, according to John H. Evans, follows several key discourses. Pro-life and religious opposition to reproductive genetic technologies revolves around the “embryonic life” discourse, which asserts that “life begins at conception” and that to destroy a life is morally indefensible; the “Promethean fatalism” discourse, which contends that God has a unique plan for an individual and that people should not interfere in these plans; the “meaningful suffering” discourse, which posits suffering as an experience rather than something to avoid or interfere with; and the “individual human dignity and equality” discourse, which asserts that all people deserve dignity because they were made in God’s own image.¹²⁵ In some ways, then, pro-life anxieties, particularly surrounding the devaluation of human life, overlap with disability rights discourses. They also signal a greater concern over “playing God” and human tampering with what they perceive as a human being’s right to life.

The political Right exhibited a complex and somewhat contradictory attitude towards genetic reproductive technologies in the late-twentieth century. In some cases,

¹²⁵ John H. Evans, *Contested Reproduction: Genetic Technologies, Religion, and Public Debate* (Chicago: University of Chicago Press, 2010), 9. Evans makes the point that religious communities do not oppose counseling whereby people are deciding to have a child, but just some of the means of avoiding having a child (42). See also Ted Peters, *Science, Theology, Ethics* (Burlington: Ashgate Publishing, 2003) Chapter 7: Genetics and Genethics: Are we Playing God with our Genes?, 139-163.

conservatives applauded the new genetics and especially the resurgence of genetic determinism since the 1970s. Much like conservative proponents of the old eugenics, they embraced hereditarian theories for laying one's expression of depression, alcoholism, intelligence, or criminality at the feet of genetics; the discovery of "genes for" various behaviours strengthened the "nature" perspective in the "nature/nurture" dichotomy and worked to uphold the status quo. Ruth Hubbard described the Right's celebration of genetic causation as a "backlash" against the hard-won victories of the Women's and Civil Rights movements, which stressed the role of environmental and social factors in moulding our lives and the people we become. She argued that, "Conservatives are quick to hail scientific discoveries that seem to show innate differences which they can use to explain the current social order," and take pressure off social reform initiatives.¹²⁶

At the same time, the Republican Party in the U.S. has often adhered to mainstream pro-life arguments and acted as one of the most tenacious critics of genetic research and technology. The party has rebuked many of the bedfellows of genetics such as germ line research and prenatal diagnosis, related as they are to abortion politics and arguments about the value of fetal life.¹²⁷ Republicans are not alone, however, as Democrats have also expressed skepticism about the ethics of embryo and stem cell research. The U.S. Congress issued a ban on federal funding for research on human embryos in 1974 for fear it would lead more women to choose abortion. The Clinton administration lifted parts of the ban in 1993 to allow for research on embryos that had been part of *in vitro*

¹²⁶ Ruth Hubbard quoted in Jeremy Rifkin, *The Biotech Century*, 156. See also Nelkin and Lindee, *The DNA Mystique*, 129.

¹²⁷ Dorothy C. Wertz, "Embryo and Stem Cell Research in the United States: History and Politics," *Gene Therapy* 9, no. 11 (2002), 674-678. Both Wertz and John H. Evans make the case that in the U.S., discourses surrounding abortion and genetic politics overlap considerably.

fertilization, and the Bush administration allowed funding for existing cell lines.¹²⁸ Overall, however, Congressional policies towards stem cell research in particular were more restrictive than permissive and greatly hindered research.

Genetic reproductive technologies of the late-twentieth century also sparked criticism from scholars and activists worried about a new eugenics. Academics like Abby Lippman, Dorothy Nelkin, Ruth Hubbard, Troy Duster, and others have been distrustful of genetic testing and counseling as a revival of biological determinism and scientific racism. They were particularly worried about the potential coercion involved in the routinization of reproductive technologies.¹²⁹ Duster's *Backdoor to Eugenics* (2003) explored the potentially-detrimental socio-political implications of the seductive "sirens' call" of genetics and hereditarianism. He cited genetic screening programs and national newborn registries as examples of how we are once again coming to view a range of human behaviours and traits through "the prism of heritability," and letting eugenics in "by the back door" through a renewed faith in biological essentialism.¹³⁰ Activist, economist, and president of the Foundation on Economic Trends Jeremy Rifkin articulated a similar perspective and urged caution in our transition into what he called the "biotech century." Rifkin, who has written prolifically on the impact of science and technology on the environment, society and labour, was one of the first critics of the

¹²⁸ Ibid.

¹²⁹ Lippman, "Prenatal Genetic Testing and Screening," 15-50; Nelkin and Lindee, *The DNA Mystique*; Hubbard, *Exploding the Gene Myth*; Duster, *Backdoor to Eugenics*.

¹³⁰ Duster, *Backdoor to Eugenics*, 4-5, 114. In chapter 7, "Eugenics by the back door," Duster explains that Hitler's *Lebensborn* project has closed the front door to eugenics, but that hereditarianism and new genetic technologies have provided a "halo of legitimacy" to genetic explanations of the human experience (114-115).

burgeoning biotechnology industry in his 1977 work *Who Should Play God?*¹³¹ Over twenty years later, in his 1998 book *The Biotech Century*, Rifkin concluded that,

The new genetic engineering tools are, by definition, eugenic instruments. Whenever recombinant DNA, cell fusion, and other related techniques are used to ‘improve’ the genetic blueprint of a microbe, plant, or human being, a eugenics consideration is built into the process itself...The new eugenics is coming to us not as a sinister plot, but rather as a social and economic boon. Still, try as we will, there is simply no way to get around the fact that the fledgling commercial effort to redesign the genetic blueprints of life on Earth is bringing us to the threshold of a new eugenics century.¹³²

Fears of a new eugenics voiced by Rifkin and others mirror the concerns of reproductive and disability rights advocates. They also circulated widely in science reporting on genetics featured in the American print media, as discussed in the next chapter.

Genetic counselors have been forced to address concerns about issues related to a new eugenics, including fears of coerced abortions for fetal indications, the creation of designer babies, and even human cloning. One counselor relayed that, “Whenever I was flying somewhere, I’d always sit next to the person who says, ‘What do you do?’ and I’d say, ‘I’m a genetic counselor’. And I would get one of two responses: ‘Oh, so you tell people whether they can have children’ or ‘Oh, so you clone people.’”¹³³ Interestingly, these concerns have rarely been explicitly articulated by patients, who seemed most interested in their personal counseling session. One counselor explained that most people who came to see them were there for very serious concerns, that “they have a child with muscular dystrophy or they have a parent who died of a neurological condition that seems

¹³¹ Ted Howard and Jeremy Rifkin, *Who Should Play God?: The Artificial Creation of Life and What it Means for the Future of the Human Race* (New York: Dell Publishing, 1977) and Rifkin, *The Biotech Century*.

¹³² Rifkin, *The Biotech Century*, 128.

¹³³ Interview with GCS26I15, 12 August, 2010.

to be inherited...Those are very serious issues. We're not talking about trying to make a blond-haired, blue-eyed kid with musical talent who will be the next Taylor Swift."¹³⁴

Genetic counselors have, in many ways, been positioned at the intersection of personal and public debates over the rights and responsibilities of American citizens. The duties and privileges of the new genetics negotiated in the private, individual encounters between counselor and patient had, by the 1960s, entered public deliberations on the promises and perils of genetic reproductive technologies as forwarded by reproductive rights activists, disability rights advocates, and others. Though perspectives certainly differed on the value of genetic counseling, testing, prenatal diagnostic services, and abortion, the discourses used by counselors, patients, and activists consistently revolved around several key principles. These principles included freedom of choice, informed decision-making, the preservation of autonomy and respect, and (usually) a rejection of eugenics and biological determinism. In many cases, they also refuted the commercialization and commodification of parenthood and reproduction, and the medicalization or geneticization of embodied differences.

Skepticism about, or even outright condemnation of, genetic science is quite understandable. Indeed, the very language of genetic citizenship raises real concerns. It was less than a century ago that eugenicists, guided by an unwavering faith in the inheritance of diseases and “undesirable traits,” suppressed the reproductive rights of individuals like Carrie Buck, an alleged “moron.” Buck’s trial and subsequent sterilization became famous through the 1927 Supreme Court decision of *Buck v. Bell*. In

¹³⁴ Interview with GCS49I18, 20 September, 2010.

this case, Judge Oliver Wendell Holmes delineated what he felt was the court's responsibility to posterity, declaring upon sentencing that "Three generations of imbeciles are enough."¹³⁵ Twenty-two years earlier, in 1905, President Theodore Roosevelt demonstrated the countervailing aspect of the nation's eugenic program by imploring "fit" American women to fulfil their reproductive responsibilities and thwart "race suicide" through the production of Americans of "good stock."¹³⁶

Genetic counselors have been involved in public debates throughout the late-twentieth century as intermediaries between public and private interpretations of genetic knowledge, and as brokers of a new social contract between Americans and an increasingly geneticized society. Their educational backgrounds in biological sciences and medical genetics; professional ethics of non-directiveness and client-centeredness; personal backgrounds in feminism and pro-choice politics; and growing involvement with the disability community means that counselors have, and will continue to, act as important interpreters of the new genetics. Perhaps genetic counselors' greatest asset will be their profession's own eugenic origins. This legacy, of which they have been ever-mindful, is invaluable to patient encounters but also larger social, political, and legal considerations of the meanings of the genetic revolution.

¹³⁵ Kevles, *In the Name of Eugenics*, 110-111.

¹³⁶ Theodore Roosevelt, "On Motherhood," March 13, 1905. Accessed 12 May, 2013, <http://www.nationalcenter.org/TRooseveltMotherhood.html>

Chapter 6: Lost in Transcription: Debating Genethics at The Hastings Center and in the American Print Media, 1960-2000.

On December 15, 1976, Tabitha Powledge, a member of bioethical institute The Hastings Center (HC), sent a proposal to the March of Dimes requesting funding for a workshop specifically targeting science journalists. The proposal outlined the workshop's purpose, stating,

'Bioethics' has become the umbrella term for a heterogeneous set of public and private issues growing out of modern research in the life sciences. The development of machines that make possible maintenance of some life functions indefinitely, the invention of a new technique for examining the genetic makeup of a 16-week old fetus...have been hailed as ways of improving the human condition, and all have created novel and complex moral and social problems...It is thus crucial that such issues be well understood by the public and its representatives, but often they are not, because the press is largely uninformed about the nature of the issues and cannot transmit accurate information about them.¹

Bioethicists' concerns with public perceptions and understandings of genetics were certainly reasonable. Over the last five decades, the American public encountered medical genetics through state-mandated screening programs for Tay-Sachs, phenylketonuria (PKU), and sickle cell anemia. The birth of Louise Brown, the first test-tube baby, in 1978 and the development of chorionic villus sampling (CVS), alpha-fetoprotein (AFP) screens, and ultrasounds by the 1980s all accelerated public interest. In the 1990s, Americans were increasingly familiar with terms like gene therapy and stem cell research,

¹ "A Proposal to the John and Mary R. Markle Foundation from the Institute of Society, Ethics and the Life Sciences: Bioethics Workshops for Journalists," 1976, Hastings Center, 1975-1986, Bioethics Advisory Committee Records, 1951-2005, Box 7, Series 2: Individuals and Organizations, March of Dimes Archives (hereafter MOD), White Plains, NY; Tammy Powledge to Mr. Albert Rosenfeld, The National Foundation-March of Dimes, 15 December, 1976, Hastings Center, 1975-1986, Bioethics Advisory Committee Records, 1951-2005, Box 7, Series 2: Individuals and Organizations, MOD.

while the prospect of cloning was thrust into the public consciousness by the infamous sheep named Dolly.

Both bioethical institutions like The Hastings Center and the American print media have been important forums for public discussions about genetic counseling, testing, and reproductive technologies. The interventions of these groups have, however, been quite different. On the whole, bioethicists have cautiously considered the ethical implications of the new genetics, and the reproductive and disability rights discourses highlighted in the previous chapter. In contrast, most print journalism has largely resorted to unbalanced and oversimplified science narratives. The Hastings Center proposal to engage with journalists exposed, then, a central problem of the new genetic citizenship. Genetic citizens are living in an age of rapid technological advancement and intense bioethical scrutiny. The everyday person is, however, increasingly distanced from this scientific enterprise on account of its overwhelming complexity. This lack of personal connection to genetic research means that the genetic literacy of the average American depends on often ill-informed media interpretations, rather than thoughtful and nuanced bioethical discussions.²

My analysis of the bioethical debates and media coverage surrounding genetic counseling, testing and reproductive technologies is informed by the feminist and disability scholarship and debates outlined in the previous chapter. Recent scholarship by Ruth Bailey, Jackie Leach Scully, and Susan Wendell demonstrated an interest in the

² The alienation of the public from the “scientific enterprise” is discussed by Dorothy Nelkin in “Selling Science,” *Physics Today* 41, 1 (1990), 41. Nelkin also discussed the ways in which scientists and the press cultivate the “mystique of science” as a “superior culture” beyond the grasp of everyday people in *Selling Science: How the Press Covers Science and Technology* (New York: W.H. Freeman and Co., 1987), 14.

intersections between feminism, disability, and bioethics similar to that of Hastings Center members. Scully's *Disability Bioethics* (2008) and Wendell's *The Rejected Body* (1996) in particular explored sites of potential interaction between feminist and disability epistemologies and experiences. These encounters were based on mutual concerns with respect and autonomy, the "effects of social categorization," and criticisms of power relationships based on bodily difference.³ Alexandra Minna Stern touched on ethics at The Hastings Center in *Telling Genes* (2012). She examined the efforts of Hastings Center member Marc Lappé to ensure that genetic counseling "embrace a situational ethics undergirded by human caring and empathy" and a commitment to autonomy.⁴ I expand upon Stern's work by moving beyond genetic counseling to larger ethical questions posed by genetic reproductive technologies, and by layering on archival evidence from The Hastings Center and the March of Dimes. Finally, a discussion of the public veneer of science is necessarily predicated on Dorothy Nelkin's *Selling Science* (1987), which investigated the relationship between scientists, science reporting, and the American public. I also draw on Dorothy Nelkin and M. Susan Lindee's *The DNA Mystique* (2004), which explored cultural appropriations of the gene in an age of renewed genetic essentialism.⁵

This chapter explores bioethical discussions at The Hastings Center and in the mainstream American print media about genetic counseling, genetic testing, and

³ Ruth Bailey, "Prenatal Testing and the Prevention of Impairment: A Woman's Right to Choose?" in *Encounters with Strangers: Feminism and Disability*, Jenny Morris, ed. (London: Women's Press, 1996), 163-165. Scully, *Disability Bioethics*, 36-37; Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), Chapter 6: Disability and Feminist Ethics, 139-163.

⁴ Stern, *Telling Genes*, 124.

⁵Nelkin, *Selling Science*; Nelkin and Lindee, *The DNA Mystique*.

reproductive technologies. I emphasize the roles of genetic counselors in these debates but draw our attention outward to more public, widespread considerations of the ethics of the new genetics, or what David Suzuki and Peter Knudtson called “genethics.” Genethics is a “recombinant’ word that splices the words ‘genetics’ and ‘ethics’ together to capture their conceptual inseparability.”⁶ I suggest that bioethicists often used a similar discourse of rights and responsibilities, as well as expectations of autonomy, voiced by feminist and disability advocates when discussing maternal versus fetal rights, prenatal diagnosis, and genetic testing. Bioethicists also situated these topics against concerns about eugenic coercion. The American print media was an important contributor to public discussions about these topics as articles on genetics appeared frequently in *Time* and *Scientific American* magazines, and in newspapers such as the *New York Times* and the *Washington Post* between 1960 and 2000.⁷

I locate a profound disconnect within public discussions of genetic reproductive technologies. The rich ethical discourses that circulated amongst bioethicists, activists, genetic counselors, and academics at The Hastings Center contrast quite sharply with the ways in which the new genetics was portrayed in the media. Indeed, despite the existence

⁶ David Suzuki and Peter Knudtson, *Genethics: The Clash Between the New Genetics and Human Values*, 2nd ed. (Cambridge: Harvard University Press, 1990), preface.

⁷ The newspaper articles I analyzed were obtained through the Proquest Historical Newspapers (1851-2009) online database through the McMaster University library. My analysis is primarily drawn from my initial search. I searched articles and editorials in the *New York Times* and *Washington Post* using the keywords “genetic counseling.” I analyzed the 323 results for repeated tropes and imagery; key figures in genetics and genetic counseling; underlying assumptions; and overall perspectives on the new genetics. I then performed related searches using the terms “genetic testing,” “genetic reproductive technology,” and “human cloning.” I scanned results for articles dealing specifically with human genetics or medicine for further analysis based on the aforementioned criteria. I obtained an online subscription to *Time* magazine where I confined my search terms to “genetics” and “genetic counseling” between January 1st 1960 and the present. I searched “genetics” in the *Scientific American* online database, where I was able to view articles between 1993 and 2000.

of sophisticated bioethical debates, media reports followed a few well-trodden narratives. In many cases, these scripts either exalted genetic discoveries or advanced science-fiction scenarios. Science reporters occasionally interviewed HC fellows, but the overlap between these two locations is most evident in concerns about a new eugenics voiced by both reporters and Hastings Center bioethicists. One particularly troubling aspect of the mainstream print media coverage of the genetic revolution is that it seldom addressed women's experiences with reproductive genetic technologies. This lacunae becomes more obvious when compared to the strong presence of woman-centered analyses of reproductive technologies found in Hastings Center debates and other bioethical literatures.⁸

Historical context for debates about the new genetics helps us to better grasp the social circumstances in which genetic counselors have practiced. Moreover, it elucidates how private biomedical matters have become highly-contested public terrain, and highlights how the politicization and popularisation of science has conditioned the contexts in which women exercise reproductive choice. Finally, I suggest that media over-simplifications of the new genetics have been harmful by washing over important nuances and perspectives that must circulate publicly so that genetic citizens can participate in their new social contract informed of both the promises and perils of genetic reproductive technologies. As biologist and feminist Ruth Hubbard has articulated, “A

⁸ By “woman-centered,” I mean analyses concerned with the rights of women, or the impact of reproductive technologies on women and the experience of motherhood, and especially from the perspectives of women themselves. A “disability-centered” perspective might also be seen as neglected in popular reporting on genetic reproductive technologies. Many of the concerns of disability advocates have, however, been addressed through larger issues of the new eugenics, and occasionally in articles on genetics and prenatal technologies from a pro-life angle.

revolution is happening in the biosciences...It is crucial that we, as citizens, not leave this process in the hands of ‘experts’...We cannot just sit by as passive worshippers or victims.”⁹

The Hastings Center: Bioethical Encounters with Reproductive Rights, Disability Activism, and the New Genetics.

The Nuremberg Trials and subsequent Nuremberg Code led to a profound engagement with bioethics amongst researchers and scientists in the U.S. In fact, bioethics surfaced as a distinct academic discipline in the post-WWII period. The field solidified and institutionalized the core bioethical principles of autonomy, self-determination, and justice in the 1960s with the emergence of movements for reproductive, disability, and civil rights.¹⁰ The first major commitment to bioethics was the U.S. Public Health Service’s 1960 endowment of \$97,000 to Boston University’s Law-Medicine Research Institute to investigate potential ethical issues of research with human subjects. Public awareness of bioethical issues was further heightened in 1972 with news of the Tuskegee experiments in which the same U.S. Public Health Service had attempted to study the effects of syphilis on mostly black men by withholding treatment for the disease.¹¹

On July 12, 1974, President Richard Nixon signed the National Research Act into public law, which formed the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, partially in response to the Tuskegee project.

⁹ Ruth Hubbard has provided a “survival handbook” on navigating the new “genomania” in *Exploding the Gene Myth*, xiii-xiv.

¹⁰ Albert R. Jonsen, *A Short History of Medical Ethics* (New York: Oxford University Press, 2000), 116.

¹¹ Jonsen, *The Birth of Bioethics*, 142, 147.

The Commission was charged with studying and evaluating the ethical standards that guide human medical experimentation, and was the first national body to delineate bioethical policies in the U.S. Other significant national attempts to govern bioethics include the 1978 Department of Health, Education and Welfare Ethics Advisory Board, and the 1980 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.¹²

Despite the federal government's interest in enacting general bioethics guidelines, the U.S. has lacked a comprehensive system for regulating genetic technologies specifically. The National Genetic Diseases Act of 1976, the Genetic Information Nondiscrimination Act of 2008, the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008, and bans on embryo research represent the federal government's major attempts at interference in genetics. The regulation of genetic technologies has been largely abandoned to a variety of state guidelines, organizations like the FDA or Centers for Disease Control, and the self-governance of genetics professionals.¹³ The work of independent bioethical institutes has therefore been crucial to a geneticized society. In an age of increasing geneticization, we have access to vast amounts of genetic knowledge hindered only by disparate and sometimes unclear guidelines as to the ethical uses of gene research.

¹² Ibid., 99, 106-107.

¹³ "Reproductive Genetic Testing: A Regulatory Patchwork," Genetics and Public Policy Center, accessed 25 April, 2013, http://www.dnapolicy.org/policy.international.php?action=detail&laws_id=63. See also Rachel Rebouché and Karen Rothenberg, "Mixed Messages: The Intersection of Prenatal Genetic Testing and Abortion," *Howard Law Journal* 55, no. 3 (2012), 983-1023. Mass screening programs for PKU are a good example of state jurisdiction over genetics regulations. See Philip Reilly, *Genetics, Law, and Society*. One of the most famous examples of professional self-regulation was the 1975 Asilomar conference on recombinant DNA where scientists debated research ethics amongst themselves.

The Hastings Center, also originally known as The Institute of Society, Ethics and Life Sciences, was founded in 1969 by philosopher Daniel Callahan and psychiatrist Willard Gaylin. The Center was established as a non-profit, non-partisan research organization in New York State. The HC received financial assistance from John D. Rockefeller III, and benefitted from the increased federal backing and popularization of bioethics in the U.S.¹⁴ The Institute's primary purpose was to "address fundamental ethical issues in the areas of health, medicine, and the environment as they affect individuals, communities and societies."¹⁵ Since the late-1960s, HC projects explored various themes including end of life decisions and public health initiatives. Reproductive rights and disability discourses on the new genetics intersected in multiple, meaningful ways at the Center. HC fellows focused intently on genetics and reproductive biology, their implications in both theory and practice, and how the work of the Center could reinforce the ethical dimensions of policy makers' work.¹⁶

The think tank's staff has been composed of interdisciplinary scholars including philosophers, theologians, political scientists, sociologists, lawyers, and medical professionals. Some of the major Hastings Center members involved in projects related to genetic reproductive technologies includes Daniel Callahan, who holds a PhD in Philosophy from Harvard. Erik Parens and Adrienne Asch, who focused specifically on the politics of reproduction and a disability critique of prenatal testing, also contributed to HC projects. Others involved with the Center's initiatives include sociologist Charles

¹⁴ Daniel Callahan, "The Hastings Center and the Early Years of Bioethics," *Kennedy Institute of Ethics Journal* 9, no. 1 (1999), 55-56. See also Jonsen, *The Birth of Bioethics*, 20-22.

¹⁵ "Our Mission," The Hastings Center, accessed 25 April, 2013, <http://www.thehastingscenter.org/About/Default.aspx>

¹⁶ Callahan, "The Hastings Center," 60, 63.

Bosk, who studied genetic counseling in a pediatric hospital, and Alexander Capron, LLB, who has written extensively on the ethics of genetic counseling. Jessica Davis, MD, who was influential in creating the first counseling program at Sarah Lawrence, and Alan R. Fleischman of the March of Dimes also worked at the bioethical institute.¹⁷

In most cases, Hastings members were less concerned with establishing a firm position on a given bioethical topic than with fostering a thorough and conscientious debate from which to make policy recommendations.¹⁸ Hastings scholars worked on diverse topics related to the new genetics including prenatal preventive measures, genetic screening, gene therapy, and the value of amniocentesis and CVS. Other topics included the implications of the Human Genome Project, alongside concepts of personhood, fetal rights, fetal surgery, abortion, embryo transfers, surrogate motherhood, disability and impairment, and the future of genetics research.¹⁹ Almost since the beginning, the Center's membership has questioned the duties and privileges of genetic citizens. They have explored our obligations to future generations, and individual and societal responsibilities in medical care. They have also debated conflicts in rights, particularly fetal rights and women's rights vis-à-vis abortion.²⁰

One of the earliest Hastings Center committees was the working group on prenatal diagnosis. The group's meetings led to the 1978 publication of "Ethical, Social, and Legal

¹⁷ "Hastings Center Fellows," The Hastings Center, accessed 23 April, 2012, <http://www.thehastingscenter.org/About/Default.aspx?id=902>

¹⁸ Gene I. Maeroff, "The Hastings Center: A Cool Look at Hot Issues," Hastings Center, 1975-1986, Bioethics Advisory Committee Records, 1951-2005, Box 7, Series 2: Individuals and Organizations, MOD.

¹⁹ "Final Draft, April 1978, 'Ethical, Social and Legal Issues in Prenatal Diagnosis,'" Prenatal Diagnosis 1976-78, Box 22, Hastings Center Records 1964-2003, ACC 2006-020 (hereafter HC), National Library of Medicine, Bethesda, Maryland.

²⁰ "General Meeting, Institute of Society, Ethics, and the Life Sciences" pamphlet, General Meeting, June 18-19, 1976, Box 106, HC; See also Daniel Callahan, "What Obligation Do We Have To Future Generations?" *American Ecclesiastical Review* 164 (1971), 165-80.

Issues in Prenatal Diagnosis.”²¹ This document was intended “to propose guidelines for the development and institutionalization of prenatal diagnostic progress and to help workers in this area provide the most favorable circumstances for thoughtful, informed, morally responsible decision-making by parents.”²² In tune with reproductive rights critiques, the group provided critical assessments of procedures like ultrasounds and amniocentesis, and established criteria that responsible prenatal screening initiatives ought to meet. These guidelines suggested that screening programs “should be designed to reach well-defined groups of pregnant women known to be at risk”; that parents should be provided with counseling services before and after the procedures; that patients’ confidentiality should be insured; and that all possible choices are outlined for patients. The prenatal diagnosis working group asserted that, “these guidelines were developed in a moral framework favoring the protection of individual choice and protecting the autonomy of parents, even when we disagree with their course of action.”²³ The Hastings Center indicated that reproductive and disability issues were central to their agenda almost from the start by focusing on the ethics of prenatal diagnosis. This emphasis also highlighted key themes in the history of bioethics related to the new genetics including concepts of risk, autonomy in reproductive decision-making, and the vital role of genetic counselors at the center of those discussions.

²¹ The results of this report were later published as: Tabitha M. Poweldge and John Fletcher, “Guidelines for the Ethical, Social, and Legal Issues in Prenatal Diagnosis- A Report from the Genetics Research Group at the Hastings Center, Institute for Society, Ethics and the Life Sciences,” *New England Journal of Medicine* 300, no.4 (1979), 169-172.

²² “Final Draft, April 1978,” HC.

²³ Ibid.

The Bioethics Advisory Committee (BAC) demonstrates the centrality of reproductive rights to The Hastings Center's agenda, and the place of feminist and disability discourses in that agenda. The BAC was a March of Dimes committee to which Daniel Callahan and other HC members contributed.²⁴ The group met approximately three times a year in White Plains, N.Y. throughout the 1980s. Each time, women's reproductive rights were central to the program. At these meetings, the links between genetics, prenatal testing, and women's rights were often discussed from a woman-centered perspective. On May 5, 1989, the Committee took abortion as their first topic of discussion due to the controversy surrounding the 1986 Missouri Supreme Court case of *William L. Webster v. Reproductive Health Services*. The ruling forbade abortions by doctors working in hospitals receiving state funding and, more broadly, required "that all state laws be interpreted to provide unborn children with the same rights enjoyed by other persons."²⁵ The group explored difficult ethical dilemmas including the inequity in access to abortion amongst middle versus lower class women. They also examined how this new law would complicate decisions for women and the professional practices of genetic counselors in facilitating reproductive choices.

The BAC discussed places where feminist activism and disability rights discourses overlapped and potentially conflicted in emerging debates about women's rights and fetal

²⁴ There is a great deal of overlap between the members of The Hastings Center and the March of Dimes. The March of Dimes often also funded HC projects. The records of the March of Dimes include several grant requests from the Hastings Center, most written by Daniel Callahan. Generally, the MOD tried to finance the work of the HC whenever possible and held the Institute in high regard. See, for example, Albert Rosenfeld to Mr. Charles L. Massey, 23 May, 1985, Hastings Center 1975-1986, Bioethics Advisory Committee 1951-2005, Box 7, Series 2: Individuals and Organizations, MOD.

²⁵ *Webster v. Reproductive Health Services*, 492 U.S. 490, Decided July 3, 1989, Legal Information Institute, Cornell University Law School, accessed 25 April, 2013, http://www.law.cornell.edu/supct/html/historics/USSC_CR_0492_0490_ZS.html

rights. The concept of fetal rights has invoked a variety of meanings. Former president of the American Association for the Advancement of Science Bentley Glass articulated what he called a fetal rights perspective in 1971. He suggested that it is the “right of every child to be born with a sound physical and mental constitution” and that in the future, no parents will “have the right to burden society with a malformed or a mentally incompetent child.”²⁶ Former Dight Institute director Clarence P. Oliver expressed a similar sentiment in 1952, arguing that while parents must make their own reproductive decisions, “I believe it is unfair to a child to start him out in life with a handicap to compete in our society.”²⁷ For Oliver and Glass, then, fetal rights entailed the right of the fetus to be born free of hereditary disease or disability. Respecting these rights meant avoiding the birth of a “damaged” fetus.

The Bioethics Advisory Committee discussed a different concept of fetal rights: the protection of fetal life at all costs. This is perhaps a more familiar version of fetal rights whereby the fetus has the right to be born, the right to life. The BAC asked if,

with fetal rights making such headway as an issue, might we see a day when prenatal therapy might help a fetus survive, and the parents may be forced to request or at least accept the therapy? Or even be prosecuted, or sued, for not taking the steps to detect the abnormality (if it was suspected) and thus deny therapy to the fetus? Major threats to the rights of women were seen in all the new language about the status of the fetus. As the fetus gains its personhood, someone commented, the woman seems to be losing hers.²⁸

The concept of fetal rights addressed by the BAC, broadly conceived as the right to be born, might reinforce a disability rights agenda. Indeed, a concept of fetal personhood

²⁶ Ruth Hubbard quoted Bentley Glass in *The Politics of Women's Biology*, 171.

²⁷ Lee R. Dice, “A Panel Discussion: Genetic Counseling,” *American Journal of Human Genetics* 4, no. 4 (December 1952), 341.

²⁸ “Bioethics Advisory Committee Meeting,” 5 May, 1989, March of Dimes-Bioethics Advisory Committee 1983-89, Box 17, HC.

seems to find commonalities with a disability critique by supporting the coming into being of all babies, including those with birth defects. At the same time, the potentially forced usage of prenatal therapies contravenes disability perspectives by demarcating disability as a problem, as something to be avoided. The implications for reproductive rights activism are perhaps more easily summarized: as Ruth Hubbard has succinctly noted, “This language of ‘rights’ of the unborn immediately translates into obligations of the born, and especially of women.”²⁹

The conflict between the rights of women and the potential rights of her fetus resurfaced at several other Bioethics Advisory Committee meetings. This debate was often connected to discussions of the responsibilities of both mothers and healthcare professionals. The BAC kept a consistent eye on women’s right to reproductive autonomy. The Committee responded in a 1983 meeting to the case of a Baltimore physician who, through legal means, forced a pregnant woman to stop using drugs he believed would harm her unborn child; the group concluded that although his underlying concern might have some legal and moral merit, the consequences of these actions for women might be quite undesirable. One participant quoted from the *New York Times* in expressing to the group that, “What bothers me about this is that it could result in putting all pregnant women in a pen and force them to adhere to state standards of good prenatal care.”³⁰ Along these lines, the BAC also debated whether neonatal screening tests for conditions like PKU should be mandatory.

²⁹ Hubbard, *The Politics of Women’s Biology*, 172. See also Petchesky, *Abortion and Woman’s Choice*, Chapter 9: Morality and Personhood: A Feminist Perspective, 330-367.

³⁰ “Bioethics Advisory Committee Meeting,” 26 May, 1983, March of Dimes Bioethics Advisory Committee, 1983-1989, Box 17, HC.

At a 1988 meeting, the BAC again discussed the ways in which the rights of the “Mother vs. Fetus” are often situated in opposition to one another. This discussion was prompted by a recent case in Westchester County, NY where a pregnant woman who had previously abused her children was court-ordered to give up her most recent child. The BAC discussed the ways in which this situation could alternately be labelled a “fetal rights” case, or an “unfit mother” case.³¹ This woman’s rights as a mother were in jeopardy as a result of her failure live up to her duties to her unborn child. The group worried about the repercussions of this precedent, with one member commenting that, “Next think you know...they’ll be punishing women or taking their babies away because they fail to get adequate prenatal care.”³² Indeed, by labelling the relationship between a woman and her fetus as a “conflict of rights,” representatives of the medical profession and legal system had given themselves just cause for intervening in reproductive matters on behalf of the fetus.³³ In essence, members of the BAC were debating the fundamental crux of reproductive rights, and unconstitutional impositions on, and surveillance of, women as mothers.

The interaction between reproductive and disability discourses on rights and responsibilities in the new genetics is highlighted by the famous 1982 ethics case of Baby Doe, in which parents allowed their baby with Down Syndrome to die by withholding lifesaving treatment. Even before this landmark case, several committees and individuals

³¹ “Bioethics Advisory Committee Meeting,” 19 September, 1988, March of Dimes Bioethics Advisory Committee, 1983-1989, Box 17, HC; Hubbard, *The Politics of Women’s Biology*, 174.

³² *Ibid.*

³³ Hubbard, *The Politics of Women’s Biology*, 174. Cheryl Krasnick Warsh described how the creation of abortion laws helped institutionalize what she called “the doctor/child/mother triad” (*Prescribed Norms*, 157). This triad is clearly at work in other reproductive and genetic contexts.

at The Hastings Center debated the ethics surrounding the care of newborns. A 1979 book proposal sent from HC member Tabitha Powledge to the March of Dimes delineated the project's efforts to “formulate ideas about how parents ought to approach parenthood” and “how should citizens behave” vis-à-vis genetic reproductive technologies.³⁴ The group identified 5 major ethical questions related to the rights, risks, and responsibilities of the parent-child relationship:

- (1) Do parents have an obligation to insure the genetic health of their children?
- (2) Should parents have the freedom to choose that their children possess particular characteristics not necessarily related to health?
- (3) Is there a parental obligation to avoid voluntary (often pleasurable) behavior if it carries some increased risk to the fetus?
- (4) What is the parental obligation to avoid behavior that may improve a parent's life but carry increased risk for the fetus?
- (5) Should parents try to maximize the potential of each child?³⁵

A Health Policy Advisory Committee Bulletin from the late-1980s considered the Baby Doe case. The bulletin brought together disability and reproductive rights perspectives in a debate between sociologist Barbara Katz Rothman and HC fellow Adrienne Asch. A vociferous critic of selective abortion for fetal indications, Asch asserted that, “Each child - including a child with a disability - has a right to a fair chance at life. If a parent's failure to provide medical treatment denies this right, it is the responsibility of the state to interfere to protect the child.” She maintained that life with a disability can be fulfilling, and that it could be even more so if there were changes in

³⁴ “Parental Obligation to the Fetus and Newborn,” Hastings Center 1975-1986, Series 2: Individuals and Organizations, Box 7, MOD. Underlines in original.

³⁵ *Ibid.*

social attitudes towards the value of people with disabilities.³⁶ Rothman countered, however, that, “No one cares more about a baby than the baby’s parents. It is the parents, therefore, that should have the right to evaluate and choose those services, medical or other, which they consider to be the most appropriate for their newborn.” Rothman saw the treatment of imperiled infants less as a disability rights question, and more as a quality-of-life decision that should be made by parents. A baby’s family, she judged, are in the best position to speak for their child and whether this child should live as someone with a disability.³⁷

The HC, particularly members working on issues related to newborns, continued to address the ethical issues of Baby Doe cases throughout the late 1980s. In a paper titled “Who Should Decide?” from 1986, Hastings members discussed the constitutional rights endowed upon parents for making decisions about their own children. They recognized, however, that these rights could be infringed upon by physicians and overruled by the state.³⁸ The group also considered government responsibility towards children with disabilities, and described that, “Difficulties surface when special obligations are alleged for children with impairments. How much further assistance should society furnish them and those who care for them?”³⁹ Other committees debated the ethics surrounding the

³⁶ “On the Question of Baby Doe,” *Health Policy Advisory Committee Bulletin* 16, no. 6 (1986) on Women’s Health Issues, 6, Newborns – Publications, 1986, Box 156, HC. Asch has famously upheld the right of women to choose to abort any pregnancy but criticized women who considered aborting an otherwise wanted baby only after receiving genetic testing results denoting fetal indications. See Adrienne Asch, “Why I Haven’t Changed My Mind About Prenatal Diagnosis: Reflections and Refinements,” in *Prenatal Testing and Disability Rights*, eds. Erik Parens and Adrienne Asch (Washington: Georgetown University Press, 2000), 234-258.

³⁷ “On the Question of Baby Doe,” 7.

³⁸ “Who Should Decide?” Newborns Section IV: Who Should Decide, 1986, Box 156, HC.

³⁹ “How Much Care Should Society Provide for Disabled and Handicapped Children?” Newborns Section VI: How Much Care Should Society Provide for Disabled and Handicapped Children? N.D., Box 156, HC.

care of newborns including issues of prevention versus rescue, and the problem that “American society emphasizes rescue over prevention.” Hastings members also considered whether healthcare costs should bear on decisions to keep alive severely handicapped children. Other topics included how to determine a course of action that is in the best interest of the infant, and what counts as a “handicap.”⁴⁰

The Hastings Center demonstrated a profound awareness of the lasting legacy of eugenics and the obligations of scientists to act ethically in the age of the new genetics. In one of his lectures, Daniel Callahan questioned, “The scientific community has been well-prepared to take responsibility (and credit) for the benefits it bestows...But to what extent should it be prepared to take equal responsibility (and blame) for the harm it can and does produce?” He suggested that while there may not be a direct causal linkage between famed geneticist Gregor Mendel and the Nazi eugenic program, there remains a “historical principle” for scientists to act in a morally responsible way.⁴¹ Hastings members also discussed the perils in sex determination and selecting for the “perfect baby,” and the dangers of what Troy Duster might call a “backdoor to eugenics,” saying, “We believe that the major advances in developing new genetic diagnostic capabilities lies less in the potential for some single, horrible abuse than in the subtle acquiescence of intolerance.”⁴²

⁴⁰ “Ethics and the Care of Imperiled Newborns,” May 1987, Newborns 1987, Box 105, HC; “Caring for the Newborn: Prevention vs. Rescue,” February 1984, Newborn-Neonates: Correspondence, 1983-84, Box 105, HC; “Ethics and the Care of Newborns: Critique of Reasons for Non-Treatment,” May/June 1984, Newborn-Neonates: Correspondence, 1983-84, Box 105, HC.

⁴¹ Daniel Callahan, “Ethical Responsibility in Science in the Face of Uncertain Consequences,” Dan’s Lectures 1975, Box 33, HC.

⁴² “Ethics and Human Molecular Genetics: Setting an Agenda for the Evaluation of New Diagnostic Applications,” Ethics and Human Molecular Genetics: Setting an Agenda, n.d., Box 113, HC.

A 1974 memo directly connected these concerns to genetic counseling and its role in the new genetic citizenship by demanding a consideration of “To what extent, if any, should the genetic counsellor be guided by social eugenic considerations in counseling,” and “To what extent, if any, should the genetic counselor attempt to determine for his clients those factors which he deems morally relevant to their reproductive decision-making and behavior.”⁴³ Marc Lappé posed a similar question in 1973 when he considered to whom the genetic counselor was responsible. He remarked, “I think that genetic counselors may be misguided if they feel that their ethical obligation is in *any way* to future generations.”⁴⁴ The implication here is that genetic counselors have a professional duty to concern themselves with client autonomy. These questions were then connected to larger issues of the obligations of society to individuals, individuals to society, and counselors to both their patients and posterity.⁴⁵

The Hastings Center is an important window into the complex overlay of reproductive rights, disability advocacy, and perhaps also pro-life perspectives throughout the late-twentieth century. Bioethicists’ concerns with a multitude of competing rights, risks, and responsibilities facing genetic citizens, however, often failed to translate in the American print media.

⁴³ Sumner Twiss, untitled document on genetic counseling, 20 April, 1974, Genetics Core Group - 1975 Meetings, 1975, Box 106, HC.

⁴⁴ Stern, *Telling Genes*, 124. Italics in original. See Lappé et al., “The Genetic Counselor: Responsible to Whom?” *The Hastings Center Report* 1, no. 2 (1971), 6-11.

⁴⁵ Twiss, 20 April, 1974, HC.

The Power of the Press: Scientific Reporting and Media Coverage of Genetic Counseling, Genetic Testing, and Prenatal Testing.

The mainstream American print media was a significant participant in public conversations about genetic counseling, testing, and reproductive technologies between 1960 and 2000.⁴⁶ Media reports often failed to reflect the complexity of discussions occurring at bioethical institutes like The Hastings Center, but nevertheless reached a broader audience. As sociologist Dorothy Nelkin suggested, “For most people, the reality of science is what they read in the press. They understand science less through direct experience or past education than through the filter of journalistic language and imagery.”⁴⁷ Indeed, a Harris Poll from 1993 reported that 40 percent of American adults had “more than a passive involvement” in keeping abreast of newsworthy science stories.⁴⁸ Since the 1980s, the popular American print media has devoted increasing attention and space to science. Particularly prominent were stories related to biomedicine generally, and genetics and reproductive technologies specifically. By 1987, eighteen daily newspapers featuring weekly sections on science topics had a collective circulation of 7 million. The influential news magazine *Time* had a weekly circulation of 4.7 million, while the *New York Times* and the *Washington Post* had a circulation of over 700,000. These newspapers and news magazines are significant touchstones for other reporters, government officials and television coverage, setting an industry standard for what

⁴⁶ For a thorough discussion of public debates about genetics and hereditarianism throughout the twentieth century, see Celeste Michelle Condit’s *The Meanings of the Gene: Public Debates about Human Heredity* (Madison: University of Wisconsin Press, 1999). A professor of speech communication, Condit explored the “rhetorical formations” that framed understandings of heredity including stock breeding, genetic code, and blueprint metaphors since the rediscovery of Mendel’s laws in 1900.

⁴⁷ Nelkin, *Selling Science*, 2.

⁴⁸ Dorothy Nelkin, *Selling Science: How the Press Covers Science and Technology*, Rev. ed. (New York: W.H. Freeman and Co., 1995), 68.

qualifies as important news in science and technology.⁴⁹ Significantly, these news outlets have the power to shape cultural meanings, practices, and interactions with genetic reproductive technologies. The news outlets make implicit (and sometimes, explicit) judgements about which stories to convey, and how to convey them, to an American public increasingly distanced from scientific research that affects them perhaps more than ever.⁵⁰

Discourses surrounding genetic counseling, testing, and prenatal diagnosis were often over-simplified in the American print media to follow a few familiar narratives despite the intricacies involved in bioethical debates on these topics.⁵¹ In his study of Anglo-American media coverage surrounding therapeutic cloning, Eric Jensen suggested that treatment of this subject area has revolved around “a dialectic of utopianism and dystopianism” at different times.⁵² Throughout the 1960s and 1970s, much of the media attention surrounding genetics and prenatal testing was a utopian celebration of genetics discoveries and the development of reproductive technologies. A 1969 article from the *New York Times (NYT)*, “Medicine: To Forecast Birth Defects,” admitted that there exists a lag between research and application, yet opened by discussing “Exciting advances made in the last few years in the prediction and detection of birth defects.” The article downplayed the risks of amniocentesis (to both the mother and fetus), and the only worry

⁴⁹ Nelkin, *Selling Science* (1987), 1-2, 8-9. Importantly, these publications do not represent, by any means, all media contributions to debates about genetic reproductive technologies. This study does not, for example, probe the coverage of genetics and associated technologies in African American or feminist newspapers and magazines. Such an analysis would certainly contribute additional dimensions to an exploration of the American media’s engagement with the new genetics and genetic counseling.

⁵⁰ *Ibid.*, 11.

⁵¹ For a thorough discussion of the media and other cultural representations of “the gene,” see Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique*.

⁵² Jensen, “Scientific Sensationalism in American and British Press Coverage,” *Journalism & Mass Communication Quarterly* 89, no. 1 (2012), 43.

discussed was that there simply would not be enough supply (ie. genetic counselors and testing programs) to meet the anticipated demand.⁵³ This theme was reflected in a 1971 *NYT* letter to the editor, amongst other articles, which proclaimed that, “New knowledge in medical genetics offers the opportunity to relieve our people of a great amount of suffering.” The author was concerned about ethical snags involved in the uses of genetic knowledge and technologies, particularly that not everyone will be able to take equal advantage. Nevertheless, American citizens were urged to support genetics researchers in their quest to eradicate increasingly-preventable diseases.⁵⁴

The wonders of amniocentesis and genetic counseling specifically were extolled in yet another *NYT* article from 1971, “Prenatal Diagnosis is Reducing the Risk of Birth Defects,” which discussed the “excellent results” stemming from the routinization of new technologies like amniocentesis and ultrasounds. The article did note that the long-term risks of the procedure had yet to be identified, and that sometimes a second amniotic tap was required due to diagnostic errors and the slow speed of fetal cell growth. The overall tone, however, was optimistic and focused on the benefits of amniocentesis for would-be mothers, with one woman describing amniocentesis as “truly a miracle...I never thought I could have normal, healthy children.”⁵⁵ Indeed, according to Celeste Michelle Condit, genetic counseling was also depicted in the popular press of the 1970s as a “productive practice” that, when coupled with amniocentesis, could ensure the birth of healthy

⁵³ Jane E. Brody, “Medicine: To Forecast Birth Defects,” *New York Times* (hereafter *NYT*), 25 May, 1969.

⁵⁴ Arthur G. Steinberg, “On the Use of Life Sciences,” *NYT*, 1 May, 1971.

⁵⁵ Jane E. Brody, “Prenatal Diagnosis is Reducing Risk of Birth Defects,” *NYT*, 3 June, 1971. See also “Genetic Counseling Making Strides,” *NYT*, 9 Aug, 1981.

children.⁵⁶ Reproductive genetic technologies were largely presented, and apparently received, as major scientific breakthroughs and something of a God-send.

In some cases, journalists throughout the 1960s and 70s described the successes and continued ventures in genetic science in terms of a sort of quest or as a new technological frontier to be conquered.⁵⁷ Alan Petersen explained that scientists are described as “involved in a quest to unlock nature’s secrets. Stories of hope, and depictions of geneticists as warriors or heroes, appear regularly.”⁵⁸ Indeed, cultivating the “mystique of science” and images of “the scientist as star” has worked to further the cultural gap between researchers and the public.⁵⁹ A 1974 article, “Will my Baby be Normal?” opened with the claim that, “Each day, roughly 700 sets of parents throughout the United States are cruelly reminded that medicine has not yet conquered genetic disease.” The very next paragraph, however, reassured readers that “the curse of genetic disease is slowly being lifted” by genetic counselors with the power to identify sixty genetic conditions in “carriers” and in the fetus. In a compelling and rather hopeful narrative of scientific progress, the article explained that as of ten years ago, “doctors faced the complexity of human deformity armed with little more than 19th century peas-and-flowers genetics.” By the 1970s, however, genetic counselors could “call upon a growing arsenal of

⁵⁶ Condit, *The Meanings of the Gene*, 127.

⁵⁷ Nelkin, *Selling Science* (1987), 34. Ruth Hubbard also described how the “reification and language of science” distances the public from scientific research and helps to uphold principles of objectivity (*The Politics of Women’s Biology*, 12-14).

⁵⁸ Alan Petersen, “Biofantasies : Genetics and Medicine in the Print News Media,” in *Social Science and Medicine* 52 (2001), 1255, 1267.

⁵⁹ Nelkin, *Selling Science* (1987), 14-15.

sophisticated tools to probe within the cell and even among the invisible genes themselves.”⁶⁰

The use of war or battle metaphors is instructive as it contributes to the image of the scientific struggle, but also seems to suggest that this is vital work that requires perseverance and, perhaps, even the occasional casualty.⁶¹ A narrative of progress was also evidenced in a 1968 *Time* article “Chances of a Defective Child.” The article opened by lamenting that until now, parents who wished to avoid the birth of a “defective” child had only two options: to conceive and hope for the best, or avoid having children all together. Now, however, “a geneticist can give parents an accurate appraisal of what their chances are of producing a second defective.”⁶² These types of “then” versus “now” scenarios were quite effective in glorifying and praising the potential of genetic science to revolutionize American conceptions of disease, disability, and parenthood.

Other publications reflected a similarly hopeful perspective on genetic counseling and testing in the 1960s and 1970s. A 1963 *Washington Post* article began with the premise that, “The birth of a misshapen or mentally retarded child is a family tragedy” and that parents’ foremost concern is to “ask why - and will it happen again?” The article then assured parents that chromosome analysis can help calculate the chances of

⁶⁰ Alan J. Anderson Jr., “Will My Baby Be Normal? Parents and Child Genetic Counselors are Having Increasing Success in Answering the Heavy Question,” *NYT*, 8 September, 1974. Celeste Michelle Condit notes that during the 1970s, more than six articles appeared with a version of “Will My Baby Be Normal?” in the title (*The Meanings of the Gene*, 132).

⁶¹ See Nelkin, *Selling Science* (1987), 81 on the use of war metaphors. She describes that battle imagery implies that the expert should not be questioned, and that there should be no limits put on scientific research.

⁶² “Genetics: Chances of a Defective Child,” *Time*, 3 May, 1967.

recurrence to avoid such a tragedy in the future.⁶³ A 1968 article from the same publication, titled “Unraveling Secrets of Cancer Cells,” outlined the current state of cancer research. The author conceded that rather than yielding hoped-for cures, digging deeper into the genetic causes of cancer has instead revealed the diseases’ startling complexities. The article did, however, conclude on a note of optimism about the possibilities of cancer research. The article explained that “it is of vital interest to medicine to be able to predict special susceptibility to the disease of cancer. It is apparent that clarification of this set of factors could be of value not only in the solution of the whole puzzle but could also play a role in genetic counseling of would-be parents and in special prophylactic and diagnostic programs for those with greater risk of cancer.”⁶⁴ A 1973 article titled “Victory Seen Closer in Cystic Fibrosis Fight,” explored “Two promising blood tests” to detect CF carriers which were extolled as “‘an important discovery’...that may be ‘a wedge’ toward further understanding and treatment.”⁶⁵ A 1971 article in *Time* celebrated the emergence of Tay-Sachs screening programs. The article opened by invoking fear with the suggestion that, “Few legacies are more lethal than Tay-Sachs disease” which “kills the patient before his fifth birthday.” Thankfully, however, although there is no cure, researchers “believe that they can prevent it.”⁶⁶

One of the few places where skepticism appeared in coverage of genetic counseling and testing throughout the 1960s and 1970s was with regards to sickle cell anemia.

⁶³ Nate Haseltine, “New Technique Aids Study of Birth Defects: Science,” *Washington Post*, 16 June, 1963.

⁶⁴ “Unraveling Secrets of Cancer Cells,” *Washington Post*, 19 Dec., 1968.

⁶⁵ Victor Cohn, “Victory Seen Closer in Cystic Fibrosis Fight,” *Washington Post*, 15, May, 1973. See also Harry Nelson, “Gene Tied To Brain Disease,” *Washington Post*, 21 August, 1969, on the meanings of new genetic knowledge for dealing with and preventing Tay-Sachs.

⁶⁶ “Medicine: Genetics for the Community,” *Time*, 13 September, 1971.

Indeed, Nelkin identified a general trend in science reporting of this period, suggesting that, “wonder about the marvels of science and technology gave way to concern about environmental and social risks,” and greater attention to problems caused by new technologies.⁶⁷ Screening programs for PKU and Tay-Sachs were largely considered to be successful and almost without controversy; Tay-Sachs in particular was applauded as a model screening program due to the high levels of involvement by the Ashkenazi Jewish community, the ethnic group most affected by the disease.⁶⁸ By contrast, screening programs for sickle cell anemia were imposed on African-American communities amidst an existing atmosphere of distrust due to forced sterilizations and black nationalist-perpetuated fears of a government genocidal plot targeting African Americans.⁶⁹

A 1972 *NYT* article titled “Resentment Complicates the Case” outlined the backlash against sickle cell anemia programs which were widely seen as based on a confluence of medical, racial, and political concerns. The article asserted that, “the most delicate issue of all is raised by genetic counseling, which is aimed at warning those with the sickle cell trait of the risks they run in having children. Already some voices have been heard in the black community charging that it is simply another white plot aimed at carrying out genocide against the black community.”⁷⁰ An African-American woman responded to this article in a December 1972 letter to the editor, and stated her opposition to screening. She admonished, “How dare the Federal and state officials and politicians legislate genetic screening for the most unpopular minority in this country. It will be many generations

⁶⁷ Nelkin, *Selling Science* (1987), 10.

⁶⁸ Cowan, *Heredity and Hope*, 148. The success of the PKU program was largely due to the involvement of the disability community, especially the NARC.

⁶⁹ *Ibid.*, Chapter 5: Genetic Screening and Genocidal Claims, 150-180.

⁷⁰ Harry Schwartz, “Resentment Complicates the Case: Sickle Cell,” *NYT*, 5 November, 1972.

before this country is racially matured and educated enough to screen any group for any disorder.”⁷¹

Similar articles focused on sickle cell screening and fears of stigmatization appeared in the *Washington Post*. A 1972 article “Disease Publicity Raises Problems” explained many issues arising from targeting African Americans for sickle cell anemia screening like the conflagration the trait with the disease and fears of discrimination in health insurance and employment, with Dr. James E. Bowman asserting that, “the potential for mischief is great.” The article even quoted a Hastings Center member as saying that “there is currently no public health justification for mandatory screening to prevent any genetic disease,” and that “individuals have a right to decide whether or not to have their genes explored.”⁷² Another article, “Birth Control Divides Anemia Experts,” addressed the dilemma facing African American mothers about whether or not to have children, but also the role of the counselor in discussing family planning as related to sickle cell anemia. The article addressed the importance of non-directiveness in genetic counseling when asked by an African American woman “what should I do?” since, according to Dr. Robert Murray of Howard University, “Family planning is a sensitive issue in the black community.”

Indeed, the sensitivity of a counseling encounter with women of color about family planning of women of color would have been reinforced by the counselor’s presumed whiteness. The article relayed that, “Counseling should be informative not advisory...The

⁷¹ Arlene B. Bennett, “View of the Review: Sickle Cell,” *NYT*, 3 December, 1972. See also Nancy Hicks, “Sickle Cell Trait Found in Athletes,” *NYT*, 21 August, 1973.

⁷² Victor Cohn, “Disease Publicity Raises Problems: Publicity about Sickle Cell Anemia Raises Problems,” *Washington Post*, 12 November, 1972.

options available through family planning techniques are therefore only appropriately used...if the couple has requested such information.”⁷³ Another article from 1973 detailed a high-incidence of sickle cell anemia amongst inhabitants of a Greek village; here, screening had many “untoward social effects” including broken engagements and the social ostracization of persons with sickle cell trait but who were otherwise healthy, as well as a generalized sense of anxiety amongst this population about their collective genetic health.⁷⁴ It seems, therefore, that concern over the social and racial implications of sickle cell anemia screening was perhaps the single exception in a plethora of news articles focusing primarily on the wonders of genetic science.

In contrast to stories of unbridled faith in the new genetic technologies, a second narrative emerged that revolved around rather extremist doomsday and science-fiction scenarios. This brand of article became increasingly common by the mid- to late-1980s with the proliferation of prenatal technologies. Negative coverage intensified into the 1990s with the cloning of Dolly the Sheep and the prospect of “designer babies.” Some of these narratives drew on the famous story of *Frankenstein*. Originally penned by Mary Shelley in 1818, this story had, as of 1982, acted as the basic script for 130 other fictional stories, eighty films, and more than eighty stage productions.⁷⁵ A 1997 article relayed an interview with Dr. Ian Wilmut who was responsible for cloning Dolly. The author described of meeting the famous scientist that, “One doesn’t expect Dr. Frankenstein to show up in a wool sweater, baggy parka, soft British accent and the face of a bank clerk.

⁷³Victor Cohn, “Birth Control Divides Anemia Experts,” *Washington Post*, 14 November, 1972.

⁷⁴ Richard Homan, “Greece: Sickle Cell, Social Stigma”, *Washington Post*, 16 September, 1963.

⁷⁵ Jon Turney, *Frankenstein’s Footsteps: Science, Genetics and Popular Culture* (Yale University Press, 2000), 27.

But there in all banal benignity he was: Dr. Ian Wilmut, the first man to create fully formed life from adult body parts since Mary Shelley's mad scientist."⁷⁶ An article from 1998 similarly invoked the imagery of a Frankensteinian monstrosity. In describing the work of laboratories at the University of Texas and the University of Bath, that were working on engineering headless mice and tadpoles respectively, the authors cried, "For sheer Frankenstein wattage, the purposeful creation of these animal monsters has no equal."⁷⁷ In their analysis of media representations of cloning, Dorothy Nelkin and M. Susan Lindee drew on a similar metaphor, suggesting that Dolly was a "Rorschach test. The public response to the production of a lamb by cloning a cultured cell line reflects the futuristic fantasies and Frankenstein fears that have more broadly surrounded research in genetics and especially genetic engineering."⁷⁸

More common were scenarios invoking the dangers of Aldous Huxley's *Brave New World*. That Huxley's work should be invoked in relation to a new age of genetics is particularly fitting given his family's illustrious place in the history of British medical sciences. Aldous Huxley's father Thomas Henry Huxley was a fierce defender of Darwinian evolution even before the theory was popularized (earning for himself the nickname "Darwin's bulldog"). Aldous' brother Julian was a noted post-war evolutionary and population geneticist, while his other brother Andrew won the Nobel Prize in Physiology or Medicine. Huxley's novel, published in 1932, invoked what John Turney called a "deeply unattractive" futuristic scenario where human life has been transformed

⁷⁶ Charles Krauthammer, "A Special Report on Cloning," *Time*, March 10, 1997.

⁷⁷ Charles Krauthammer, "Of Headless Mice...and Men," *Time*, January 19, 1998.

⁷⁸ Dorothy Nelkin and M. Susan Lindee, "Cloning in the Popular Imagination," *Cambridge Quarterly of Healthcare Ethics*, Special Section: Cloning: Technology, Policy, and Ethics 7 (1999), 145.

by a range of biomedical technologies including genetic selection, mandatory contraception, and euthanasia.⁷⁹

Commenting on the impact of Huxley's work, Turney suggested that once the dystopic vision of *Brave New World* took hold in the public imagination, it became the imagery through which to visualize biomedical research.⁸⁰ A *Time* article from 1978, "The First Test-Tube Baby," began with the following excerpt from Huxley's famous work:

The Director...continued with some account of the technique for preserving the excised ovary and actively developing; passed on to a consideration of optimum temperature, salinity, viscosity...actually showed them...how the eggs...were inspected for abnormalities, counted and transferred to a porous receptacle; how...this receptacle was immersed in a warm bouillon containing free-swimming spermatozoa...⁸¹

A 1992 article from the same publication, "Catching a Bad Gene," explored the dangerous potentials of amniocentesis and CVS. The article reflected disability perspectives from a concern that, "the test also takes society into the brave new world of genetic screening, raising the spectre of eugenically minded parents throwing out embryo after embryo in search of the 'perfect' child."⁸² Another article from the following year addressed the cloning of human embryos by quoting the French President François Mitterrand saying he was "horrified"; the debate about embryo cloning was characterized by the feeling that, "A line had been crossed. A taboo broken. A Brave New World of cookie-cutter humans,

⁷⁹ Turney, *Frankenstein's Footsteps*, 114-115.

⁸⁰ *Ibid.*, 113-117, 160.

⁸¹ "First Test-Tube Baby," *Time*, 31 July, 1978.

⁸² Philip Elmer Dewitt, "Catching a Bad Gene," *Time*, 5 October, 1992.

baked and bred to order, seemed, if not just around the corner, than just over the horizon.”⁸³

A 1978 *Washington Post* article, amongst others, described the birth of the first test tube child as a “brave new baby,” while a 1988 article from this same publication described the ethical conundrums posed by surrogacy, egg donors, and *in vitro* fertilization as “situations that seem like a chapter out of Aldous Huxley’s *Brave New World*.”⁸⁴ A 1992 article from the *NYT*, “Tales from the Baby Factory”, wondered at the fact that “somehow, whenever we’re presented with news of the latest breakthrough in the fertility frontier, the dreary day-to-day horrors of trying to conceive in a brave new world take a back seat to all the ‘Miracle Baby,’ ‘Last Chance Baby,’ ‘Most Expensive Baby in the World’” hoopla.”⁸⁵ It seems that Shelley’s and Huxley’s literary works provided the American print media and the public with frightening tropes and imagery through which to understand genetic science of the late-twentieth century. Significantly, these tropes were drawn on at the expense of, or in preference to, the vocabulary and discourse used by bioethicists, activists, and genetic healthcare professionals themselves to debate genetic reproductive technologies.

Into the 1990s and 2000s, journalists also drew increasingly on the fears of other perhaps unlikely scenarios prompted by films like *Gattaca* (1997) and *Jurassic Park* (1993). A 1998 article in *Scientific American* titled “Where Science and Religion Meet” profiled the U.S. head of the Human Genome Project Francis S. Collins. Collins

⁸³ Philip Elmer-Dewitt, “Cloning: Where Do We Draw the Line,” *Time*, 8 November, 1993.

⁸⁴ Victor Cohn, “Also Born: A Divisive New Era of Genetics,” *Washington Post*, 26 July 1978; “Whose Baby Is It, Anyway?: Surrogates, Donors and Petri Dishes Are All in the Family,” *Washington Post*, 12 April, 1988.

⁸⁵ Joanna DePierro, “Tales from the Baby Factory,” *NYT*, 15 March, 1992.

explained that, “The recent movie *Gattaca* thrust before the public eye the prospect that genetic research will in the near future allow the engineering of specific desirable traits into babies,” despite his insistence that it is “premature to start wringing our hands.”⁸⁶ “A Brief History of Cloning,” a 2008 article in *Time*, told of scientists at Penn State who had pieced together 80 percent of a woolly mammoth genome, and speculated that their work was “bringing the world one step closer to the *Jurassic Park* fantasy of using recovered DNA to bring an extinct species back to a shaggy, lumbering existence.” After recounting recent attempts at cloning that seemed to suggest that reproducing dinosaurs and woolly mammoths were within what Steven Spielberg called “the science of eventuality,” the author included a quote by the scientist conducting the Penn State research as saying of that scenario that, “there is a workable route to do that, but it is at this time technically, and cost-wise and time-wise, not feasible.”⁸⁷ Despite scientists’ cautions against these technology-run-amok scenarios, such narratives circulated repeatedly. The persistence of these stories may be due to the fact that genetic science is so complex and still so changeable that it is tempting to fill in the missing pieces with overblown speculation.⁸⁸

Other, more moderate fears circulated around the eugenic potential of prenatal technology, and genetic counseling and testing.⁸⁹ Indeed, The Hastings Center and media

⁸⁶ Tim Beardsley, “Profile: Where Science and Religion Meet,” *Scientific American* 278 (Feb. 1998), 28-29.

⁸⁷ Alyssa Fetini, “Cloning,” *Time*, 21 November, 2008; Jeffrey Kluger, “A Brief History of: Cloning,” *Time*, 26 November, 2008. See also Maxine Singer, “No, You Can’t Make Dinosaurs,” *Washington Post*, 7 July 1993. Dorothy Nelkin and Susan Lindee also explored the “serious practical problems” with the scenario proposed by Michael Crichton, author of *Jurassic Park* (*DNA Mystique*, 53).

⁸⁸ Celeste Michelle Condit made a similar observation in *The Meanings of the Gene*, when she suggested that we lack “concrete representations” through which to understand new technological developments (111).

⁸⁹ In *The Meanings of the Gene*, Condit thoroughly analyzed the ways in which public reactions against the new genetics were often similar to arguments invoked against the old eugenics. Public rhetoric argued

coverage of genetic reproductive technologies overlapped primarily through concerns about a new eugenics. Many of these critiques revolved around ethical issues of selecting for the perfect baby, moral dilemmas around cloning, and fears of state intervention in reproductive matters. Often, such critiques invoked the history of the eugenics movement and what Jensen called “‘mad’ science,” either in the United States or in Hitler’s Germany.⁹⁰ For example, a 1999 *Time* article “Cursed by Eugenics” extolled the virtues of remembering the eugenics movement, saying,

At a time when science promises such dazzling advances in the practice of medicine, it may be prudent to cast a glance over the shoulder, back to an earlier era when scientists – or people who thought they were doing science-stirred hopes that better days were only a generation or so away. The rise and fall of the theory known as eugenics is in every respect a cautionary tale.⁹¹

The spectre of eugenics was raised explicitly with regards to issues of race. A 1972 *NYT* article on questions arising from sickle cell screening quoted a Chicago doctor as comparing state-mandated screening laws to the racist eugenic ideals that “led to the final solution in Nazi Germany.”⁹² In a 1993 article in *Scientific American* called “Eugenics Revisited,” the author considered that, “Scientists are linking genes to a host of complex human disorders and traits, but just how valid- and useful- are these findings?” The article proclaimed that “eugenics is back in fashion” given recent discoveries of the role of genetics in intelligence, sexual preference, and a large number of diseases. Critics

against human genetic improvement on the grounds that it was both biologically and socially undesirable and unpractical (116-123).

⁹⁰ Jensen, “Scientific Sensationalism,” 48-49.

⁹¹ Paul Gray, “Cursed by Eugenics,” *Time*, 11 January, 1999.

⁹² Cohn, “Disease Publicity Raises Problems,” *NYT*, 12 November, 1972.

worried, however, that “no good can come of bad science” and that “the field of behavioral genetics is mired in the same problems that have always plagued it.”⁹³

In many cases, however, eugenic fears were not explicitly mentioned but rather invoked through a broader discussion of genethics. Articles of this nature occurred occasionally throughout the 1980s and 1990s, and are an example of what Jensen described as “balanced hype” articles. These stories discussed both “utopic” and “dystopic” aspects of genetics, though rarely in equal measure and often without an attempt to reconcile or resolve the problems presented.⁹⁴ One early example of such coverage was a 1986 article from the *NYT*, “Advances in Genetic Forecasts Increase Concerns.” This article opened with the issue that “Genetic analysis to predict a person’s health and life expectancy may soon give society unprecedented influence over people’s choices in areas ranging from life insurance to careers or even mates.” The piece enumerated many of what would become the standard ethical concerns about the uses of genetic information including discrimination in insurance and employment, and the consequences of predictive genetic testing for diseases with no known cure.⁹⁵

Importantly, many articles of this genre that appeared in publications such as the *NYT*, the *Washington Post* or *Scientific American* actually featured bioethicists and other scholars. In 1983 the *NYT* featured a photograph of, and excerpts from, a roundtable debate about the ethics of the Baby Doe case that included well-known geneticist and bioethicist Dr. Ruth Macklin, as well as Dr. Alan R. Fleischman, director of neonatology

⁹³ John Horgan, “Eugenics Revisited,” *Scientific American* 268 (June 1993), 123-131.

⁹⁴ Jensen, “Scientific Sensationalism,” 47, 49.

⁹⁵ Harold M. Schmeck Jr., “Advances in Genetic Forecasts Increase Concerns,” *NYT*, 19 August, 1986.

at Albert Einstein College of Medicine.⁹⁶ Into the 1990s, the *NYT* repeatedly interviewed Dr. Michael Kaback, who was integral in developing Tay-Sachs screening programs, as well as genetic counselors like Karen Copeland.⁹⁷ Francis S. Collins, head of U.S. Human Genome efforts, was also interviewed by both the *NYT* and *Scientific American*; both publications also interviewed Jeremy Rifkin, a long time critic of biotechnology.

In some cases, experts from The Hastings Center were interviewed to give an informed opinion about the potential ethical snags of genetic testing and prenatal diagnosis. Early on, a 1971 *NYT* article “Potential Risks as Well as Values Seen in Genetic Screening” quoted Daniel Callahan, co-founder of the Hastings Center, who warned against the social pressures that create the illusion of choice in aborting a “mentally defective” child.⁹⁸ Tabitha Powledge was interviewed for a 1979 *Washington Post* article about the ethical dilemmas of using prenatal testing for sex selection.⁹⁹ Arthur Caplan, who acted as the Center’s Associate Director between 1984 and 1987, was a frequently cited Hastings Center member. In a 1987 article, Caplan summarized the big ethical questions about genetics and genetic testing, saying, “Genes are the blueprint that are you...How will the information be controlled?...How will our value calculus turn out?.” He also objected to the fact that genetic screening seemed to be sold to the public as ethically neutral, saying, “I think that is false. Prenatal screening is done today with the

⁹⁶ “Infant Handicaps Test the Meaning of Mercy, Roundtable: Morality, Ethics and Baby Doe Cases,” *NYT*, 13 November, 1983.

⁹⁷ Gina Kolata, “Rush is On to Capitalize on Testing for Gene Causing Cystic Fibrosis,” *NYT*, 6 February, 1990; Harold M. Schmeck Jr., “Battling the Legacy of Illness: The Double Helix, Code for Sickness or Health,” *NYT*, 29 April, 1990.

⁹⁸ Harold M. Schmeck, Jr., “Potential Risks as well as Values Seen in Genetic Screening,” *NYT*, 13 October, 1971.

⁹⁹ Victor Cohn, “Fetuses Aborted to Prevent Child of ‘Wrong’ Sex,” *Washington Post*, 6 September, 1979.

intent of terminating pregnancies that are defective. The practice is defensible on certain moral grounds. My fear is that there will be an inevitable slide down the slope from [a] definition of genetic disease to a promulgation of eugenic goals.”¹⁰⁰ He conveyed his ethical insights in the *Washington Post* in 1986, again in the *NYT* in 1996 and 1998, and in *Scientific American* in 1995, each time outlining the bioethical issues arising from genetics and prenatal technologies.¹⁰¹

On the one hand, it is encouraging that the media sometimes cited Hastings Center members. On the other, however, it is perhaps alarming that despite their awareness of the Center’s important bioethical work, they drew on its expertise so rarely. In general, articles foregrounding the expertise of bioethicists on the new genetics tended to be the exception rather than the rule and, in many cases, their words of caution and balanced criticism were buried amidst wilder speculation.

There are unmistakable themes in the major print media as it covered these issues in the late-twentieth century. There are also, however, striking absences. While discussions of eugenics took up many concerns of disability rights activists, print media coverage of genetics seldom highlighted the voices of women or engaged in what feminist scholars would call a woman-centered analysis. An exploration of the implications of genetic reproductive technologies *for* women, and especially *by* women, was often only treated

¹⁰⁰Sandra Blakeslee, “Genetic Discoveries Raise Painful Questions,” *NYT* 21 April 1987.

¹⁰¹ Arthur L. Caplan, “Sex: Are We Wise Enough to be Able to Select a Baby’s Gender,” *Washington Post*, 19 October, 1986; Gine Kolata, “In the Game of Cloning, Women Hold all the Cards,” *NYT*, 22 Feb 1998; Claudia Dreirus, “Who will get the liver transplant? Which One’s the Mother,” *NYT*, 15 December 1996; “Medicine,” *Scientific American* 273 (Sept. 1995), 142-143. Caplan often provided a full article contribution.

briefly.¹⁰² Throughout the 1960s and 70s, the press usually covered women's interactions with reproductive technologies and procedures within the confines of abortion debates. For example, a 1968 *NYT* article covered a bill proposed by New York Governor Rockefeller to change the state's "cruel and antiquated" abortion law on account of advances in genetics making it possible to prenatally diagnose severe defects. The article concluded that since we can identify these defects and perform hospital abortions, "To forbid such abortions should be criminal, not the other way around."¹⁰³ A 1966 *Washington Post* article "Abortion of Defectives Urged by Obstetrician" gave voice to physicians' support for amniocentesis and abortion based on fetal indications. Dr. Cecil B. Jacobson suggested that, "A parent should not be handicapped by the theological or legal problems when high risk of malformation is diagnosed and therapeutic abortion is counseled."¹⁰⁴ A *Time* article from 1967, "Gynecology: Disease of Unwanted Pregnancy," described the debates over better, safer access to abortion amongst theologians, sociologists, and physicians.¹⁰⁵ While it is significant that the reform of abortion laws was being championed by various groups, the voices of "non-professional" women were often either pushed to the background or entirely absent from these discussions in the media; similarly, the impact that connecting greater abortion leniency to new genetic technologies might have on women and their reproductive choices remained unaddressed.

¹⁰² Celeste Michelle Condit's study of public debates about heredity suggested that despite a lack of concern about women's experiences with genetic technologies, "background sexism" was prominent. She similarly observed that feminist voices were absent from debates about genetics, outside of *Ms. Magazine* (*Meanings of the Gene*, 144-145).

¹⁰³ "Genetics and Abortion Reform," *NYT*, 6 Feb, 1969.

¹⁰⁴ "Abortion of Defectives Urged by Obstetrician," *Washington Post*, 9 September, 1966.

¹⁰⁵ "Gynecology: Disease of Unwanted Pregnancy," *Time*, 15 September, 1967. These debates happened at the Washington Conference, where most participants were men. Interestingly, activist Pat Maginnis picketed outside despite not having been invited and gave lectures on self-induced abortions.

After *Roe v. Wade*, and with the proliferation of genetic technologies throughout the 1980s and 90s, women's access to the fruits of the new genetics was sometimes seen as quite positive. News outlets often celebrated the benefits of genetic reproductive technologies despite the concerns voiced by FINRRAGE and the NWHN about the over-medicalization of women's bodies. A 1987 *NYT* article conceded that women now faced "bewildering decisions" due to the number and sophistication of prenatal testing procedures like CVS and AFP. Rather than worrying about issues of choice and the possibility of refusing the technology, the author summed up the main issue as "more women are facing increasingly difficult decisions about which prenatal tests to accept and how to act on their results."¹⁰⁶ There is an assumption at work here that women will certainly use prenatal testing; the question, rather, is which method. A 1990 *NYT* article outlined the possibilities new reproductive technologies held for women who had delayed childbirth into their 30s and 40s. It quoted a study from the *New England Journal of Medicine* that suggested that, "Given sound genetic diagnosis and counseling, together with appropriate prenatal care and the judicious management of labor and delivery, the increasing number of women postponing first pregnancies can look forward to excellent outcomes."¹⁰⁷ Resources such as *in vitro* fertilization were also heralded as God-sends for women facing infertility issues with one doctor explaining that, "When we are successful, we make a difference in somebody's life forever...We change the world."¹⁰⁸ One of the

¹⁰⁶ Gina Kolata, "Tests of Fetuses Rise Sharply Amid Doubts," *NYT*, 22 September, 1987.

¹⁰⁷ "Low Risk Seen in Delayed Pregnancy," *NYT*, 8 March, 1990.

¹⁰⁸ Darcie Bailer, "Resource for Women Burdened by Infertility," *NYT*, 30 July, 1995.

only times this technology was really problematized for women and their bodies was in relation to surrogacy, which was seen as fraught with moral and legal dilemmas.¹⁰⁹

Though genetic reproductive technologies were sometimes seen as significant enhancements to women's reproductive autonomy, media discussions of genetics and prenatal testing also came to focus on fears that women's rights had run rampant. In a 1989 *Time* article "Science: The Perils of Treading on Heredity," the author asked whether women should have the right to abort for a minor defect or for the purposes of "sex-balance," and suggested that "only the most hardened pro-choice advocate" would argue that a woman or couple could abort until they had the "perfect baby." The main concern here was that with new prenatal technologies, perfectly healthy children would be aborted in order to satisfy women's lofty goals of a genetically-ideal family.¹¹⁰

The worry about women's choices run rampant was also expressed in a *Time* article from 1997, "The Age of Cloning." The article summarized that in the wake of cloning Dolly the Sheep, a flurry of journalists had been writing anxiously about how human cloning would enable "virgin births" and women giving birth to cloned versions of themselves. They also worried that, in line with the aspirations of feminist technophiles like Firestone and Haraway, reproductive technologies would condition a complete shift

¹⁰⁹ The case of "Baby M" was a surrogacy case that was highly-publicized in the American media. In this case, a woman had entered into a surrogacy arrangement with prospective parents but, upon the birth of the child, decided she wanted to keep the baby. The 1987 ruling decreed that the surrogacy contract was invalid and that the surrogate was the child's legal mother. For just some examples of surrogacy media coverage, see Dan Colburn, "Redefining 'Mother' and 'Father': The Ethical and Emotional Dilemmas of Surrogacy," *Washington Post*, 24 February, 1987 or Anne Taylor Fleming, "Our Fascination with Baby M: At Stake in the Trail is Our Sense of Ourselves, Our Concept of Motherhood, of Parenthood," *NYT*, 29 March, 1987.

¹¹⁰ Philip Elmer-Dewitt, "Science: The Perils of Treading on Heredity," *Time*, 20 March, 1989. Francis S. Collins expressed a similar worry that "genetic testing and abortion will be used to prevent conditions that are less than disastrous" in Tim Beardsley's, "Where Science and Religion Meet," *Scientific American* 278, no. 2 (February 1998), 29.

away from traditional motherhood by giving birth through artificial wombs. Indeed, cell biologist Ursula Goodenough even joked in the *New York Times* that if cloning is eventually refined and harnessed, “there’d be no need for men.”¹¹¹ Fears about women’s reproductive powers were expressed as early as 1937 in a *Collier’s* magazine article that charged Gregory Pincus (one of the scientists involved in the development of oral contraceptives,) with creating a species of “Amazons” where women’s self-determination and sexual liberation would eclipse the value of men.¹¹² A similar point was expressed in a 1998 *NYT* article in which Dr. Davor Solter asked “have you ever thought of the feminist aspect of cloning?” Essentially, since women’s bodies produce eggs (which he saw as essential to cloning processes), “women could become all powerful in this future society.”¹¹³ These types of scenarios, although potentially empowering, tended to sideline the more realistic concerns and criticisms of reproductive technologies by groups like FINRRAGE or the NWHN. While this brand of article latently addressed the central feminist question of whether technologies enhance or erode women’s status and autonomy, their analyses were often extreme and seldom included a woman-centered perspective.

Genetic Counselors, Bioethics, and Genetic Literacy.

Part of the importance in exploring how genetics has been portrayed and discussed in print media is that Americans are bombarded with reports of genetic discoveries and their socio-political implications on an ongoing basis. While genetic counselors generally

¹¹¹ J. Madeleine Nash, “The Age of Cloning,” *Time*, 10 March, 1997.

¹¹² Elaine Tyler May, *America and the Pill*, 23.

¹¹³ Kolata, “In the Game of Cloning, Women Hold all the Cards,” *NYT*, 22 Feb, 1998.

supported their patients' quest for more information about genetics, they also felt that the average American was still lacking in genetic literacy and the ability to critically evaluate the content and context of the scientific information presented. Many counselors commented explicitly on the sensationalism surrounding genetics in the mainstream American media and its impact on patient encounters. A second-generation counselor remembered that,

I got interviewed, actually, by a couple of the news networks when Dolly was cloned, and that was something, of course, for sensationalism that they like to do. And, of course, when they actually ran the piece, they showed cartoons about clones of people etc...The thing I said was there are so many genetic diseases that need address. That's where the medical interest lies. We will occasionally get somebody who will be like, 'I want the testing for everything.' And really, we have to kind of straighten them out and say, 'there's no such thing as testing for everything. Stuff happens.'¹¹⁴

Another counselor elaborated on how difficult it is to reclaim (perhaps inaccurate) information patients have gleaned from the media once they've "educated" themselves about a given genetic condition or procedure. She explained that, "It's a real fight to get people to drop that very sexy scientific page of the *New York Times*...I don't know a card-carrying genetic counselor who thinks 'Gee, wouldn't it be nice to design babies?' So in that respect, when it does come up, it's a constant fight not necessarily to debate the morality of it, but to say that even if I wanted to, I don't know enough to do that."¹¹⁵ Genetic counselors have advocated for greater informed debates but have also developed tools like the "Trust it or Trash It" tool, run through the Genetic Alliance. This database helps people sift through "good" versus "bad" information related to genetics, and rectify

¹¹⁴ Interview with GCS104I13, 10 August, 2010.

¹¹⁵ Interview with GCS26I15, 12 August, 2010.

the often over-simplified and unbalanced portrayals of genetic intentions in the media.¹¹⁶ Despite their efforts and the genetics community's insistence on the medical intentions of their research and new technologies, there continues to exist a gap between bioethicists' discussions of reproductive genetic issues, and those that confront the everyday American through the mainstream print media.

Since the 1960s, the profession of genetic counseling developed alongside public debates on genetic reproductive technologies and the new genetic citizenship. These public negotiations have significantly influenced the socio-political contexts in which counselors practice, and their transition from the old eugenics to the new genetics. Sophisticated and nuanced debates about genethics have occurred around disability and reproductive rights issues at bioethical institutes like The Hastings Center through the discourse of rights and responsibilities, and a concern with the preservation of autonomy as set against scenarios of eugenic coercion. With the exception of eugenic concerns and the occasional input from a member of the HC, however, bioethical perspectives on the new genetics generally failed to trickle down to the public through the American print media. Science reporters instead often produced repetitive and oversimplified narratives that expressly ignored a woman-centered perspective. This media silence has neglected how women's personal reproductive decisions have been made public, occurring against the intense politicization and popularization of genetics, a silence which is quite alarming considering women are the primary targets and clients of genetic technologies.

¹¹⁶ Interview with GCS89I17, 24 August, 2010. See also "Trust It or Trash I? Tool," Genetic Alliance, accessed 12 May, 2013, <http://geneticalliance.org/atcg.tot>

Moreover, unbalanced media reports have contributed to misinformation and worked against the attempts of genetic counselors and others to foster greater genetic literacy amongst Americans living in an age of rapid scientific advancements. As Daniel Callahan noted in 1995, transformations in genetic knowledge are “changing the way human beings think about the ancient threats of disease, illness, and death—and thus about the meaning of human life itself.”¹¹⁷ How problematic and paradoxical, then, is the precarious position of the genetic citizen who is more removed than ever from bioethical and policy discussions, and indeed scientific research itself, at the same time that their health and everyday lives have become increasingly geneticized.

¹¹⁷ Daniel Callahan, “The Goals of Medicine: Toward a Sustainable Future,” 25 August, 1995, Consensus Statement, 1995, Box 20, HC.

Conclusion: Our Genetic Past, Present, and Future.

On October 27, 2011, *Time* featured an article titled, “Do All Women Need Genetic Testing Before Pregnancy?”¹ The piece announced the development of a single genetic screening test invented by GenPath Women’s Health (part of New Jersey-based Bio-Reference Laboratories) that could detect 600 mutations implicated in 160 different diseases. GenPath touted their test as the most comprehensive genetic screen ever developed, and publicized their discovery at the NSGC’s Annual Education Conference. *Time* reported that genetic counselors generally felt that, “increased interest in genetic testing is welcome because it encourages women to better understand how their genetic makeup could impact their children.” NSGC President Karen Dent, however, also articulated the profession’s view that genetic testing should be mediated by a genetic counselor, and that sometimes counselors’ professional ethics means “not testing because the patient would not benefit” from the results.²

Perhaps the most fascinating aspect of GenPath’s test was the way its marketing targeted women of diverse backgrounds. GenPath called the test the “Pan-Ethnic Carrier Screen,” and the developers clearly intended to “signal to all women, regardless of ethnicity, that genetic testing is important for them.” The screen was meant to reach beyond ethnic groups like the Ashkenazi Jewish community, which had a well-entrenched history of interest and involvement in genetic screening, to promote the value of the new genetics to all women. Using rhetoric favoured by the “genetically literate,” Bio-

¹ Bonnie Rochman, “Do All Women Need Genetic Testing Before Pregnancy?” *Time*, 27 October 2011.

² *Ibid.*

Reference CEO Marc Grodman assured patient-consumers that “knowledge is power” when it comes to genetic testing and prenatal diagnosis.³

The Pan-Ethnic Carrier Screen is just one example of developments in genetic testing since 2000. It is particularly intriguing in that it highlights major themes within the history and contemporary practice of genetic counseling: the relationship between the new genetics and overlapping gender, race, and ethnic identities; the increasing socio-scientific pressures facing women bombarded with an array of genetic testing options; the professional interests of counselors in genetic testing and their roles as mediators between technology and the public; and the increasing push to think genetically in twenty-first century America.⁴

The history of genetic counseling in the United States between 1930 and 2000 elucidates the process through which we have arrived in an age of increasing geneticization.⁵ Genetic counselors have been key historical actors in this transition as interpreters of the new genetics positioned at the interstices of science, health, medicine, and American society. Genetic counseling has roots in the early-twentieth century American eugenics movement but emerged as a distinct field in the post-WWII period amidst larger shifts in cultural meanings and material practices. These shifts included the transition from mainline to reform understanding of eugenics, dramatic advances in genetic research and technology, and attitudinal changes towards sex, family planning, and population control. Sheldon Reed’s work remains the most recognized historical

³ Ibid.

⁴ Heath, Rapp, and Taussig, “Genetic Citizenship,” 159.

⁵ Lippman, “Prenatal Genetic Testing and Screening,” 19.

script for the field he described as “a kind of genetic social work without eugenic connotations.”⁶ The history of genetic counseling also finds roots in Paul Popenoe’s marriage counseling and the work of the American Institute of Family Relations in California, and in the Human Betterment League of North Carolina (amongst other locales). This new field of clinical genetics surfaced “to guarantee that children will be well born” at different times and according to local circumstances in a testament to the profound blurring between the old eugenics and new genetics.⁷

By the 1960s, debates over the promises and perils of genetics, and anxieties about a new eugenics, were common in American public discourses. Genetic counselors often acted as frontline negotiators of the genetic revolution by facilitating their clients’ personal reproductive decisions, and mediating the terms of the new genetic citizenship. Indeed, genetic technologies have been couched in “the language of rights and freedoms – ‘right to know’ and ‘freedom of choice.’” But they have also carried implicit expectations that citizens will minimize their own role in the perpetuation of genetic disease as part of their responsibility to posterity since “genetic risk management always ha[s] an intergenerational dimension.”⁸ The privileges and duties of genetic citizens were considered within reproductive rights activism, a familiar advocacy niche for genetic counselors with self-described “feminist leanings.”⁹ The disability community also debated the meanings of genetic reproductive technologies in ways that encouraged

⁶ Reed, “A Short History of Genetic Counseling,” 4-5.

⁷ “Meeting Minutes, May 9, 1972,” Charter (Original) and Minutes, 1947-1972, Folder 24, Series 1, Files of Marian Moser, 1947-1980, HBL.

⁸ Petersen and Bunton, *The New Genetics and the Public’s Health*, 57-58.

⁹ Interview with GCS00I22, 12 November, 2010.

counselors to imbue their practice with a “balanced” and “more realistic perspective” of life with a disability.¹⁰

Disability and reproductive rights perspectives encountered one another at The Hastings Center where scholars from a range of disciplines debated genetics from a nuanced and often woman-centered perspective. The general proliferation of genetic knowledge and reproductive technologies, but also specific cases like that of Baby Doe in 1982, gave Center members plenty of material for debating prenatal diagnosis, maternal versus fetal rights, and the responsibilities of parents to their offspring. Despite these sophisticated bioethical conversations, many Americans encountered geneticization through a print media that often neglected the impact of genetics on women, the primary targets and patient-consumers of prenatal diagnostics and reproductive technologies. In many cases, mainstream newspapers and magazines published articles that alternately emphasized “a dialectic of utopianism and dystopianism.”¹¹ Public engagement with genetic science highlights how contemporary genetics has been popularized and politicized. It also elucidates the socio-political contexts in which genetic counselors practice, and women and people with disabilities encounter a host of competing discourses about their risks, rights, responsibilities, and choices.

The professional development and patient-counselor relationships of genetic counselors are central to the field’s history. They also contribute to larger themes in the history of health and medicine by urging recognition of more diverse professionalization experiences. The professional evolution of genetic counseling occurred within Andrew

¹⁰ Interview with GCS94I01, 26 July 2010.

¹¹ Jensen, “Scientific Sensationalism,” 43.

Abbott's system of professions, and was characterized by interprofessional competition over jurisdiction related to genetic healthcare. The system of genetics professions certainly structured important professional moments like the establishment of graduate programs in genetic counseling, the National Society of Genetic Counselors, and the American Board of Genetic Counseling. Within this system, counselors' gender, Masters-level education, and overall whiteness clearly mattered. Indeed, the profession's evolution was profoundly shaped by its positionality between sympathy and science. Genetic counselors balanced the scientific objectivity and rationality encapsulated in the "genetic" portion of their job title, and the values of empathy, nurturance, and social concern implied in their counseling roles. They negotiated what Regina Markell Morantz-Sanchez described as "the hard and soft sides of medical practice" through their femaleness in relation to the overall maleness of physician-geneticists, and their Masters-level education as set against the MDs or PhDs of other genetics professionals.¹² While counseling in a prenatal or pediatric setting was perhaps "a nice comfort zone for women," counselors were adamant that, "We have a stiff background of solid science behind us. They don't just teach us how to hold hands and pass Kleenex."¹³

Genetic counselors also defined their client interactions in relation to others working in genetic healthcare. The counselor-patient dynamic, which consistently centered on concepts of risk and the maintenance of patient autonomy, was situated against the traditional doctor-patient relationship. Counselors identified areas of overlap between their professional responsibilities and those of physicians; they also emphasized points of

¹² Morantz-Sanchez, *Sympathy and Science*, 5, 308.

¹³ Interviews with GCS00I21, 12 November, 2010 and GCS26I15, 12 August, 2010.

divergence like their ability to spend more time with patients, or their therapeutic rather than strictly medical skill set resulting from their counseling training. As Susan E. Hodge argued, physicians were prone to paternalism and a certain amount of egotism, but “genetic counselors are supposed to exemplify a different attitude.”¹⁴ Counselors also placed their client relationships within an anti-eugenic framework and institutionalized the principles of non-directiveness and client-centeredness as the field’s ethical cornerstones. As one pioneering counselor recalled, “Early on in genetic counseling, the [Second World] war was recent and eugenics was still fresh in people’s minds, and most genetics was related to prenatal diagnosis. So non-directiveness was really appropriate for those times when you didn’t want to be telling people ‘have a baby, don’t have a baby.’”¹⁵ Counselors have remained committed to “creat[ing] an atmosphere where the client can make decisions that are best for themselves,” however imperfect or challenged that ideal may be.¹⁶

The story of genetic counseling in a prenatal setting is inherently gendered as the profession has often centered on women counseling women about pregnancy, motherhood, and reproductive issues since the late-1960s. The field’s history has also been conditioned by the relative privilege of genetic counselors as professionals working within a larger American healthcare hierarchy devoting increasing time and resources to genetic health. The overall whiteness of genetic counselors is frequently reflected in their client base, as well as in the counselor demographic that participated in my doctoral

¹⁴ Hodge, “Paternalistic and Protective?” 351-52.

¹⁵ Interview with GCS00I24, 19 November, 2010.

¹⁶ Interview with GCS42I05, 28 July, 2010.

study. Oral history interviews with genetic counselors are integral to understanding the influence of race, class, gender, and educational credentials on the profession's history. As members of a relatively-new health profession, the voices and stories of genetic counselors also furnish a necessary perspective on the history of a field that is becoming increasingly relevant and valuable in the twenty-first century.

My history of genetic counseling is of significant import to historians and others interested in genetics, medical professions, reproductive politics, and bioethics for three reasons. First, my study provides a close, nuanced analysis of the previously under-explored profession of genetic counseling. My history takes this health field, which has been explored at the periphery of other literatures, as its central focus with an emphasis on the voices and perspectives of genetic counselors themselves. Second, my analysis forges important linkages between the historical and the contemporary, the past and the present, in the histories of genetics, hereditarianism, and reproductive technologies. I trace the history of genetic counseling from its origins in the early-twentieth century eugenics movement to its post-WWII development under medical geneticists like Sheldon Reed; I then connect the profession's early history to the its "feminization" in the 1970s, the growth of genetic reproductive technologies in the 1980s and 90s, and contemporary public discourses surrounding genetic citizenship. As such, my study is of interdisciplinary value to historians but also sociologists, anthropologists, bioethicists, and scholars of disability and gender studies interested in genetics and prenatal diagnosis in North America. Third, the history of genetic counseling illuminates the process through which we have arrived in an age characterized by ever-greater geneticization in which we

are pushed to think genetically about our health, our families, and our futures. The evolution of genetic counseling elucidates historical experiences that can help us navigate contemporary ethical problems facing not just healthcare professionals, but an American public confronted with the pervasive authority of genetic science.

Genetic counseling in a prenatal context is fascinating for the ways in which it interweaves histories of eugenics, professionalization experiences, patient-practitioner dynamics, the ethics of genetic testing, reproductive rights and abortion politics, and disability activism. There are also many other areas for further inquiry in the histories of genetic counseling, genetic research, and how women and people with disabilities have experienced the new genetics. Research in, and genetic counseling for, adult-onset conditions like Huntington's disease and cancer deserve further historical exploration. Most studies, mine included, focus predominantly on genetic counseling in a prenatal and sometimes pediatric context with attention to the thorny ethics of prenatal diagnosis, reproductive decision-making, and abortion. Cancer and Huntington's, however, have their own history centered on the ethics of predictive genetic testing, the "right to know" one's genetic predisposition versus the psychological toll of knowing, and the experiences of "at risk" individuals living between health and illness.¹⁷

There is also much more to be said about the complex history of disability and genetics. Throughout the twentieth century, people with various disabilities or impairments have encountered hereditarian theories, medicalization, and geneticization as

¹⁷ Alexandra Minna Stern touched on Huntington's disease in relation to concepts of risk in *Telling Genes*. Ilana Löwy briefly explored the meanings of the BRCA 1 and 2 genes for cancer treatment in *Preventive Strikes: Women, Precancer, and Prophylactic Surgery* (Baltimore: Johns Hopkins, 2010). See also Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven: Yale University Press, 2008).

patients and activists. Nevertheless, further studies are needed on these experiences from a historical perspective.¹⁸ Finally, the ways in which women interact with genetics and reproductive technologies deserves greater scholarly attention. I have explored the experiences of women as genetic counselors and sometimes as patients, but it is crucial to further analyze women's encounters with genetics, prenatal diagnosis, and reproductive technologies as scientists, activists, policy makers, mothers, and daughters.¹⁹

Studies of genetics and genetic counseling will become of even greater significance as the impact of geneticization becomes more pervasive. When asked what they thought genetic counseling would look like in the next ten to fifteen years, several genetic counselors focused on their expanding professional roles courtesy of the accelerating pace of genetics research and available technology. Direct-to-consumer testing is already popularizing genetic knowledge amongst the American public. Websites like 23andMe, which encourage consumers to “Explore your DNA,” will profile your ancestry and genetic health for just \$99.²⁰ The DNA Diagnostics Center, which conducts paternity testing for “The Maury Show,” offers DNA testing for adoption, immigration, maternity, siblingship, and for Native American tribal status. The center also perform DNA banking

¹⁸ The existing scholarship on disability and genetics comes largely from bioethics and disability studies (see chapters 5 and 6). The better-known historical works on genetics and disability focused on “mental retardation” or “mental hygiene,” often in the context of eugenics. See, for example, Ian R. Dowbiggin, *Keeping America Sane: Psychiatry and Eugenics in the United States and Canada 1880-1940* (Ithaca: Cornell University Press, 1997); Noll and Trent, eds., *Mental Retardation in America*. Significantly, David Wright's *Downs: The History of a Disability* explored the interaction of genetic technologies, prenatal testing, and disability.

¹⁹ One of the best studies to date is Ruth Hubbard's *The Politics of Women's Biology*. She explored women as scientists through the figure of Rosalind Franklin; feminism and the construction of scientific facts; and women's experiences as mothers and targets of prenatal diagnostics.

²⁰ 23andMe: Explore your DNA, accessed 18 August, 2013, <https://www.23andme.com/>

and “cell line authentication” services.²¹ As recently as March 2013, genetic testing company Natera launched their non-invasive prenatal test called “Panorama,” which tests for Trisomies 21, 13, 18, and other conditions through a simple maternal blood test.²²

Counselors also spoke of anticipated technological advancements in, and demand for, pharmacogenomics and personalized medicine. Personalized or genomic medicine is expected to improve patient outcomes and save healthcare dollars by using genetic information to better fit diagnoses and prescriptions to a patient’s individual needs. Indeed, pharmacogenomics makes use of genetic testing to better predict which drugs will work for a given individual in areas like depression, cancer and HIV, thereby theoretically increasing the effectiveness of drug therapy.²³ This is particularly important as genetics moves into many more areas of healthcare like cancer treatment, drug and alcohol addiction counseling, obesity and weight management, smoking and nicotine dependence, and a range of identifiable hereditary disorders.

Genetics is changing the ways in which we think about our families and relationships. It can help us better understand our kinship organizations and patterns of hereditary disease, and offers new hope for the treatment and even prevention of various health conditions. It can also reveal disquieting facts about our carrier status and the presence of genetic mutations that forever change how we think about our bodies, our

²¹ DNA Diagnostics Center, accessed 12 July, 2012, <http://www.dnacenter.com/dna-testing.html>

²² K.H. Nicolaides, A. Syngelaki, M. Gil, V. Atanasova, and D. Markova, “Validation of Targeted Sequencing of Single-Nucleotide Polymorphisms for Non-Invasive Prenatal Detection of Aneuploidy of Chromosomes 13, 18, 21, X, and Y,” *Prenatal Diagnosis* 33 (2013), 1-5; “Press Release: ARUP Labs Announces Availability of Natera’s Non-Invasive Prenatal Test, Panorama (TM)”, Panorama Prenatal Test, accessed 12 May, 2013, http://www.panoramatest.com/arup_labs

²³ Quiang Ma and Anthony Y.H. Lu, “Pharmacogenetics, Pharmacogenomics, and Individualized Medicine,” *Pharmacological Reviews* 63, no. 2 (June 2011), 437-359.

health and our futures. Perhaps the most interesting aspect of living in a geneticized society is that the impact of DNA extends far beyond the realm of health and medicine.

As Dorothy Nelkin and M. Susan Lindee have shown, the “gene of popular culture” is,

a symbol, a metaphor, a convenient way to define personhood, identity, and relationships in socially meaningful ways. The gene is used, of course, to explain health and disease. But it is also a way to talk about guilt and responsibility, power and privilege, intellectual or emotional status. It has become a supergene, used to judge the morality or rightness of social systems and to explore the forces that will shape the human future.²⁴

The gene has, in fact, become an American cultural icon. References to DNA and genetics are made frequently on TV crime shows like Law and Order or CSI, and in car and computer advertisements. Genetic images are invoked through beauty products like Revlon’s Age Defying with DNAdvantage Cream Makeup, or Nivea’s DNAge Cell Renewal Firming System which features a double-helix on its packaging despite the fact that it has no effect on genes whatsoever.²⁵ Ours is an era in which you can save your beloved pet’s DNA so they can live past their natural life through imminent cloning technology. You can also buy sperm or eggs on BeautifulPeople.com to better your chances of conceiving an aesthetically-attractive baby since, according to the site’s founder, “everyone – including ugly people – would like to bring good-looking children into the world and we can’t be selfish with our attractive gene pool.”²⁶

²⁴ Nelkin and Lindee, *The DNA Mystique*, 16.

²⁵ Ibid., xv-xvi; Revlon Age Defying with DNAdvantage Cream Makeup, accessed 10 April, 2013, http://www.revlon.ca/Revlon-Home/collections-menu/col_AgeDefying.aspx; Nivea Visage DNAge, accessed 10 April, 2013, <http://www.en.nivea-me.com/products/Face-Care/DNAge>.

²⁶ “‘Beautiful People’ Dating Site Launches Sperm and Egg Bank,” *The Telegraph*, 23 June, 2010; BeautifulPeople.com Online Dating, accessed 16 July, 2012, <http://www.beautifulpeople.com/en-CA>; PerPetuate, Inc.: Animal Cloning Head Start, accessed 16 July, 2012, <http://www.perpetuate.net/>

Genetic counselors will likely become increasingly visible as the genetic revolution continues to transform healthcare. They will also be in demand as the new genetics continues to acquire an omnipresent public facade, and as Americans witness the geneticization of aspects of their lives previously outside a medical paradigm. The last word, fittingly, belongs to a genetic counselor. She astutely summarized the role of genetic health professionals in the ongoing genetic revolution, and mused that,

I think we just keep finding more areas that need someone who is personable, who can talk to people and connect with people, but understands the genetic ramification of whatever it is that's going on. And it's becoming more and more widespread in all types of medicine and industry that there are going to be more roles for genetic counselors...I was saying the other day, "if there's one thing genetic counselors understand, it's evolution".²⁷

²⁷ Interview with GCS34I04, 27 July, 2010.

Appendix A

Online Survey for Study of Genetic Counseling

Directions to participants: For each of the twenty questions, you may write your answer in the text-box provided. While some questions require only short answers, you are encouraged to elaborate and write as much about your experience as you like. Thank you for participating in this survey.

A) Educational Background.

To understand how training for genetic counseling has evolved, please provide information about your educational background.

Undergraduate Degree (non-MD):

1. In what field did you obtain your undergraduate degree?
2. At what institution was this degree obtained?
3. What year was this degree obtained?

Graduate Degree/M.D:

4. Do you have an M.D?
5. Do you have a graduate degree?
6. If you answered yes to question 5 or 6, at what institution did you receive this degree?
7. If you graduated from a graduate program, what was the official title of the program?
8. What year was this degree obtained?

B) Personal Background.

To understand the diverse backgrounds and experiences of genetic counselors, please provide information on your personal history.

9. Please describe your personal background including your age, gender, and ethnicity.
10. Where did you grow up? Where do you currently live?
11. How did you become interested in science and genetics generally?
12. How did you become interested in genetic counseling specifically?

C) Professional Background and Work Experience.

This section seeks to better understand the profession of genetic counseling by examining the varying work experiences of genetic counselors.

13. How do you define genetic counseling?
14. When did you start working as a genetic counselor?
15. How many years have you worked as a genetic counselor?
16. In which cities or regions have you worked as a genetic counselor?
17. What kinds of facilities have you worked in (ie. public hospital, private clinic)?
Please briefly describe your experience at each facility.
18. Approximately how many genetic counseling sessions do you facilitate per year?
19. How long do you see yourself pursuing a career in genetic counseling?
20. Is there anything about your career as a genetic counselor or your interaction with clients that you feel is particularly exceptional or unique? Do you feel that your experiences in any way vary from the rest of your professional colleagues? If so, how?

Final questions:

Do you wish to be contacted for an interview about your experiences as a genetic counselor? Yes No

Do you wish to be sent a summary of the survey's preliminary findings? Yes No

If you answered Yes to either of the above questions, please leave your contact information in the text box provided, including your name and email address.

Thank you very much for your participation.

“Submit”.

Appendix B

Interview Questions for Genetic Counselors

Information About Interview Questions: These questions provided guidelines for the oral history interviews, and were deliberately broad and open-ended so as to encourage more than a “yes” or “no” answer. Shorter questions and comments were used to supplement these guidelines, such as “Could you tell me more about...,” or “Why do you think that is...” Importantly, these questions evolved as the oral history project unfolded. I modified questions according to feedback and answers I received from genetic counselors; as I learned more and continually enhanced my knowledge about genetic counseling; and as I moved from interviewing contemporary to more experienced counselors.

The Genetic Counseling Session.

1. What is the purpose of genetic counseling?
2. What are the general components of the counseling session? Do they happen in any particular order?
3. What is the ideal counselor/client relationship or power dynamic?
4. Do you think this dynamic or the relationship between counselor and client changes depending on certain variables such as the type of institution at which genetic counseling is performed; the age, gender, ethnicity of each party; the individual or couple’s reproductive history and number of existing children?
5. What kinds of tools do you use to help clients understand their genetic background?
6. How do you end a session? What kind of follow-up occurs?

Dealing with Genetic Risk.

1. How do you express to the client that they may carry a genetic risk? What is the next step?
2. Genetic counseling is often described as being “non-directive” and “client-centered.” How well is this concept applied in practice? How do you deal with clients who want you to be directly involved in their decision about whether or not to pursue prenatal testing?
3. Under what circumstances is the prospect of abortion usually raised during a counseling session? Who usually raises the topic of abortion? As the genetic counselor, how do you structure or guide that conversation?
4. Do you ever feel that your personal opinions about abortion, Down syndrome or other conditions impinge upon your professional practice? If so, how do you deal with that? If not, why not?

Professionalization.

1. While most of the first genetic counselors were primarily male scientists with PhDs or MDs, the profession has come to be dominated by women with Masters degrees since the 1970s. Do you think there has been a tension between these two groups? If so, is it based on gender? Professional qualifications? A combination of factors?
2. Do you feel like your educational background influences your approach to counseling?
3. What are the opportunities like for continuing education and training as a genetic counselor? Are there educational programs, conferences etc...? Tell me about these.
4. Do you feel there are adequate support programs for genetic counselors given the often-emotional nature of the profession?

The Broader Social Context.

1. Do you think that genetic counseling is in any way related to the eugenics movement of the early 20th century? If it is related, how? If not, why not? Is genetic counseling part of a “new eugenics”?
2. Do you think your professional assessment is based on common societal values about “normal” children and a “normal” family?
3. How do you feel about the suggestion made by some disability rights advocates that prenatal services like genetic counseling contribute to the stigmatization of people with disabilities?
4. More and more people are becoming genetic counselors and the service is becoming an increasingly routine as part of prenatal services. Why do you think genetic counseling is growing in popularity?
5. What do you see as the future potential for genetic counseling?

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Oral History Project

- 25 interviews with genetic counselors across the United States between July 2010 and October 2011.

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