“WILL MY BABY BE NORMAL?”: A HISTORY OF GENETIC COUNSELING IN THE UNITED STATES, 1940-1970

by

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A THESIS

Presented to the Department of History
and the Graduate School of the University of Oregon
in partial fulfillment of the requirements
for the degree of
Master of Arts

June 2012

THESIS APPROVAL PAGE

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Title: “Will My Baby Be Normal?”: A History of Genetic Counseling in the United States, 1940-1970

This thesis has been accepted and approved in partial fulfillment of the requirements for the Master of Arts degree in the Department of History by:

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Degree awarded June 2012

THESIS ABSTRACT

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Master of Arts

Department of History

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Title: "Will My Baby Be Normal?": A History of Genetic Counseling in the United States, 1940-1970

Genetic counselors today are at the forefront of helping clients interpret genetic information to help them make decisions, often about childbearing, based on testing and medical histories. Scholars of medicine, reproduction, and gender in the United States have traced the medicalization of pregnancy and interactions between parents and medical authorities. These works explore the interplay of medicine, society, and reproduction, but they do not address the history of genetic counseling. I argue that doctors and patients reciprocally shaped each other's thinking about reproduction in the mid-twentieth century. Parents' desires for normal, healthy children shaped the development of genetic counseling by motivating them to seek the services of genetic counselors. These prospective parents' expectations and desires had an outsized influence on the development of genetic counseling because counselors were sensitive to possible associations with eugenics and were careful not to tell parents what to do with the genetic information they provided.

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ACKNOWLEDGMENTS

All three members of my committee provided valuable support and feedback on my thesis. I am indebted to all three for their suggestions, comments, and questions. They helped to clarify my thinking and opened new avenues for research that added valuable perspectives to my thesis. Professor Elizabeth Reis has been an incredible source of advice and wisdom. Her work on gender, and her insights into prenatal testing, have proven extremely helpful to my work, and particularly my third chapter. Professor April Haynes has offered valuable questions about the gendered nature of medical and counseling services and helped a great deal in thinking about affective relationships and the historical nature of emotion. Finally, Professor Ellen Herman has guided and assisted me in every step of this project. She helped point me in the direction of genetic counseling initially and has pushed my thinking with provoking questions and valuable suggestions. She has also been a better advisor than I ever imagined I would find.

I also owe a massive debt of gratitude to all of the participants of Grad Lab, the history graduate student writing workshop, for reading my work and sharing their thoughts—and for giving me the chance to reciprocate. Special thanks go to Carrie Adkins who has read multiple iterations of this work and whose comments and advice have been invaluable. Thanks as well to Professors James Mohr, Marsha Weisiger, and Judith Raiskin for providing me with exceptional feedback on this and other projects.

A special thanks, as well, to Alissa Bourbonnais—my spouse, my partner, and my friend—whose support made this project possible and who has kept me on a relatively even keel these past two years.

For my family.

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CHAPTER 1

INTRODUCTION

One can easily sympathize with couples who have worried about the myriad complications that might develop to alter their visions of life for their future children. These sympathies persist, even after the disability rights movement of the 1970s called into question the traditional assumption that people with atypical development had unfulfilled, not wholly satisfied lives. The fields of science and medicine in the twentieth century United States often based their practice on the assumption that physical and genetic atypicality are things to be fixed and eventually eliminated. This perspective formed the foundation of not only broadly beneficial developments such as the polio vaccine, but also of more complicated, potentially harmful medical paradigms such as eugenics. The field of genetic counseling developed in the gray cultural space in between.

Genetic counseling, today a profession with its own education and credentialing system, provided interpretive, educational, and counseling services to people with questions about genetic conditions. Since its origins in 1940s heredity clinics genetic counselors have focused on helping clients understand the science behind inherited conditions, as well as the probability of those conditions appearing in themselves or their children. What the history of genetic counseling makes clear is that these seemingly opposing poles have not always been quite so clearly separate, and might still be more interrelated than they are different. The history of genetic counseling in the United States speaks to these complexities and the ways the came together in women's and couple's reproductive decision making.

Genetic counseling developed out of the combined interests of medical professionals and would-be parents within the context of mid-twentieth-century ideas about science, reproduction, and normality. The medical community, in concert with government and private initiatives, promoted rational, scientific approaches to pregnancy to meet both doctors' and parents' desires for normal, healthy babies. Doctors and patients frequently shared notions of health and normality, but they often approached these concepts from different directions. Doctors often viewed normality and health from a clinical standpoint as the absence of atypicality and disease: a normal, healthy baby was one that matched the medical averages and was free of illness. Parents, particularly after the birth of a child, approached normality and health with the added perspective of affection. A normal, healthy baby was one that was free of serious health conditions (such as Tay Sachs) and that fit their understanding of what physical and mental characteristics provided the best opportunities for a happy, fulfilled life for their child. Doctors' and parents' notions of normal, healthy children did not always diverge significantly prior to the birth of a disabled child. A child born with Down syndrome or epilepsy, both agreed, was not necessarily healthy or normal. But individual parents' responses to their atypical children could sometimes differ in interesting ways from medical and cultural responses, and from the decisions of other parents, as their emotional connections coexisted with, but did not necessarily replace, their cultural understandings of normality. For many parents interacting with genetic counselors, at the same time they expressed intense love for their disabled child, they nevertheless viewed them as abnormal and often desired a more "normal" family.

Would-be parents' interactions with genetic counselors suggest they shared notions of acceptable levels of difference when planning for a pregnancy, but that parents did not always respond to the birth of a child with atypicalities as counselors then, or historians now, might have expected. Geneticists and would-be parents, acting within and sometimes against their cultural assumptions, increasingly came to discuss pregnancy in rational, scientific terms even while grappling with emotionally charged desires for normal, healthy children. Genetic counseling's foundations in the 1940s, its growth and movement towards standardization in the 1950s, and its dramatic expansion and growing complexity in the 1960s were all influenced by the desires of clients and counselors, their understandings of genetics and the ability to predict normality, and their notions of disability and reproduction. Genetic counseling developed at the intersection of medical and science professionals' interest in preventing physical and mental disorders with parents' desires for normal, healthy children.

Genetic counseling grew up alongside similar professions, such as marriage counseling and psychoanalysis, which developed in the mid-twentieth century and have remained significant parts of the American social service sector into the twenty-first century. These professions shared characteristics such as faith in scientific methods, a conviction that everyone is entitled to health and happiness (which relies on cultural definitions of what it means to be healthy and happy), and the notion that these scientific methods to achieve health and happiness depend on expert intervention in private aspects of family life. Doctors and patients reciprocally shaped each others' thinking about pregnancy in the mid-twentieth century in ways that suggested a vision of at least nearly perfectible reproduction. This vision of pregnancy not only fed the expansion of the genetic counseling profession, but also altered the ways geneticists, doctors, and prospective parents interacted. Their notions of pregnancy, normality, and reproductive decision-making were most evident in the interactions between genetic counselors and those who went to them for advice.

My thesis, like the practice of genetic counseling itself, combines multiple areas of scholarship that are often considered separately: eugenics, genetics, and the role of the expert in everyday life; pregnancy, reproduction, and abortion; and constructions of disability and normativity. The little history there is about genetic counseling most often appears in either literature focused on genetics or eugenics, as brief historical works produced by people in the genetic counseling field itself, or as a short introduction to discussions of contemporary issues in genetic counseling or prenatal testing. There are, with the exception of Alexandra Stern's forthcoming *Telling Genes*, no detailed histories that trace either the origins of genetic counseling in the United States, its development into a health care specialty, or the way clients and counselors interacted.

This thesis contributes to this otherwise neglected field by exploring not only the origins and development of the field, but also the ways in which genetic counselors and clients together shaped the character of the practice. Genetic counselors today are at the forefront of helping individuals and couples interpret complex genetic information to help them make decisions about whether to have children, to proceed with a pregnancy or have an abortion, or to make plans for future health challenges. As the scope of genetic testing continues to increase at a startling pace, so too does the demand for genetic counselors.[1] An in-depth history of genetic counseling is needed to better understand the assumptions and expectations that undergird genetic counseling today. This work will also make an important contribution to the histories of medicine, reproduction, and

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[1] Alexandra Stern, "Rejecting and Reinscribing Racial Differences," in *Telling Genes: The Story of Genetic Counseling in America*, manuscript chapter in possession of author (Baltimore: Johns Hopkins University Press, 2012); "Career Profiles: Genetic Counselor," *National Human Genome Research Institute*, n.d., http://www.genome.gov/genomiccareers/career.cfm?id=19.

genetics by exploring the intersection of topics such as the role of patients in medicine, abortion and reproductive decision making, and the continued salience of eugenic ideas in the mid-twentieth century.[2]

There are no detailed histories of genetic counseling as yet, but forthcoming work by Alexandra Stern and a recently published monograph by Leslie Reagan provide important foundations by looking at reproductive decision making in terms of science, medicine, and disability. Alexandra Stern's forthcoming book promises to make a valuable contribution to the field and will, in part, trace the shifting racial ideology of genetic counselors in the mid-twentieth century. Leslie Reagan's recently published *Dangerous Pregnancies*, while it does not examine genetic counseling specifically, deserves mention because her history of German measles touches on many of the same issues involved in the history of genetic counseling. She explores how mothers and parents during and after the epidemic not only helped to discover and define the problem, but also pushed to change the cultural and legal apparatus of both abortion law and disability services. Her approach to the role of patients in the medical system and broader culture is valuable for considering the role of genetic counseling clients in the development of the profession.[3]

Scholarship in disciplines such as medical ethics, sociology, political science, and philosophy trace some aspects of the history of genetic counseling, but lack the

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[2] Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 1999), 3.

[3] Leslie Reagan, *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in America* (Berkeley: University of California Press, 2010). Nancy Theriot's call to "take seriously" interactions between patients, doctors, and families in her chapter on women patient's influences on nineteenth-century medical practice and understanding also influenced my approach to the power of patients to shape medical definitions, see Nancy M. Theriot, "Women's Voices in Nineteenth-Century Medical Discourse: A Step Toward Deconstructing Science," in *Gender and Scientific Authority*, ed. Barbara Laslett et al., 1st ed. (University of Chicago Press Journals, 1996), 124–154, quote on 146.

complexity possible in a more extensive study. Most of these works are chapters and articles that focus either on broad surveys of the field from before the 1940s through the present day or that focus specifically on periods such as the formation of the National Society of Genetic Counselors in 1979. This scholarship almost universally focuses on the leaders in the field to explore the relationship to eugenics, the ethos of nondirectiveness (the concept that the genetic counselor should not provide a recommended course of action to her or his clients), or the professional tension in the 1970s between Master's level genetic counselors and medical doctors. These sources are valuable contributions to a broad scholarship of genetic counseling; however, they lack the depth that comes with a more extensive exploration of the interaction between doctors, patients, and counselors.[4]

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[4] Two of the most critical of these brief historical treatments are Diane Paul, "Eugenic Origins of Medical Genetics," in *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature-Nurture Debate*, ed. Diane Paul (Albany: State University of New York Press, 1998), 133–156; James R. Sorenson, "Genetic Counseling: Values That Have Mattered," in *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, ed. Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan (New York: Aldine De Gruyter, 1993), 3–14. Diane Paul's chapter explores some of the ways eugenic ideology influenced genetic counselors and the way they approached interactions with clients. Sorenson traces the ethic of non-directiveness from the early twentieth-century eugenics movement through to post-1970s genetic counseling field to suggest that while genetic counseling today cannot be value neutral its values are important to examine. Both Paul and Sorenson focus almost exclusively on the perspective of genetic counselors. Other work that examines the long view of genetic counseling in the United States include: Robert G. Resta, "The Historical Perspective: Sheldon Reed and 50 Years of Genetic Counseling," *Journal of Genetic Counseling* 6, no. 4 (1997): 375–377; Robert G. Resta, "In Memoriam: Sheldon Clark Reed, PhD, 1910-2003," *Journal of Genetic Counseling* 12, no. 3 (June 2003): 283–285; Robert G. Resta, "Eugenics and Nondirectiveness in Genetic Counseling," *Journal of Genetic Counseling* 6, no. 2 (1997): 255–258; Robert G. Resta, "Historical Aspects of Genetic Counseling: Why Was Maternal Age 35 Chosen as the Cut-Off for Offering Amniocentesis?," *Medicina Nei Secoli* 14, no. 3 (2002): 793–811; Michael Stehney, "Legacy of the American Eugenics Movement: Implications for Primary Care," *Primary Care* 31, no. 3 (September 2004): 525–541, ix. There are also some accounts of developments in genetic counseling after 1970, which include . Regina H. Kenen, "Genetic Counseling: The Development of a New Interdisciplinary Occupational Field," *Social Science & Medicine* 18, no. 7 (1984): 541–549; Joan H. Marks, "The Training of Genetic Counselors: Origins of a Psychosocial Model," in *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, ed. Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan (New York: Aldine De Gruyter, 1993), 15–24; Audrey Heimler, "An Oral History of the National Society of Genetic Counselors," *Journal of Genetic Counseling* 6, no. 3 (1997): 315–336. Other historical chronicles of the origins of genetic counseling can be found in larger works, particularly histories of eugenics and genetics such as Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Berkeley: University of California Press, 1985), 253–258, which offers an international perspective by looking at developments in the United States and Britain, and Edwin Black, *War Against the Weak: Eugenics and America's*

The majority of genetic counselors in the 1940s, 1950s, and 1960s were men who had their initial training in other areas of science or medicine. Sheldon Reed, an influential genetic counselor who gave the field its name, earned his PhD in biology, then went on to study the genetics of small mammals and fruit flies, and moved from there to human genetics after taking over the directorship of a heredity clinic in 1947.[5] Others followed similar trajectories to the field. The founder of another early heredity clinic, Lee Dice, received his initial training in zoology, and others came from areas of science such as zoology, biology, or, like James Neel, combined degrees in medicine and animal genetics. Still others, such as the founder of an early heredity clinic in Winston-Salem, North Carolina, named Allan White made the shift directly from medicine to human genetics.[6] The origins of the human genetics field, though, lay in the eugenics movement. Human geneticists like Sheldon Reed and F. Clarke Fraser, looking back on their field in

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Campaign to Create a Master Race (New York: Four Walls Eight Windows, 2003), 411–26. A final category of work on the history of the eugenics movement falls more into the category of primary source, but is nonetheless useful in considering the origins of the field. These sources were written by people personally involved in the initial development of the field: Sheldon C. Reed, “A Short History of Genetic Counseling,” *Social Biology* 21, no. 4 (1974): 332–9; F. Clarke Fraser, “Introduction: The Development of Genetic Counseling,” *Birth Defects Original Article Series* 15, no. 2 (1979): 5–15; Sheldon C Reed, “A Short History of Human Genetics in the USA,” *American Journal of Medical Genetics* 3, no. 3 (1, 1979): 282–295.

[5] Resta, “The Historical Perspective,” 375; V. Elving Anderson, “Sheldon C. Reed, Ph.D. (November 7, 1910–February 1, 2003): Genetic Counseling, Behavioral Genetics,” *American Journal of Human Genetics* 73, no. 1 (July 2003): 2.

[6] Francis C. Evans, “Lee Raymond Dice, (1887-1977),” *Journal of Mammalogy* 59, no. 3 (1978): 635–638; Reed, “A Short History of Human Genetics in the USA,” 288–291; Kevles, *In the Name of Eugenics*, 223. There was also a fair amount of overlap between the sort of work human geneticists did and both the field of population genetics and some anthropological work, particularly as both studied concepts of race and populations. For valuable histories of genetics and human genetics, an area that has received comparatively little historical analysis, see: Stern, “Rejecting and Reinscribing Racial Differences”; Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics* (Princeton University Press, 2004); Rachel Caspari, “From Types to Populations: A Century of Race, Physical Anthropology, and the American Anthropological Association,” *American Anthropologist* 105, no. 1, New Series (March 1, 2003): 65–76; Barton Childs, *Genetic Medicine: A Logic of Disease* (Baltimore, MD: Johns Hopkins University Press, 1999); M. Susan Lindee, *Moments of Truth in Genetic Medicine* (Baltimore, MD: Johns Hopkins University Press, 2005); Alice Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*, 1st ed. (New York: Times Books: Random House, 1995).

the 1970s, identified self-proclaimed eugenicists like Charles Davenport, founder of the Eugenics Records Office at Cold Spring Harbor, one of the nation's leading eugenics institutions between 1910 and the 1930s, as some of the first human geneticists in the United States.[7]

Human geneticists' tried to distance themselves from aspects of the traditional eugenics movement, particularly its racial prejudices and scientific methods that were coming under increasing fire from social scientists in the middle of the twentieth century, but at the same time they retained concerns about the eugenic effects of their work (that is, what effect their counseling might have on the population as a whole). Sheldon Reed recalled that it was regrettable that "eugenics was well established before the advent of mendelism," because human genetics and its study of heredity might have been more widely accepted without the association with eugenics.[8] Nevertheless, the connections between early human genetics and eugenics are clear not only in the ways geneticists thought about the significance of their work, but also in their professional associations. Four of the first five presidents of the American Society of Human Geneticists, founded in 1948, were board members of the American Eugenics Society.[9]

The eugenics movement in the United States flourished between the early 1900s and the 1930s, at which point it began to fracture. Eugenics was a scientific ideology based on the understanding that a wide array of human characteristics, from eye color, physical stature, and skin color, to "feeble-mindedness," work ethic, and criminality were all inherited. Eugenicists believed that undesirable traits could be controlled for and

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[7] Reed, "A Short History of Human Genetics in the USA," 282–238; Fraser, "Introduction," 7.

[8] Reed, "A Short History of Human Genetics in the USA," 283.

[9] Paul, "Eugenic Origins of Medical Genetics," 138.

eventually eliminated because they were thought to follow a pattern of simple inheritance—one gene to one trait. These understandings provided a rational, scientific underpinning for the racial science of the early twentieth century; eugenicists promoted everything from "Better Babies" and "Fitter Families" contests, in which people had their eugenic quality "judged" by experts, to immigration restriction and compulsory sterilization laws.[10]

Even as traditional eugenics came to be associated in the 1930s and 1940s with racial prejudice, poorly supported science, and Nazi atrocities during World War II, many people continued to adhere to its core principles. These adherents still believed that it was possible, through science, to improve the health and well-being of the human race through selective reproduction, and they distanced themselves from traditional eugenicists like Harry H. Laughlin and Charles Davenport. These perspectives can be discerned not only in popular media, but also the work of human geneticists, genetic counselors, and associated fields like marriage counseling in the 1930s, 1940s, and 1950s.[11]

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[10] Alexandra Stern, *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America* (Berkeley: University of California Press, 2005); Wendy Kline, *Building a Better Race: Gender, Sexuality, and Eugenics from the Turn of the Century to the Baby Boom* (Berkeley: University of California Press, 2005); M S Pernick, "Eugenics and Public Health in American History," *American Journal of Public Health* 87, no. 11 (November 1, 1997): 1767–1772; Paul A. Lombardo and Gregory M. Dorr, "Eugenics, Medical Education, and the Public Health Service: Another Perspective on the Tuskegee Syphilis Experiment," *Bulletin of the History of Medicine* 80, no. 2 (2006): 291–316; Molly Ladd-Taylor, "Eugenics, Sterilisation and Modern Marriage in the USA: The Strange Career of Paul Popenoe," *Gender & History* 13, no. 2 (2001): 298–327; Kevles, *In the Name of Eugenics*; Martin S. Pernick, *The Black Stork: Eugenics and the Death of "Defective" Babies in American Medicine and Motion Pictures Since 1915* (New York: Oxford University Press, 1996); Laura Lovett, *Conceiving the Future: Pronatalism, Reproduction, and the Family in the United States, 1890-1938* (Chapel Hill: University of North Carolina Press, 2007); Nancy Ordover, *American Eugenics: Race, Queer Anatomy, and the Science of Nationalism* (Minneapolis: University of Minnesota Press, 2003).

[11] Rebecca Louise Davis, "'The Wife Your Husband Needs': Marriage Counseling, Religion, and Sexual Politics in the United States, 1930-1980" (Dissertation, Yale University, 2006), http://search.ebscohost.com/login.aspx?direct=true&db=ahl&AN=45917909&site=ehost-live&scope=site; Rebecca L. Davis, *More Perfect Unions: The American Search for Marital Bliss* (Cambridge, MA: Harvard University Press, 2010). On the continuity of eugenic ideology beyond the

Genetic counselors adopted a so-called non-directive approach to counseling their clients in which they refrained from giving specific recommendations as to whether or not clients should have children, but at the same time reassured themselves that their counseling would have a gradually positive influence on the gene pool. This client-centered approach meant that genetic counseling was often more sensitive to client desires and hopes than other medical fields in the mid-twentieth century. This reliance on individual decision making gave prospective parents an outsize role in shaping the development of genetic counseling. While early genetic counselors were concerned about the population effects of their work, their clients were more often interested in the outcomes for their own, individual families and prospective children.

As parents worried about their future children, genetic counselors worried about their association with the eugenics movement. Geneticists like Sheldon Reed seemed to suggest that the core principles of eugenics were sound (particularly that scientifically managed reproduction could improve the population as a whole), but that they had suffered by association with the popular eugenics movement, and especially its exaggerated promises of rapid race betterment and its notions of racial superiority. Many genetic counselors openly discussed the eugenic potentials of their work through the 1950s at the same time they adopted a non-directive stance that stipulated they would not provide direct guidance to their clients. By always leaving the decision firmly in the hands of the would-be parents who came to them for information, and recognizing that many traits (like intelligence) could not be easily predicted, genetic counselors avoided the coercive elements and exaggerated scientific claims of the eugenics movement that

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1930s, see Stern, *Eugenic Nation*; Kline, *Building a Better Race: Gender, Sexuality, and Eugenics from the Turn of the Century to the Baby Boom*; Pernick, *The Black Stork*.

they criticized. At the same time they relied on very similar notions of normality, health, and quality of life as the earlier eugenics movement.[12]

The traditional eugenics movement and genetic counseling shared a concern with parents passing on “defective” genes to their offspring, but while they overlapped in this regard, genetic counselors’ focus on client decision-making meant that in their counseling they were often more focused on individuals rather than populations. Many of the overlaps lay in genetic counselors’ conceptions of hereditary conditions—everything from Huntington’s disease and hemophilia to mental illness and blindness—and the perpetuation of these traits in the population. The continuities between eugenics and genetic counseling are most evident in cases when counselors in the 1940s and 1950s, and much less in the 1960s, directly discussed the “eugenic” and “dysgenic” effects of their work. In these cases they spoke specifically in regards to their hopes that if people with these conditions refrained from reproducing then it would be possible to eliminate the traits from the population in time. This focus on the population effects of individual reproduction, and the implication that individuals had a responsibility to reproduce or not reproduce depending on assessments of their hereditary character, represent the clearest continuity with the eugenics movement. This is where genetic counselors’ non-directiveness intervened in traditional eugenics. In individual counseling sessions, genetic counselors focused less on the repercussions of clients’ decisions on the population and more on the effects on their individual families.

Psychotherapist Carl Rogers developed non-directive therapy as a response to criticism of Freudian psychoanalysis, which identified many emotional and mental complaints with neuroses, and as a component of humanistic psychology. The non-

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[12] Paul, “Eugenic Origins of Medical Genetics.”

directive approach assumed that all people (except the seriously mentally ill) had the potential to work their problems out on their own and only needed a helpful guide to listen.[13] It is unclear whether genetic counselors adopted this particular perspective specifically, or if they instead arrived at a similar technique through their desire to avoid being accused of coercion or social engineering. Nevertheless, both fields shared an expectation that their clients were capable of coming to their own conclusions if provided clear, expert information and a sympathetic ear.

Other fields that developed in the middle decades of the twentieth century, such as marriage counseling, shared the belief that everyday Americans could make "good" decisions with the help of experts. Recent histories of marriage counseling demonstrated how Americans increasingly perceived marital relationships as perfectible and sources of lifelong joy and self-fulfillment. Similarly, genetic counseling's stated intention has been to reduce clients' odds of having a child with birth defects—to envision, in a sense, "perfectible" reproduction. Both marriage and genetic counseling also contribute to the discussion of everyday Americans' interest in measuring their own happiness and normality (two frequently intertwined concepts) against experts' rubrics.[14] They showed a growing willingness throughout the twentieth century to trust and depend upon experts' analyses of, and prescriptions for achieving, the happiness and normalcy they desired. These same Americans brought their own ideas, beliefs, and desires to bear on expert

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[13] Davis, *More Perfect Unions*, 188–191; Ellen Herman, *The Romance of American Psychology: Political Culture in the Age of Experts* (Berkeley: University of California Press, 1995), 264–275.

[14] Davis, *More Perfect Unions*; Kristin Celello, *Making Marriage Work: A History of Marriage and Divorce in the Twentieth-Century United States* (Chapel Hill: University of North Carolina Press, 2009); Natalia Gerodetti, "Rational Subjects, Marriage Counselling and the Conundrums of Eugenics," *Studies in History and Philosophy of Biological and Biomedical Sciences* 39, no. 2 (June 2008): 255–262; Davis, "'The Wife Your Husband Needs'."

advice and often served to reshape professional ideologies in their daily application.[15] Genetic counseling extends the conversation about the powerful role of institutions of authority in defining and influencing personal relationships, beliefs, and identities. It also serves as a reminder of how everyday Americans shaped the real-world manifestations of expert services in the twentieth century.

This history of genetic counseling develops an additional perspective on issues of normality and disability in the middle decades of the twentieth century United States by exploring the ways that genetic counselors and their clients sought to control reproduction in order to avoid abnormality. Would-be parents did not always react the way genetic counselors expected them to, and often proceeded to have children even after they were warned of above-average risk of birth defects. Scholars of disability have explored the rise of the disability rights movement in the second half of the twentieth century, the stigmatizing portrayal of disabled people as freaks, criminals, and irreconcilably "different," and the institutions that hid them away from the rest of society.[16] There is much less work, however, that examines the ways that parents responded to disability, particularly in their own children and prospective children.

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[15] On the complex relationship between therapy, counseling, and religion, and especially interesting discussions of how everyday client and patient needs and desires can shape professions in ways that diverged from their stated professional positions, see Stephanie Natalya Muravchik, *American Protestantism in the Age of Psychology* (New York: Cambridge University Press, 2011); Susan E. Myers-Shirk, *Helping the Good Shepherd: Pastoral Counselors in a Psychotherapeutic Culture, 1925-1975* (Baltimore, MD: Johns Hopkins University Press, 2009); Stephanie Natalya Muravchik, "Came to Believe: American Faith in an Age of Psychology" (Dissertation, University of Virginia, 2007).

[16] Catherine J. Kudlick, "Disability History: Why We Need Another 'Other'," *The American Historical Review* 108 (June 2003): 763–793; Catherine Kudlick, "The Blind Man's Harley: White Canes and Gender Identity in America," *Signs* 30, no. 2 (January 1, 2005): 1589–1606; Joseph P. Shapiro, *No Pity : People with Disabilities Forging a New Civil Rights Movement*, 1st ed. (New York: Three Rivers Press, 1994); Paul K. Longmore and Lauri Umansky, eds., *The New Disability History: American Perspectives* (New York University Press, 2001); Rachel Adams, *Sideshow U.S.A: Freaks and the American Cultural Imagination* (Chicago: University of Chicago Press, 2001); Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (New York: Verso, 1995); James Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley: University of California Press, 1994).

Scholarship that has addressed some of these issues has looked at parents who spoke out for the needs of their disabled children. Recent research on birth defects explores similar issues and makes valuable connections to the broad history of reproduction in the United States.[17] Genetic counseling developed at the intersection of expert advice, client decision-making, and notions of disability.

Beginning in the late 1800s, obstetricians, physicians, and both public and private organizations sought to encourage women to rely on doctors and hospitals during pregnancy. Childbirth before the twentieth century was dominated by women, but during the first half of the twentieth century increasing numbers of middle-class women chose to give birth in hospitals, attended by generally male obstetricians and physicians. By the 1940s, obstetricians and general practitioners were still working to dispel misconceptions about the biological and medical aspects of pregnancy, such as belief in maternal marking, and were meeting with growing success. Continuing the program begun in the late 1800s, they sought to establish new standards for thinking about becoming pregnant and for prenatal care that included dependence on scientific and medical authority and a growing focus on consumer products. The medical and scientific community worked to

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[17] Janice Brockley, "Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History," in *Mental Retardation in America: A Historical Reader*, ed. Steven Noll and James W. Trent, Jr. (New York: New York University Press, 2004), 130–164; Katherine Castles, "'Nice, Average Americans': Postwar Parents' Groups and the Defense of the Normal Family," in *Mental Retardation in America: A Historical Reader*, ed. Steven Noll and James W. Trent, Jr. (New York: New York University Press, 2004), 362–63; Pernick, *The Black Stork*; Janet Golden, *Message in a Bottle: The Making of Fetal Alcohol Syndrome* (Cambridge: Harvard University Press, 2005); Lindee, *Moments of Truth in Genetic Medicine*; Keith Wailoo, *The Troubled Dream of Genetic Medicine: Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease* (Baltimore, MD: Johns Hopkins University Press, 2006); Wexler, *Mapping Fate*; Reagan, *Dangerous Pregnancies*. Sarah Igo's recent work provides another perspective on disability by looking at how Americans constructed definitions of normality. Her work provides a valuable insight into the ways that expert technologies and techniques were integrated into American culture and society and were used to create, alter, and perpetuate concepts of normality, pathology, and health. Sarah Igo, *The Averaged American: Surveys, Citizens, and the Making of a Mass Public* (Cambridge, MA: Harvard University Press, 2007).

redefine pregnancy as a medical condition in need of expert attention.[18] Genetic counselors, in a sense, sought to further extend this medical supervision to include the decision making prior to even becoming pregnant.

Rayna Rapp describes the sort of "hard thinking" that women and parents engage in when faced with genetic testing. The types of prenatal testing she discusses were not available until the very end of the period under consideration in this work, but it is important to consider how the difficult and deeply emotional decisions women had to make about whether to have children or whether to pursue other means of family making might have been similar to the decisions faced by women given the choice of prenatal genetic testing. Barbara Katz Rothman reports that the widespread use of prenatal testing today contributes to women and would-be parents thinking about their pregnancies as "tentative." Pregnant women today are, as Rapp suggests, "moral pioneers" as they grapple with the confusion, anxiety, and ambiguities presented by prenatal testing and abortion. Abortion was illegal for the entire span of this thesis, but the vaguely defined

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18. Kriste Lindenmeyer, *"A Right to Childhood": The U.S. Children's Bureau and Child Welfare, 1912-46* (Urbana: University of Illinois Press, 1997); Molly Ladd-Taylor and Lauri Umansky, *"Bad" Mothers: The Politics of Blame in Twentieth-Century America* (New York: New York University Press, 1998); Charlotte G Borst, *Catching Babies: The Professionalization of Childbirth, 1870-1920* (Cambridge, Mass: Harvard University Press, 1995); Philip Wilson, *Childbirth: Changing Ideas and Practices in Britain and America 1600 to the Present* (New York: Garland Pub., 1996); Andrea Tone, *Controlling Reproduction: An American History* (Wilmington, DE: SR Books, 1997); Deborah F. Weinstein, "Culture at Work: Family Therapy and the Culture Concept in Post-World War II America," *Journal of the History of the Behavioral Sciences* 40, no. 1 (2004): 23–46; Barbara Rothman, *Encyclopedia of Childbearing: Critical Perspectives* (Phoenix, AZ: Oryx Press, 1993); Allen Wilcox, *Fertility and Pregnancy: An Epidemiologic Perspective* (New York: Oxford University Press, 2010); Lynne Curry, *Modern Mothers in the Heartland: Gender, Health, and Progress in Illinois, 1900-1930* (Columbus: Ohio State University Press, 1999); Rima D. Apple, *Perfect Motherhood: Science And Childrearing in America* (New Brunswick, NJ: Rutgers University Press, 2006); Molly Ladd-Taylor, *Raising a Baby the Government Way: Mothers' Letters to the Children's Bureau, 1915-1932* (New Brunswick, NJ: Rutgers University Press, 1986); Cheryl K. Lemus, "'The Maternity Racket': Medicine, Consumerism, and the Modern American Pregnancy, 1876-1960" (Dissertation, Northern Illinois University, 2011); Julie Tharp, *This Giving Birth: Pregnancy and Childbirth in American Women's Writing* (Bowling Green, OH: Bowling Green State University Popular Press, 2000); Molly Ladd-Taylor, "Toward Defining Maternalism in U.S. History," *Journal of Women's History* 5, no. 2 (Fall93 1993): 110; Rickie Solinger, *Wake up Little Susie* (New York: Routledge, 2000); Linda Gordon, *Woman's Body, Woman's Right: Birth Control in America* (New York, NY: Penguin Books, 1990).

and unevenly interpreted potential of therapeutic abortion meant that women in the 1940s, 1950s, and 1960s faced some of the same challenges women today do in regards to prenatal testing. Even women and couples before the legalization of abortion who did not consider therapeutic abortion, though, genetic counseling still presented hard decisions. Genetic counseling clients engaged in something similar to the "hard thinking" that Rapp describes when counselors presented them with complex genetic data about the probability of their future children fulfilling their hopes for a healthy, normal child.[19]

This work traces the development of genetic counseling on its way toward formal professionalization in the 1970s. To that end, it follows a relatively consistent chronological order. The periodization, 1940 to 1970, begins with the founding of the first heredity clinics in Ann Arbor, Michigan, and Minneapolis, Minnesota, and ends just before the first class of Master's level genetic counselors graduated from Sarah Lawrence College. The decade of the 1970s saw a massive expansion in genetic counseling services, as well as its formal professionalization. The 1940s through the 1960s, then, trace the antecedents of these changes. Each chapter looks at a decade in the history of genetic counseling and examines the changes in genetics and approaches to reproduction that influenced developments in the field.

Chapter one describes the foundations of genetic counseling in the 1940s by

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[19] Rapp, *Testing Women, Testing the Fetus*; Barbara Katz Rothman, *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood* (New York, NY: Penguin Books, 1987). On abortion in the United States see Leslie J. Reagan, *When Abortion Was a Crime: Women, Medicine, and Law in the United States, 1867-1973* (Berkeley: University of California Press, 1997); Rickie Solinger, *Abortion Wars: A Half Century of Struggle, 1950-2000* (Berkeley: University of California Press, 1998); Rickie Solinger, "'A Complete Disaster': Abortion and the Politics of Hospital Abortion Committees, 1950-1970," *Feminist Studies* 19, no. 2 (July 1, 1993): 241–268; Kate Maloy, *Birth or Abortion?: Private Struggles in a Political World* (New York: Plenum Press, 1992); James Mohr, *Abortion in America: The Origins and Evolution of National Policy, 1800-1900* (New York: Oxford University Press, 1978). For a valuable perspective on family making and the desire for children see Marsh and Ronner's history of infertility in American: Margaret Marsh and Wanda Ronner, *The Empty Cradle: Infertility in America from Colonial Times to the Present* (Baltimore, MD: Johns Hopkins University Press, 1999).

examining the development of human genetics, the medicalization of pregnancy, and the first heredity clinics. The early years of genetic counseling involved a comparatively small number of people working out of multipurpose human genetics labs that combined research, education, and consultation. Genetic counseling by the end of the 1940s lacked clear standards of practice, but had developed to such a point that these conversations were beginning to take place between leaders in the field.

Chapter two examines the efforts on the part of genetic counselors to define the best practices of their field as it continued to grow in the 1950s. As of 1955 Sheldon Reed reported there were approximately 20 heredity clinics across the United States. Numbers of clients served are difficult to come by, but as of 1959 the Dight Institute alone had counseled more than 2,200 individuals since 1947.[20] Chapter two also traces the ways changes in understandings of human genetics, continued efforts to convince women to depend on science and medicine to rationally manage pregnancy, and notions of disability all influenced the growth and development of the genetic counseling field. Genetic counselors envisioned a national network of genetic counseling centers where Americans could get advice about how to have the normal, healthy babies they hoped for. Genetic counselors engaged in discussions through books, academic publications, and conferences that moved towards establishing generally accepted standards of practice in providing counseling in genetics.

Chapter three in many ways traces the fragmentation of these efforts in the face of dramatic changes in human and medical genetics that not only drew increased client interest, but also attracted many new specialists to the field in the 1960s. By the end of

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[20] Sheldon C. Reed, *Counseling in Medical Genetics* (Philadelphia, PA: W. B. Saunders Company, 1955), 3; Sheldon C. Reed, “Report of Progress, 1957-1959,” *Bulletin - Dight Institute of the University of Minnesota*, no. 11 (1959): 1.

the 1960s the number of clinics offering genetic counseling had increased more then three-fold (see Appendix A). The developments in genetic counseling during the 1960s were still shaped by both clients' plans for normal families and by counselors' ideas about disease and disability, but they were complicated by the possibilities, and the legal and moral ambiguities, of prenatal genetic testing and therapeutic abortion. This chapter details what these developments were, how media and genetic counselors responded to them, and how these changes led some genetic counselors away from prior standards and set up the impetus for formal professionalization in the 1970s.

The field of genetic counseling for the period addressed in this work did not have any professional qualifications or credentialing mechanisms to either control access to their field or to establish agreed-upon procedures for counseling. Because there were no formal requirements, and no evident moves toward local or state licensing requirements, professionals in any number of fields could feasibly practice genetic counseling. Genetic counseling was largely a specialization of research and clinical geneticists and medical doctors throughout this period. During the 1940s and 1950s they were primarily employed out of university departments, medical schools, and the occasional hospital or psychiatric institution. By the 1960s the bulk of genetic counseling moved to medical settings. Formal professionalization in the 1970s included establishment of the first professional organization, the National Society of Genetic Counselors, and the first training program specifically in genetic counseling. The American Board of Genetic Counseling was incorporated in 1993 as the credentialing organization for the genetic counseling profession. There are currently only eleven states that offer state licensing in genetic counseling.[21]

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[21] "States Issuing Licenses for Genetic Counselors," *National Society of Genetic Counselors*, April 26,

The field of genetic counseling contributed to efforts to encourage women, in particular, and parents in general to depend on science and medicine to help manage their pregnancies and make rational decisions about reproduction. It combined these goals with the assumption that the newest discoveries in genetics could help would-be parents produce children that matched their expectations for health and normality, and help genetic counselors slow or stop the spread of genetic diseases. Parents' own desires for normal, healthy children further shaped the development of genetic counseling by motivating them to seek the services of genetic counselors. These prospective parents' perspectives and desires had an outsized influence on the shape of genetic counseling largely due to counselors' sensitivity to client decision making. Genetic counseling developed at the intersection of understandings of human genetics, interests in safer, more rationally managed reproduction, and parents' desires for normal, healthy children.

2012, http://www.nsgc.org/Advocacy/StatesIssuingLicensesforGeneticCounselors/tabid/347/Default.aspx.

CHAPTER II

FOUNDATIONS IN THE FORTIES

In the late 1940s or early 1950s, a concerned mother wrote to the University of Minnesota's Dight Institute for Human Genetics for advice. She had recently lost a child who was born "with single harlip, no palate, hypospadius" and with a partially unformed skull, and had another child with similar conditions. "My husband and I," she wrote, "feel a great need and desire for a normal family," but they were barred from adopting without placing their first child in an institution, which they were reluctant to do out of concern for the child. "I would like to have another baby," the woman concluded, "but if studies such as yours prove that the odds are against us, then, the Lord's Will be done, and we will not have another." The Dight Institute staff advised her in part with an analogy: "each time the mother is pregnant she can 'draw straws' from a bundle, three of which are marked 'normal' and one which is marked 'abnormal.'" They suggested that having another child would be "a real gamble" but left the decision with the parent "where it belongs."[22]

The case of this worried mother, who cared deeply for her disabled child but longed for a "normal" family, and wrote to a group of experts she had read about in the newspaper for help, offers a window into the development of genetic counseling in the 1940s. It is easy to sympathize with this mother's hopes and fears, but at the same time, culturally loaded phrases like "normal family" lead us to consider the historical contingency of ideas about pregnancy, disability, and genetics, and how medicine and culture were intertwined in all three. Furthermore, the fact that she wrote to the geneticists at the Dight Institute for advice—and the type of advice they gave—speaks to

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[22] Reed, *Counseling in Medical Genetics*, 62–63.

the role of experts in the mid-twentieth century United States. It highlights the ways that parents' expectations of both pregnancy and the role of science in their lives were changing. Women in the 1940s were more likely to seek the advice and care of an obstetrician or a physician than they had been in previous decades, and many Americans in the mid-twentieth century were more likely to perceive science and medicine as responsible for making sure that they and their families were healthy and happy.

In the 1940s, a new group of medical science specialists contributed to extending these expectations to include American's fetuses and newborns. Genetic counseling developed along with a growing sense in the mid-twentieth century on the part of many Americans, especially those with access to medical care and the consumer economy, that they were entitled to health and normality—defined in opposition to illness, physical difference, and deviation from the average. These more privileged parents looked to the rapid expansion of scientific and medical knowledge for help and they make up the main voice of genetic counseling clients in this story. In a country with stark divisions based on race, gender, class, and ability, these expectations of health and normality were influenced by understandings of difference and inheritance, and complicated by access to medical and social services. Popular beliefs about genetics and inheritance did not always keep pace with the rapid changes in scientific understandings between the 1930s and 1950, but the sense of optimism in the face of wondrous scientific advances did not suffer for it. Genetic counseling was sandwiched between popular understandings of inheritance and a desire to give Americans new genetic information with which to manage their lives.

Genetic counselors sought to combine efforts to expand access to scientific pregnancy with the newest discoveries in genetics to help would-be parents produce children that matched their expectations and to slow the spread of genetic diseases. At the same time, parents' own desires for normal, healthy children motivated them to seek the services of genetic counselors and further shaped the development of the field. Genetic counseling developed at the intersection of these three factors: understandings of human genetics and heredity, state and medical interests in safer, more mindful, medically managed reproduction, and parents' desires for normal, healthy children. Genetic counseling originated in the minds and the professional literature of human geneticists, but took its shape from the interactions between geneticists and the would-be parents who took their questions, concerns, and hopes by foot and by mail to the nation's new heredity clinics.

Human Genetics in the 1940s

In the 1940s, the fields of both human genetics and genetic counseling were still in their infancy. Some of the most influential human geneticists in the United States founded the nation's first heredity clinics in 1940 and 1941 and ran them alongside their human genetics research labs. These clinics were often multipurpose and pursued research, education, and consultation with the public. Their initial outreach and counseling efforts were based on some combination of a desire to serve and educate the public and the fact that much of their funding required them to do some degree of consultation or educational work. These goals overlapped, though, as human geneticists were often able to use the patient histories they gathered during counseling to contribute to their research into the occurrence of specific conditions in the general population and the likelihood these conditions were inheritable. Human geneticists in the 1940s focused a great deal on what characteristics in people were inherited, how they were inherited, and how these traits might be changed, avoided, or encouraged, depending on their desirability.

Dr. F. Clarke Fraser, a medical geneticist and genetic counselor at McGill University, remembered that, in the 1940s, there were only “a few lonely souls” who called themselves human or medical geneticists in North America. In an interview with historian Daniel Kevles, James V. Neel, one of the preeminent human geneticists in the United States in the 1940s and 1950s, recalled how, at the end of the 1930s, starting a career in human genetics seemed like “a pretty lonely gamble.”[23] A number of factors help to explain the “loneliness” that both Fraser and Neel observed in medical and human genetics. One that historians tend to point to most often is the social and political taint of eugenics and the racial prejudice of people like Charles Davenport and Harry H. Laughlin. Looking back on his early years as a geneticist, though, Fraser recalled less the social implications and more the widespread belief that genetic science—like eugenic science—was inadequately proven and oversimplified.[24] At a time when human geneticists were just beginning to apply more modern statistical methods to the human pedigrees they used for their primary research data, this belief was probably accurate.[25]

Human geneticists responded to these criticisms by carefully distinguishing between “simple mendelian” traits—those that could be traced directly from parent to offspring using basic probability—and characteristics that were inherited in a more complex manner (perhaps they only manifest in men, or they depended on other genes

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[23] James V. Neel, interview and correspondence with Daniel Kevles, quoted in Kevles, *In the Name of Eugenics*, 223.

[24] Fraser, “Introduction,” 5–7.

[25] Kevles, *In the Name of Eugenics*, 194–195.

being present), like intelligence or mental illness.[26] In short, human geneticists still had a lot to learn about heredity, but they used this dearth of knowledge as a shield, of sorts, against association with traditional eugenics. By arguing that even human geneticists—the scientific experts in the field—still had a great deal to learn and could only make strong predictions about a relatively small number of traits, human geneticists built a professional wall between themselves and eugenicists like Laughlin. Human geneticists walked a fine line between distinguishing those traits and conditions they felt they could confidently predict for and clarifying for the public those qualities (like temperament) that could not be inherited or were not well known enough to predict (like intelligence). Though human geneticists worked to distinguish their own scientific credibility from the biased work of their eugenic predecessors, the wall they built was porous. Many human geneticists still considered the eugenic (tending to benefit the human population) and dysgenic (tending to harm the human population) affects of the genes they studied.[27]

During the 1940s genetic counseling and human genetics developed hand-in-hand. In an academic sense, human genetics achieved a measure of legitimacy in December of 1949 with the first annual meeting of the American Society of Human Genetics, formally established just three mothers earlier, on September 11, 1948.[28] Research in human genetics had proceeded at an increasingly fast rate over the course of the 1940s, particularly in the area of blood types and hemolytic diseases. Philip Levine discovered

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[26] Ibid., 194.

[27] Black, *War Against the Weak*, 411–426. For examples of how human geneticists and other scientists sought to explain how their knowledge of genetics was different—more scientific and more accurate—than previous understandings (in a sense, explaining why people should trust them when they themselves highlighted what they did not yet know) see the “Heredity in the Media” section, and particularly articles formulated around debunking prior understandings of heredity.

[28] Kurt Hirschhorn, “A Short History of the American Society of Human Genetics,” *The American Journal of Human Genetics* 83, no. 3 (September 12, 2008): 307–310.

the Rh (Rhesus) factor in 1939. This discovery kicked off a fervor of additional research that associated the Rh factor with an often fatal hemolytic (blood) disease in which the father and child possessed an antigen (that is, they were Rh positive) and the mother did not (Rh negative). If the mother had previously encountered Rh positive blood then she would have antibodies prepared to attack the blood of her Rh positive fetus. This type of research was a boon to human geneticists—and by extension to genetic counselors—because it drew additional attention, and funding, to the field, and eventually led to therapies that helped save children's lives and prevent hemolytic disease in the first place.[29]

Heredity in the Media; or, "How Much Do You Know About Heredity?"

The developing field of human genetics shaped genetic counseling in significant ways: it largely determined the information counselors could impart to their clients, it shaped their understanding of which characteristics could be inherited and which could not, and, as many of the early genetic counselors were also human geneticists, it provided needed funding and academic credibility to the initial heredity clinics where genetic counselors developed their field. As much as human genetics shaped genetic counseling, however, the clients arguably shaped it more. These clients could theoretically be anyone. As one *Newsweek* article reported about the Heredity Clinic at the University of Michigan, in Ann Arbor, most clinics charged no fee for their "frank advice on the mode and manner of heredity" to help parents "decide whether or not to take the risk" of a

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[29] R. A. Fisher, "The Rhesus Factor a Study in Scientific Method," *American Scientist* 35, no. 1 (January 1, 1947): 95–113; Sheldon C. Reed, "A Short History of Human Genetics in the USA," *American Journal of Medical Genetics* 3 (1979): 288; A. W. F Edwards, "R. A. Fisher's 1943 Unravelling of the Rhesus Blood-Group System," *Genetics* 175, no. 2 (February 1, 2007): 471–476; Kevles, *In the Name of Eugenics*, 195–197.

"defect" appearing in their would-be children.[30] In spite of the availability, most genetic counseling clients were white, middle class, and generally well educated. As such, they were also the target audience for many large-circulation magazines, like *Newsweek*, *Life*, and the *Ladies' Home Journal*. While few publications in the 1940s had begun reporting on heredity clinics specifically, these articles are nevertheless important for what they sought to teach readers about genetics.[31] Clients brought a set of assumptions, understandings, and anxieties about genetics, heredity, and health with them to every interaction with a genetic counselor. Mass media, in tandem with conversations with friends and family, shaped at least some of these beliefs.

When human geneticists published in popular sources, then, they sought to overturn older, often eugenic, notions of human inheritance. It is difficult to pinpoint what the general public knew or believed about heredity and genetics in the 1940s, but if the prevalence of articles along the lines of a 1941 piece in the popular *Ladies' Home Journal* titled, "How much do you know about heredity?" are any indication, they still believed a lot of what science had told them in the 1910s and 1920s. Or at the very least doctors, scientists, and editors thought they did. These articles were very often framed as quizzes with questions like: "if a pregnant mother is shocked or severely frightened, the impression passed on to her unborn child may produce some mark or deformity"; "a Negro child may be born to an apparently white couple if one of them had a Negro

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[30] "Clinic for Ancestors," *Newsweek* 28 (December 23, 1946): 56. Detailed information about the finances at all of the early heredity clinics are difficult to come by. The Dight Institute's funding is detailed later, and came partially from its endowment but largely from grants. Anecdotal evidence suggests that the Heredity Clinic stayed afloat through similar means. This is an area that deserves additional study, particularly in looking at how the fee model might have changed over time, particularly in regards to insurance.

[31] A notable exception was a detailed article in *Newsweek* on December 23, 1946, that detailed the activities of the Heredity Clinic: "Clinic for Ancestors."

ancestor"; "sterilization of persons with serious hereditary defects would quickly reduce the proportion of children born with such defects"; and "a taint of character, or a depraved streak, may be inherited from a remote ancestor." The *Ladies' Home Journal* article prefaced the correct answers with the assurance that they were approved by leading scientists and based on knowledge that people inherit their traits through a set of twenty-four chromosomes from each parent, which carry "beadlike particles called 'genes'" that determine hereditary traits.[32]

Readers would have learned from this article that: a mother cannot affect her fetus by impressions alone; a Black child can only be born "if both parents have Negro blood," sterilization would have only a slight gradual effect on the population because "most of the children born with hereditary defects are produced by the mating of two outwardly normal parents who are 'carriers' for defective genes," and traits for personality are too complex to skip several generations."[33] Similar articles reassured curious Americans with the exaggerated claim that genetics was "one of the most exact of all biological sciences" and that "many problems of heredity [had] been solved." They also might have learned that, while mental improvements gained during a parents' life could not be passed on, baldness and musical ability could be.[34]

Articles also tried to sort out the comparative importance of both environment and heredity. In a 1941 *Ladies' Home Journal* article, the Chicago Board of Health's Dr.

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[32] Amram Scheinfeld, "How Much Do You Know About Heredity?" *Ladies' Home Journal* 58 (November 1941): 121. Articles in *Life* and *Newsweek* described genes and inheritance in similar terms: "Lottery of the Genes," Newsweek 22 (September 13, 1943): 86–87; "Genetics: Young Science Studies Continuity of Life," Life, March 17, 1947. It was not until the 1950s that the correct number of chromosomes from each parent, 23 (46 total), was determined.

[33] Scheinfeld, "How Much Do You Know About Heredity?," 122–123.

[34] Alan A. Brown, "What Do You Know About Heredity?" *Hygeia* 25, no. 6 (June 1947): 454.

Herman N. Bundesen used a horse racing analogy to explain the dual importance of inherited traits and environment. "Both breeder and trainer will agree," he assured readers, "that you cannot train a draft-horse cold to win a horse race." Bundesen proceeded to explain how a child inherited "that which is seen, such as the color of his eyes, tallness or shortness, curly or straight hair," as well as "the unseen, such as structural strength and weakness inside his body . . . and mental characteristics, such as temperament and personality."[35] Bundesen concluded by instructing readers to "work with [their] physician" to overcome defects in their children in any way possible.[36]

Bundesen's recommendation was one women (and to a lesser extent men) had been receiving from doctors, obstetricians, and organizations like the United States Children's Bureau for the past three decades. Readers who followed Bundesen's advice to depend on their physicians might have found themselves waiting in a doctor's office reading an article like the one in a 1947 issue of *Hygeia,* the American Medical Association's "consumer health magazine." In it, Nathan Fasten described the inheritance of colorblindness. Fasten concluded with some advice to would-be parents: "Those who desire to have normal children, minus the deficiencies which have been considered, provided they themselves are normal, must give attention to the mates whom they marry." "As a rule," Fasten continued, "normal parents give origin to normal children." But, he warned, "some of these presumably normal parents may carry hidden genes for defective traits, which may appear in the offspring. Therefore, it is exceedingly important to know not only something of the immediate parents, but also of a number of

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[35] Herman Niels Bundesen, "Heredity," *Ladies' Home Journal* 58 (December 1941): 142.

[36] Ibid., 144.

generations of the ancestors which preceded them."[37] We can envision the reader, perhaps a young woman considering children, mentioning the article to her doctor during the routine visit, and the doctor perhaps referring her to a heredity clinic. This was, at least, what genetic counselors hoped would happen.

Pregnancy and Medicine in the 1940s

Genetic counseling built upon the expectation that Americans considering having children would look to their doctors and other medical specialists for advice. For much of the 1910s, 1920s, and 1930s, eugenics advice encouraged Americans to carefully consider the characteristics in their potential husbands and wives because, as a 1922 American Social Hygiene Association poster reminded young girls: "If you want your children to be well-born, choose your husband because of the fine qualities in his family as well as in himself."[38] By the 1940s, American women in particular had been subject to almost half a century of encouragement to seek professional medical services during and after pregnancy. Genetic counseling extended this medicalized expectation to would-be parents' decisions to have children in the first place.

Genetic counselors and would-be parents increasingly came to view pregnancy in rational, scientific terms even while responding to emotionally charged desires for normal, healthy children. But while genetic counseling contributed to these approaches to pregnancy and reproduction in the mid-twentieth century, it by no means created them. In the early-twentieth century Progressive Era reformers and obstetricians worked to address the maternal mortality rate in the United States by producing policies and advice literature focused on encouraging women to discard the "superstitions" of the past, such

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[37] Nathan Fasten, "Sex-linked Factors in Heredity," *Hygeia* 25, no. 8 (August 1947): 641.

[38] American Social Hygiene Association, "Youth and Life: What Kind of Children?" Image, *Social Hygiene Posters*, 1922, http://special.lib.umn.edu/swha/exhibits/hygiene/youth_and_life/index.htm.

as the “maternal marking” evident in the “How much do you know about heredity?” article discussed earlier, and depend instead on trained experts for guidance. These desires to address infant and maternal mortality by focusing on maternal health, prenatal care, and child care, wound up also politicizing pregnancy—this made maternal health into a public affair rather than a more private matter for family and the local community. Women reformers, “maternalists,” promoted notions of women’s health that included professional prenatal and postnatal care. These notions had not only political and legal outcomes in things like the United States Children’s Bureau (1912) and the Sheppard-Towner Maternity and Infancy Protection Act (1921), but also served to build a new identity for mothers. This new role was meant to be based on science and medicine rather than religion and tradition.[39]

New perspectives on pregnancy and motherhood also came to shape popular perceptions of “good” and “bad” mothers. Good mothers were women who sought adequate, professional prenatal and postnatal medical care. Bad mothers, on the other hand, were often Black, immigrant, or working women who could not meet these expectations due to racial, financial, or educational limitations.[40] These same barriers stood between nonwhite, immigrant, and poor women and parents when it came to access to genetic counseling. Though many heredity clinics in the 1940s were free, simply finding out about them assumed a certain level of engagement with the same white, middle-class environment that provided access to other aspects of modern prenatal care.

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[39] Reagan, *Dangerous Pregnancies*, 7–21; Apple, *Perfect Motherhood*; Lemus, “‘The Maternity Racket’: Medicine, Consumerism, and the Modern American Pregnancy, 1876-1960”; Rima D. Apple, *Mothers and Medicine: A Social History of Infant Feeding, 1890-1950*, 1st ed. (Madison: University of Wisconsin Press, 1987), especially 114–134; Richard W. Wertz and Dorothy C. Wertz, *Lying-In: A History of Childbirth in America* (New Haven: Yale University Press, 1989).

[40] Lemus, “‘The Maternity Racket’: Medicine, Consumerism, and the Modern American Pregnancy, 1876-1960,” 8–9; Ladd-Taylor and Umansky, *“Bad” Mothers*, 10–12; Solinger, *Wake up Little Susie*.

Premarital medical exams were another aspect of 1930s and 1940s science that promoted—and in some states legally mandated—relying on medical specialists for advice about reproduction. A marital advice textbook published in 1940 described this commonly suggested practice. Such exams were meant "for the definite purpose of determining the adequacy of health and hereditary foundation of the proposed mating," and to "promote marital adjustment." Part of this examination was meant to clear up any concerns regarding the potential for "feeblemindedness, insanity, epilepsy, or other inheritable defects" in children.[41] The textbook, like the American Social Hygiene Association posters of twenty years earlier, suggested that when "choosing a mate" one should not overlook the "importance, during the courtship period and before engagement, of each partner making an inquiry, without unnecessary officiousness, into the hereditary background of the proposed mate" to check for normality.[42]

Unobtrusive "checking up" on a potential husband's or wife's family to watch for hereditary conditions, regular check-ups with doctors and obstetricians before, during, and after pregnancy, and cultural notions of what it meant to be a good, responsible mother all served to create an environment in which women were increasingly called upon to depend on medical specialists. In terms of statistics, attempts to convince women to depend on doctors during pregnancy seemed to have worked. By 1939, three quarters of all women living in urban areas, and half of all women, gave birth in a hospital.[43] Women's decisions to give birth in hospitals, on the one hand, represented an increased

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[41] Norman Himes, *Your Marriage: A Guide to Happiness* (New York: Farrar & Rinehart, Inc., 1940), 130, 135. On premarital medical exams, heterosexuality, and medicine in the 1950s see Carolyn Lewis, *Prescription for Heterosexuality Sexual Citizenship in the Cold War Era* (Chapel Hill: University of North Carolina Press, 2010), chapter 4..

[42] Ibid., 62.

[43] Wertz and Wertz, *Lying-In*, 133.

degree of agency in their reproductive decision making, but on the other hand represented a loss of control over the birthing process.[44] In this climate of increased medicalization genetic counseling offered yet another avenue through which to "control" the process of reproduction, but, like hospital births, genetic counseling offered women both more decision-making power and circumscribed the acceptability of their choices.

Genetic Counseling: Negotiating with Eugenics

While the fields of human genetics and genetic counseling were taking their first professional steps in the 1940s, groups of obstetricians, public health activists, and physicians continued the work of bringing science to reproduction that they had been engaged in for the past few decades. The first heredity clinics positioned themselves to fill these needs. Three of the earliest clinics were the Dight Institute at the University of Minnesota, in Minneapolis, the Heredity Clinic at the University of Michigan, in Ann Arbor, and the medical genetics program in the Bowman Gray School of Medicine at Wake Forest University, Winston-Salem, North Carolina.

The Heredity Clinic was established in 1940 with funding from a research grant from the Board of Governors of the Horace H. Rackham School of Graduate studies. The first staff members were C. W. Cotterman, C. Nash Herndon, and Lee Dice the first director. They hired human geneticist and Dr. James V. Neel six years later to serve as the physician-in-charge of the clinic. By the early 1950s, the clinic subsisted on the budget of the Institute of Human Biology and on research grants.[45] The Bowman Gray School of Medicine's genetics program had similar origins. William Allan, a physician with an

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[44] Lemus, "'The Maternity Racket': Medicine, Consumerism, and the Modern American Pregnancy, 1876-1960," 5–6.

[45] Lee R. Dice, "Heredity Clinics: Their Value for Public Service and for Research," *American Journal of Human Genetics* 4 (1952): 9–10.

interest in eugenics started the program in the early 1940s. After Allan died in 1943, C. Nash Herndon moved to Wake Forest to take over his position.[46]

A bequest left to the University of Minnesota by Dr. Charles Fremont Dight made possible the founding of the Dight Institute. In the 1930s, Dight had been in contact with the presidents of both the University of Michigan and the University of Minnesota about setting up a bequest to fund research in human genetics. Clarence Cook Little, then the president of the University of Michigan, responded to Dight that the money would be used to fund fellowships and scholarships. Evidently preferring something more direct, Dight instead left his money to the University of Minnesota, where they established the Dight Institute under the directorship of Clarence P. Oliver.[47] Dight meant for his endowment "to support the study and promulgation of genetics as it applies to man." The $4,500 annual income from this gift provided for the basic needs of the Dight Institute: a part-time director and researcher, a part-time research assistant and secretary, and "a modest program of research in human genetics."[48] By the end of the decade, though, the institute's goals had outgrown its endowment. The Dight Institute, in Minneapolis, and the Heredity Clinic, in Ann Arbor, represented the earliest efforts in the application of human genetics through consultation and counseling. Small, part-time, perennially understaffed and underfunded—at least below the hopes of their directors—the physical realities of these centers stood in sharp contrast to their professional aspirations.

These professional and scientific goals were evident not only in the research and

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[46] Stern, "Rejecting and Reinscribing Racial Differences," 92.

[47] Evadene Burris Swanson, "Biographical Sketch of Charles Fremont Dight, M.D.," *Bulletin - Dight Institute of the University of Minnesota*, no. 1 (1943): 18.

[48] Clarence P. Oliver, "Report on the Organization and Aims of the Dight Institute and Its Accomplishments for the Year Ending June 30, 1942," *Bulletin - Dight Institute of the University of Minnesota*, no. 1 (1943): 1.

academic literature these genetics labs produced, but also in the sources of their funding. Charles F. Dight is a perfect example. Dight was a eugenicist, a socialist, and had an intense interest in social reform that is clear in the guidelines for his bequest. His enthusiasm as a doctor, public speaker, political candidate, and philanthropist centered on efforts such as "socialized medicine," public health, and eugenics.[49] Dight wrote that he wanted most to be remembered for his efforts to teach people "the importance of race betterment through eugenics, because man's biology to a greater degree than anything else determines his capacity and behavior."[50] Dight made clear in his will that he hoped his bequest would further research and education in genetics and eugenics.

The Dight Institute, in keeping with the terms of the bequest, sponsored lectures and produced pamphlets on genetics, the eugenic impact of human genetics work, and related topics. They also established themselves as a consulting organization for people with questions about heredity and an interest in "predicting the probable occurrence of traits in a member of a family." The institute's research program to collect family histories of traits to study the hereditary nature of these characteristics also matched Dight's hopes for a genetically savvy populace.[51] Even as the Dight Institute relied on the bequest of a more traditional eugenicist like Charles Dight—among whose publications were titles like *Human Thoroughbreds, Why Not?* (1922) and "Heredity, Eugenics, and Human Betterment" (1930)—the Dight scientists worked to distance themselves from the social and racial aspects of the "old" eugenics by not telling their clients whether or not to have children, and by debunking older eugenic theories of inheritance.

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[49] Evadene Burris Swanson, "Biographical Sketch of Charles Fremont Dight, M.D.," 9, 11.

[50] Ibid., 13.

[51] Oliver, "Report on the Organization and Aims of the Dight Institute and Its Accomplishments for the Year Ending June 30, 1942," 1–2.

The Dight Institute was not the only human genetics institute that accepted funds from what they acknowledged were questionable sources. The Heredity Clinic, in Ann Arbor, and the human genetics clinic established at Wake Forest University at the Bowman Gray School of Medicine both accepted about $100,000 from millionaire, Nazi admirer, and Pioneer Fund underwriter Wickliffe Draper.[52] Both James Neel at the Heredity Clinic and C. Nash Herndon at Wake Forest University justified accepting funds from Draper as a compromise between their fear of his driving their research to find (qualitative) racial differences between Blacks and Whites and their desperate need for money.[53] Neel was initially very cautious about accepting the money, but relented by 1950, when he wrote to Sheldon Reed—who never accepted Draper's overtures—that he believed the Heredity Clinic "would benefit in the not too distant future from Col. Draper's largesse." Neel continued, in a reference to his earlier concerns about Draper's and the traditional eugenics movement's racial ideologies, that he was organizing a large research project on "assortative mating which we sincerely hope can be kept entirely out of the realm of racist problems."[54]

Leading geneticists like Reed and Neel felt they could accept funding from people like Draper and at the same time distance themselves from what they perceived to be poor science and potentially embarrassing social positions—essentially using bad money

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52. Stern, "Rejecting and Reinscribing Racial Differences," 88–91. The Pioneer Fund was created in 1937, shortly before the close of the Eugenics Record Office in 1939. Harry H. Laughlin, a staunch eugenicist openly prejudiced towards the superiority of the White race, was the Pioneer Fund's founding president. The organization proceeded to fund research into racial superiority and gained particular notoriety in 1994 with the publication of Richard Herrnstein's and Charles Murray's *The Bell Curve*. See Michael G. Kenny, "Toward a Racial Abyss: Eugenics, Wickliffe Draper, and the Origins of the Pioneer Fund," *Journal of the History of the Behavioral Sciences* 38 (2002): 259–283; William Tucker, *The Funding of Scientific Racism: Wickliffe Draper and the Pioneer Fund* (Urbana: University of Illinois Press, 2002).

53. Stern, "Rejecting and Reinscribing Racial Differences," 90.

54. James V. Neel to Dr. Sheldon Reed, March 28, 1950, quoted in Ibid., 91.

for good research. The genetics program at the Bowman Gray School of Medicine in Winston-Salem was the only heredity clinic of the three that accepted Draper's money without evident qualms. In return for $100,000 to endow a medical genetics professorship, which he would later hold, Nash Herndon accepted without concern Draper's conditions that the Bowman Gray clinic would "not advocate miscegenation" and would accept sterilization "as a therapeutic weapon where medically indicated."[55] This willingness to cooperate with Draper's requests was less surprising coming from the Bowman Gray clinic than from someone like Neel, who was critical of Draper's approach to science. The genetics department at Bowman Gray supported North Carolina's sterilization program, and Allan and Herndon were involved in establishing a eugenics program in their county that worked with the local health office to gradually "eliminate certain genetically unfit strains from the local population."[56] Most early heredity clinics were not as enthusiastic about accepting such funding. Fledgling clinics and the similarly nascent field of human genetics in the United States in the 1940s were willing, however, to hold their noses in order to fund their projects.

At the same time early genetic counselors tried to distance themselves from, or at least avoid public association with, supporters of traditional eugenics they acknowledged eugenic qualities in their studies. In fact, many of the first genetic counselors in the 1940s and into the 1950s openly—if carefully—discussed the eugenic and dysgenic implications of their work. Genetic counselors argued that their field should by no means engage in coercion and should never tell a couple what to do, but they were conflicted

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[55] Nash Herndon to L. H. Snyder, March 10, 1950, quoted in Stern, "Rejecting and Reinscribing Racial Differences," 92.

[56] "Report of Department of Medical Genetics," May 1, 1943 to May 1, 1944, Nash Herndon and William Allan Papers, quoted in Stern, "Rejecting and Reinscribing Racial Differences," 93.

over the potential for reproducing hereditary disease in a larger population as a result of their non-action. Furthermore, human and animal geneticists like Lee Dice and H. J. Muller openly worried about the future health of the human race if undesirable genes were allowed to spread unchecked. These concerns fed into genetic counselors' attempts to convince everyday people to seek genetic counseling and to encourage physicians to refer their patients.

This is not to say that all, or even most, genetic counselors were really eugenicists underneath, or even that they supported eugenics. It is evident from their writings that they saw no cognitive dissonance between considering the "eugenic" and "dysgenic" affects of their counseling efforts, while simultaneously rejecting traditional eugenic understandings. They widely disagreed with the idea that a wide variety of traits and behaviors could be inherited, with the hierarchical organization of race, and with the belief that individuals could and should be coerced into making "eugenic" decisions. Genetic counselors had a lot more in common with pronatalist eugenics that sought instead to encourage eugenically responsible behavior through incentives and education. As a result, genetic counselors resisted giving clients advice about how they should use the genetic information provided to them. There was, nevertheless, a lot of overlap with eugenics in genetic counselors' expectations of what constituted a good client decision and with their clients' own desires.

Geneticists at heredity clinics wanted more people to consult with them in order to counteract the belief that modern medicine, by curing a wider range of medical conditions, allowed more people with genetic conditions to pass their "defective genes" on to their offspring. H. J. Muller, who won a Nobel Prize for showing that x-rays caused mutation in fruit flies, articulated this concern during his 1949 presidential address to the then newly established American Society of Human Genetics. Muller argued that, because of modern medicine, people carrying particularly undesirable genes who would previously have died before passing those genes on were more able to reproduce.[57] Many genetic counselors echoed these concerns in their writings. They worried about an increase in genetic disease that might be caused by more effective treatment of those conditions. These concerns, while perhaps logical coming from the medical community in terms of making an intervention in lethal conditions such as Tay Sachs disease, nevertheless raise questions because of their historical similarity to eugenic discourse.

Geneticists and genetic counselors also addressed the notion that a person's environment played an important role in their development by stressing that genetics established the limits and susceptibility to disease within which environmental influences operated. A dramatic warning along these lines came from a scientist named Elmer Roberts in his address for the 1945 annual Dight Institute Lecture. His argument not only reflected Muller's statement about the spread of disease, but also shows how geneticists still tended to group medical conditions with social factors like productivity. Roberts issued an almost apocalyptic warning, that

> the Fourth Horseman rides today as he has ridden during the past ages. His vigor from infectious diseases which are the result of environment is being continually weakened by the remarkable achievements of the medical profession, but through heredity he is receiving constant nourishment from the biological stream running through successive generations.[58]

Roberts not only echoed Muller's concern that American medicine's success in

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[57] H. J. Muller, "Our Load of Mutations," *American Journal of Human Genetics* 2, no. 2 (June 1950): 170–171.

[58] Elmer Roberts, "Biology and Social Problems," *Bulletin - The Dight Institute of the University of Minnesota*, no. 4 (1946): 18–19.

combating infectious disease had only intensified the danger posed by genetic disease, but also modeled the way that human geneticists began to incorporate both environmental and hereditary influences into their approaches. Roberts' perspective was that while environment had an effect on human characteristics, it could only act on an individual's genetic potential. He believed a person could become only as healthy or productive as his or her heredity allowed. He asked, then, why people neglected to improve the heredity of the human race even while they strove to improve the environment. His suggestion was to inculcate "a sense of individual responsibility for the improvement of one's self and of the social order in which one lives" at the same time.[59] Scientists like Roberts, Muller, and Dice believed the only way to prevent "a full fledged resumption of ordinary natural selection" (Roberts' "Fourth Horseman") would be through "purposive control over reproduction."[60] This suggestion was very much in keeping with what had, since the late-nineteenth century, fallen under the rubric of eugenics.

Leaders in the field of genetic counseling such as Lee Dice and Sheldon Reed assumed that people would make what geneticists perceived to be good choices (good for the population) if genetic information was available to them.[61] Many scientists, politicians, professionals in the broadly-defined social welfare field, and everyday Americans continued to support eugenic-minded programs after 1945, although eugenics had acquired negative associations with Nazi Germany in World War II.[62] But human

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[59] Ibid., 20.

[60] Muller, "Our Load of Mutations," 150.

[61] Diane Paul makes a similar argument in Paul, "Eugenic Origins of Medical Genetics," 134.

[62] See, for example, the excellent descriptions of eugenic ideology in areas such as marriage counseling, public policy, and popular culture in Kline, *Building a Better Race: Gender, Sexuality, and Eugenics from the Turn of the Century to the Baby Boom*; Stern, *Eugenic Nation*; Pernick, *The Black Stork*.

geneticists could not merely shrug off the association with fascism, authoritarianism, and genocide. Proponents of heredity counseling, then, were faced with a dilemma. Their solution? Faith. Faith that any normal couple would avoid having a disabled child if properly informed. With knowledge of genetics and inheritance "it would be an abnormal person indeed who would not refrain from having children" if there was a risk those children would be "defective."[63]

Sheldon Reed also argued that human geneticists were not advocating anything new by suggesting that some people refrain from having children. He wrote in a 1949 Dight Institute *Bulletin* that the challenge of eugenics is of "drawing with justice a line between those whose offspring will be assets to society in the future and those whose offspring will be liabilities."[64] He suggested that, because the courts did this all the time by institutionalizing people, "there is no clear distinction between a eugenics program and the effects of our socio-legal structure." Reed advocated genetic counseling as a way to add knowledge of human genetics to the "eugenics trend" already produced by the court system.[65] Reed's position further suggests how early genetic counselors comfortably retained notions of eugenics consistent with stopping the spread of "defective" genes while at the same time rejecting the blatantly hierarchical, racially motivated eugenics of previous decades.

These perspectives formed an important foundation of the genetic counseling profession that have been too often ignored or downplayed since the 1970s. Discussions have appeared in conversations about medical ethics, but genetic counseling since these

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[63] Dice, "Heredity Clinics," 2.

[64] Sheldon C. Reed, "Counseling in Human Genetics," *Bulletin - Dight Institute of the University of Minnesota*, no. 6 (1949): 7.

[65] Ibid., 8.

early years has depended on the notion of non-directiveness—in which, as the early genetic counselors suggested, the counselor gives no instructions or suggestions to the client—as a means to avoid associations with eugenics.[66] It is clear from the history, however, that genetic counselors since the 1940s adopted a so-called non-directive approach while at the same time reassuring themselves that their counseling would be, on balance, eugenic; that is, counseling would result in a gradual bettering of the human gene pool. This client-centered approach focused on not giving direct instructions meant a high degree of sensitivity to individual client needs, anxieties, and hopes. This dependence on individual decision-making would give prospective parents a large role in shaping the emerging practice of genetic counseling.

Historicizing the use of a non-directive approach in genetic counseling raises important questions about its underlying assumptions. It is evident from the ways genetic counselors discussed the potentially eugenic and dysgenic effects of their work that they were perhaps only partial converts to the notion of non-directiveness: they accepted that their role was not to tell clients what to do, but they also had faith that these clients, if properly educated, would make the "right" decisions.

Geneticists concerned themselves with avoiding coercion and fretted over whether their work would ultimately help or harm the human race, but counselors were not the only ones worried about babies born with atypical bodies. Their clients were also

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[66] For a good sample of some of the discussions among medical ethicists and genetic counselors in the 1980s, 1990s, and 2000s about these issues see: Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan, eds., *Prescribing Our Future: Ethical Challenges in Genetic Counseling* (New York: Aldine De Gruyter, 1993); Erik Parens and Adrienne Asch, eds., *Prenatal Testing and Disability Rights*, Hastings Center Studies in Ethics (Washington, DC: Georgetown University Press, 2000); Dorothy C. Wertz and John C. Fletcher, "Communicating Genetic Risks," *Science, Technology, & Human Values* 12, no. 3/4 (July 1, 1987): 60–66; Burke Meredith, "Genetic Counselor Attitudes Towards Fetal Sex Identification and Selective Abortion," *Social Science & Medicine* 34, no. 11 (June 1992): 1263–1269; Silja Samerski, "Genetic Counseling and the Fiction of Choice: Taught Self-Determination as a New Technique of Social Engineering," *Signs* 34, no. 4 (June 1, 2009): 735–761.

interested, and came to the situation with a different set of worries. Would-be parents who came to them for help often seemed far less interested in the eugenic or dysgenic nature of their decisions and much more focused on their hopes for a normal, healthy baby. It was a difference, in a sense, between concern for the "population" and concern for their individual family. Other clients—physicians, state institutions, and adoption agencies making up the bulk of them—had questions that ranged from inquiries about basic genetics to requests for professional consultation.

Many genetic counselors rejected the hierarchical racial categories favored by the traditional eugenics movement, but at the same time treated race as a concrete, inheritable trait. Between 1947 and 1949, the Dight Institute saw 216 clients. This is not a staggering number, and was indicative of the field's relative newness, but it nevertheless marked an increase from previous years. Most questions in the 1940s came from adoption agencies concerned about the inheritance of skin color or the effects of consanguinity on a child's "suitability" for adoption. The Dight Institute based its racial matching recommendations on the understanding that "there will be no reversion to characteristics any more Negroid than those which" an individual himself or herself might possess (as long as she or he had children with someone as "white" or "whiter" than him or herself).[67] At the same time, though, they often defined children as nonwhite based on very minor characteristics, such as slight skin coloration on a child's knuckles. Though such questions from adoption agencies made up a large portion of their consultation load, in their writing geneticists like Reed and Dice focused more of their attention on questions about the reappearance of genetic defects.[68] Many human geneticists tended to support degrees of racial equality,

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[67] Reed, "Counseling in Human Genetics," 10–11, quotation on page 10.

[68] Stern, "Rejecting and Reinscribing Racial Differences," 94, 94–103. Because this thesis is necessarily limited in scope to focus on pregnancy and the ways genetic counseling shaped, and was shaped by,

and seem to have preferred focusing their research and attention on genetic disease. Many of the individuals and couples who sought out their services had similar priorities.

By seeking out genetic counselors, everyday Americans brought the problems they observed in their bodies and the bodies of their loved ones to the attention of medical science. In this sense they were active participants in defining their conditions as in need of treatment or prevention. Conditions like epilepsy, "mongolism," Huntington's chorea, diabetes, schizophrenia, and polydactyly came to the attention of human geneticists primarily in the bodies and anxieties of their clients.[69] It is important to bear in mind the complexity of disease, and particularly of individual diseases, as historically contingent concepts that have been created and recreated in conversations between patients, family, friends, doctors, and scientists in, as Nancy Theriot suggested, "a dialogue in which symptoms of illness were transformed into disease entities."[70] Through this approach we can get at the voices of those otherwise largely voiceless patients in medical and scientific case studies. These patients are particularly important in a history of genetic counseling because of their formative role in shaping the direction of the profession and, particularly in the context of disease and abnormality, in the outlining the

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reproductive decision making in the mid-twentieth century, it will not focus on genetic counselor's negotiations of racial definitions and difference. For more on this topic, see Alexandra Stern's history of genetic counseling, *Telling Genes*, forthcoming from Johns Hopkins University Press in 2012, which delves more deeply into genetic counselors' work with adoption agencies and the ways that their continued scientific categorization of race defied their own proclamations of racial equality. Stern argues that early genetic counselors relied on the construct of populations—a concept with marked similarities to earlier concepts of race—to sometimes support desegregation and interracial unions and at other times "reinscribe" racial differences. See also Ellen Herman, *Kinship by Design: A History of Adoption in the Modern United States* (Chicago, IL: University of Chicago Press, 2008), especially 130–133 and 196–201.

[69] Reed, "Counseling in Human Genetics," 14, Table 1.

[70] Theriot, "Women's Voices in Nineteenth-Century Medical Discourse: A Step Toward Deconstructing Science," 139. Leslie Reagan employed a similar approach in her history of motherhood, disability, and abortion that looked at the German Measles epidemic of the mid-twentieth century: Reagan, *Dangerous Pregnancies*, 22–54.

conditions that genetic counselors studied. Many of their records came from such clients and the detailed “human pedigrees” they collected based on clients’ observations.

It is difficult to discern exactly what counselors said to clients and whether they conveyed these attitudes specifically, but clients anxieties about atypical children are evident from the growing numbers of clients and the types of concerns they brought to geneticists. Genetic counseling clients, influenced by their own culturally motivated ideas about normality and acceptable kinds of difference in their families, brought their concerns in growing numbers to genetic counselors directly, and to their physicians and obstetricians, who in turn consulted with geneticists. In one such case, for example, an obstetrician asked the genetic counselors at the Dight Institute about the odds of a family having more than one child with albinism. “The young couple is much perturbed about the situation,” the obstetrician recounted. The Dight Institute’s response, as much as the couples’ initial anxiety in the face of albinism, says a great deal about how difference, and this condition in particular, were interpreted at the time. “The chance,” replied the Dight Institute counselor, “that this unhappy couple will produce an albino at the next ‘try’ is exactly one in four, statistically speaking.” The description of the couple as “unhappy,” not to mention the fact that the child is often referred to not as a person, but as a condition (“an albino”), speaks volumes about the way human geneticists perceived atypicality negatively. Furthermore, the fact that the clients brought up this concern to their obstetrician suggests a similar perspective on this condition specifically, and atypicality in general. This counseling encounter, like many others, did not end with a specific recommendation to have another child or not. Like in other counseling sessions, the Dight Institute maintained that it was up to the couple to determine “whether or not to accept the risk."[71]

From the backward gaze of the historian, issues of perspective, power, the role of the expert, and the cultural relativity of categories like normal and healthy are easier to discern. But for the historical actors themselves, these concepts were so embroiled in the everyday as to be nearly invisible. It is the job of the historian not only to make these theoretical concepts and their implications clear, but also not to lose sight of the lived experiences of those historical actors who actually experienced the fear of having a "defective" child, the joy of having a healthy one, or the relief in response to good news from a genetic counselor.

The Heredity Clinics

Looking back on the early heredity clinics in which genetic counselors performed research, taught genetics courses, and counseled people on topics of heredity, the contrast between their inauspicious surroundings and tools and their far-reaching goals is striking. Much like the high-technology medical equipment of today, paper was the lifeblood of heredity counseling in the 1940s. Patient histories were taken down on paper. Detailed family pedigrees used to track traits such as epilepsy and albinism were traced out on paper. Reams of research data, disease incidence statistics, and frequency tables all were stored on paper. These records formed the critical foundation of human genetics research and counseling. In the 1940s the Heredity Clinic at the University of Michigan in Ann Arbor stored this invaluable paper in a dry "two-story wooden building" at 1135 East Catherine Street. Built in 1910 as a private home, it later served as the interns' residence until the University provided more suitable quarters. A cast-off sort of building, the

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[71] Reed, "Counseling in Human Genetics," 12. The "risk" quotation was in response to an inquiry about the inheritance of harelip and cleft palate.

Catherine Street house stood vacant for at least a year before the Heredity Clinic moved in. Lee Dice, the Heredity Clinic's founding director, described the initial location as "a constant fire hazard to the valuable clinic records." Though "badly crowded and not well adapted for clinic purposes," he admitted the building had served its purposes for the early years of the clinic.[72] In 1964 the clinic would move into the newly constructed Lawrence D. Buhl Research Center for Human Genetics, a physical affirmation of the dramatic expansion genetic research and counseling had undergone by that time. But in the 1940s they remained in the second-hand, cramped quarters on East Catherine Street.

The aspirations behind early heredity counseling centers like the Heredity Clinic and the University of Minnesota's Dight Institute bore little resemblance to their modest surroundings. A decade after founding the Heredity Clinic, Dice lamented the "flood of requests for advice" that followed "any publicity in the paper," because their lack of funding left them unable to study families that could not make the trip to Ann Arbor.[73] Sheldon Reed of the Dight Institute similarly lamented that reliable funding sources needed to be secured in order to maintain consistent research and counseling operations and to keep up with predicted demand.[74] Geneticists like Reed and Dice envisioned "heredity clinics in every state so that any family . . . can go to a clinic in its own city or at least in its own county."[75] Both Reed and Dice implied that they were barely hanging

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[72] Fred J. Hodges, "University of Michigan Medical Center," ed. Ferol Brinkman, *The University of Michigan: An Encyclopedic Survey* (Ann Arbor: The University of Michigan Bentley Historical Library, 1977), 188; Lee R. Dice, "The Buildings and Lands: Heredity Clinic Building," ed. Walter A. Donnelly, *The University of Michigan: An Encyclopedic Survey* (Ann Arbor: University of Michigan Press, 1958), 1640.

[73] Dice, "Heredity Clinics," 11.

[74] Sheldon C. Reed, "Report of Progress, 1955-1957," *Bulletin - Dight Institute of the University of Minnesota*, no. 10 (1957): 1–2.

[75] Dice, "Heredity Clinics," 11.

on financially because the growing interest in their services outpaced funding and of the availability of trained geneticists and doctors. But, in spite of the old, uncomfortably flammable offices and the year-to-year struggle for funding, the demand for genetic counseling continued to expand. In 1955 there were just over twenty clinics and individuals providing heredity counseling services in the United States. By 1970 there were more than three times that many.[76] In the early years, though, the grand future of counseling in human genetics existed more in the minds of people like Lee Dice and Sheldon Reed, and the increasing numbers of anxious couples who sought their advice, than in any physical realities.

When Sheldon Reed took over the directorship of the Dight Institute in 1947 he had already established himself in both genetics and biometrics. In 1940, after serving as an instructor in genetics at McGill University for four years, Reed accepted a position at Harvard to teach genetics; however, he would spend much of World War II (from 1942 until 1945) in London, England, doing statistical research for war applications and interrogating captured German scientists. Upon returning from the war, Reed's life took two important turns. In 1946 he married Elizabeth Wagner Beasley, a scientist whose late husband had worked with Reed at Harvard and had been killed in the war. A year later, Reed joined the Dight Institute, where he and Elizabeth Reed devoted themselves to research, consultation, and education in issues of human genetics until Elizabeth left for another position in 1966 and Sheldon retired in 1978.[77]

Reed shaped the developing field of genetic counseling not only through his

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[76] Reed, *Counseling in Medical Genetics*, 2; "Medical News," *The Journal of the American Medical Association* 213, no. 13 (September 28, 1970): 2167.

[77] Anderson, "Sheldon C. Reed, Ph.D. (November 7, 1910–February 1, 2003)," 1–4; Sheldon C. Reed, "Report of Progress, 1963-1966," *Bulletin - Dight Institute of the University of Minnesota*, no. 13 (1966): 7.

evolving interests in human biology and counseling, but also with his affably dry humor and dedication to the interests of his genetic counseling clients. After Reed took over the directorship of the Dight Institute and started fielding requests for advice about human genetics and heredity, he sought a name for the work the Dight Institute and other heredity clinics were engaged in. In Europe this sort of consultation work was referred to as "genetic hygiene," in keeping with earlier concepts of social and mental hygiene. But Reed felt that this term would not be appropriate in the United States because "the word hygiene is usually associated with strong soaps, tooth pastes and other products employed in personal sanitation."[78] Reed, speaking to contemporary F. Clarke Fraser, also suggested a less humorous reason for avoiding the term "genetic hygiene" when he called it "eugenically tainted."[79] He settled on "genetic counseling," which he described as "a kind of genetic social work without eugenic connotations," and his colleagues across the country eventually adopted the term.[80] Reed, though interested in the eugenic implications of genetic counseling and the reproduction of people with genetic conditions, consistently argued for the importance of client decision making. While his assumptions about what constituted a rational or informed decision might not have coincided with those of future genetic counselors, his perspectives nevertheless laid the foundations for later, increasingly patient-centered genetic counseling methodology.[81] This focus on counseling efforts is most evident in the case histories of clinics such as the

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[78] Sheldon C. Reed, "Counseling in Medical Genetics," in *Proceedings of the First International Congress of Human Genetics*, ed. Tage Kemp, Mogens Hauge, and Bent Harvald (Basel, CH: S. Karger, 1957), 937.

[79] Fraser, "Introduction," 7.

[80] Resta, "In Memoriam: Sheldon Clark Reed, PhD, 1910-2003," 283.

[81] Resta, "The Historical Perspective," 377.

Dight Institute.

In the four years after Sheldon Reed took over directorship of the Dight Institute —between July 1, 1947, and July 1, 1951—the Institute responded to 672 requests for information about human genetics. The top five subjects people asked about were: general information about heredity, skin color (often requests from adoption agencies), epilepsy, consanguinity, and mental deficiency.[82] These questions came to the Dight Institute headquarters through the mail, by phone, and in person. They came from curious individuals, concerned couples, physicians looking for consultation, and state agencies. Couples and individuals, who made up the majority of clients, often went to Reed and his colleagues for advice after having a disabled child. Their question was almost always: what are the chances of this happening again?[83] One couple's story, accessible only through a short case study in one of the Dight Institute's biennial reports, offers a glimpse into these counseling encounters. For one poignant moment we are able get close to the cautious hopes and nagging fears of a couple that wanted nothing more than a "normal" family.

Some time between 1947 and 1951, the Applebys made their way to the University of Minnesota campus in Minneapolis, and the corner of Washington Avenue SE and Church Street: the Zoology building.[84] After what Sheldon Reed described as a

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[82] Sheldon C. Reed, "Counseling in Human Genetics, Part II," *Bulletin - Dight Institute of the University of Minnesota*, no. 7 (1951): 6, 9–10.

[83] Sheldon C. Reed, "Counseling in Human Genetics, Part III," *Bulletin - Dight Institute of the University of Minnesota*, no. 8 (1953): 16.

[84] All names connected to case studies are pseudonyms. The case studies most often refer either to anonymous "couples," "husbands" and "wives," or they identify clients by their initials: Mr. and Mrs. R, for example. This history is focused on the clients as active participants in genetic counseling and, as such, I have created pseudonyms to give them a greater degree of humanity and a somewhat more three-dimensional character. Furthermore, at the same time I try to maintain the relationship between wives and husbands who sought the assistance of genetic counselors, I wish to maintain the degree to which they *were* separate individuals. I particularly wish to highlight the ways that people like the

"harrowing experience" with Down syndrome (which was called "mongolism" in the medical literature of the time), the Applebys were desperate for answers. Some years earlier, while her husband was away on military service, Mrs. Appleby gave birth to their first child, who was subsequently diagnosed with "mongolism." Though upset, Mrs. Appleby was reassured by her doctor's promise that such an occurrence could not happen again. Sure enough, her second pregnancy resulted in a "normal" child, and she "was now ready to go ahead and round out a good-sized family." Her doctor again assured her that "nothing could go wrong" and her third pregnancy proceeded without anxiety. But, when presented with the baby, Mrs. Appleby made the diagnosis of "mongolism" herself. Wracked with emotion, the parents placed the baby on a waiting list for one of the state institutions. After Mrs. Appleby "recovered her equilibrium sufficiently" she began visiting obstetricians in search of answers.[85]

Eventually she arrived at the Dight Institute. We can assume that the couple arrived at the institute with mixed feelings of anxiety, hope that an answer was close at hand, and perhaps anger that answers were so long in coming. It is safe to expect that Mrs. Appleby, having taken it upon herself to obtain multiple medical opinions, would have heard promising things about the Dight Institute from other Minnesota organizations, many of which worked with the Institute. At the same time, while it is impossible to know for sure what she was thinking, she undoubtedly would have harbored fears that her dream family would remain only that.

Good descriptions of the Dight Institute are hard to come by, but scattered details

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pseudonymous "Mrs. Appleby" took a proactive stance in their own reproductive futures by tirelessly pursuing answers to their questions—visiting multiple doctors and specialists—when they were unable to get acceptable answers. Location of the Zoology building from: "General Program of the Meeting of Biological Societies," *AIBS Bulletin* 1, no. 4 (1951): 39.

[85] Reed, "Counseling in Human Genetics, Part II," 17.

suggest a suite, headquartered in room 10, on the first floor of the imposingly academic, four-story Zoology building at the University of Minnesota.[86] The Dight Institute was, for the first decades of its existence, perennially underfunded. Sheldon Reed often complained that the roughly $5,000 they received annually from the Charles F. Dight bequest was "inadequate to fulfill even the most essential functions of the Institute."[87] The Institute also occasionally accepted research material from other organizations—in 1948 they received eighteen tons of material from the Eugenics Record Office in Cold Spring Harbor, New York, along with 96 new file drawers. Combined with the lack of funding, it is likely that their offices were either increasingly crowded or that they expanded into additional rooms.[88]

Kathleen Cummings, the Dight Institute's part-time receptionist and research assistant, may well have greeted the Applebys at the door. While waiting to meet with Dr. Ray C. Anderson, who did much of the counseling at the Dight Institute in the late 1940s and early 1950s, the Applebys must have looked around at the charts and photographs put up shortly after the institute opened.[89] Whether carefully studying the diagrams of human inheritance or probability charts, or gazing distractedly at the posters describing the difficulties introduced by variations in gene expression, it would be understandable if the Applebys' anxiety only increased as they searched for themselves in the graphs.[90] Or

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[86] Physical description of the Zoology building based on a photograph in: "General Program of the Meeting of Biological Societies," 38.

[87] Sheldon C. Reed, "Report of Progress, 1951-1953," *Bulletin - Dight Institute of the University of Minnesota*, no. 8 (1953): 1.

[88] Sheldon C. Reed, "Reactivation of the Dight Institute," *Bulletin - Dight Institute of the University of Minnesota*, no. 6 (1949): 3.

[89] Sheldon C. Reed, "Report of Progress, 1949-1951," *Bulletin - Dight Institute of the University of Minnesota*, no. 7 (1951): 5.

[90] Oliver, "Report on the Organization and Aims of the Dight Institute and Its Accomplishments for the

perhaps the posters distracted from the Applebys from their worry that they would never have the normal family they hoped for. Whatever the case, they soon met with one of the genetic counselors at the Institute and began sharing their troubles for what must have felt like the hundredth time.

The Dight Institute used an extensive questionnaire to gather as much data as possible about a client's family, the affected person, and the incidence of the condition among relatives. After providing basic identifying information about themselves and their relatives, the Applebys answered a battery of questions about the incidence of stillbirths, miscarriages, or birth defects in their immediate families and among their relatives. They described the physical traits—eye color, hair color, left- or right-handedness, sight defects, and more—of themselves and their close relatives. They also provided information suitable to create a detailed family tree for the couple to trace incidence of the trait in question—a personalized pedigree chart. Eventually, they got around to the question at the heart of Mrs. and Mr. Applebys concerns: what are the chances "that a third Mongoloid might be produced"?[91]

"There is no satisfactory answer to this question yet," was the counselor's response. But he told the couple that there was "an actual danger" of having another affected child—a chance "somewhere in the vicinity of 14.5 per cent." As a piece of final advice, the counselor told the couple that, regardless of what their previous doctor had said, "the fact that two abnormal children have already appeared does not safeguard you

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Year Ending June 30, 1942," 1.

[91] Clarence P. Oliver, "The Collection of Records in the Study of Human Heredity," *Bulletin - Dight Institute of the University of Minnesota*, no. 2 (1945): 1–34; Reed, "Counseling in Human Genetics, Part II," 17.

against a third; indeed, your now increased age makes the situation less hopeful."[92] It was the Dight Institute's policy not to tell a couple whether they should or should not have another child, and so this is where the counselor's advice likely ended. In other cases, the counselor might also make an effort to explore a couple's attitudes towards parenthood and disability ("defectiveness"), but the Appleby's history would have answered many of these questions already.

Mr. and Mrs. Appleby returned home with the knowledge that there was no way to be confident that they would ever have another "normal" child. A brief follow-up in the case record noted that the couple and their physician—now armed with the probabilities of recurrence—all agreed that another pregnancy would be a poor decision.[93] The records are silent from there. We do not know whether the couple pursued other means of family making after this no-doubt difficult news, but many families in their situation did pursue adoption.

Historians will never be able to effectively sit in on counseling sessions from this era or get a full picture of what clinics like the Dight Institute really looked like, but we can begin to piece together the emotional texture of the space. The voices of genetic counseling clients—concerned couples who wanted nothing more than a family that conformed to their expectations of health, happiness, and a future for their children—drift up through the medical language of case studies like these. It is clear, for example, that some families did not perceive living with a disabled child to be possible or in keeping with their visions of life for themselves. Many new parents placed their disabled children in institutions before trying again to produce a family that met their desires.

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[92] Reed, "Counseling in Human Genetics, Part II," 17.

[93] Ibid.

Most geneticists and social welfare institutions shared the expectation that parents institutionalize their disabled children. Many adoption agencies would not place children with families that did not first institutionalize their "defective" children. Nevertheless, parents and would-be parents did not always follow this advice. Many parents, in fact, resisted the push to institutionalize their "defective" children both out of affection and concerns for their well-being, and because it could be expensive to institutionalize a child in one of the private institutions that did not have the long waiting lists and overcrowded conditions of public institutions.[94]

Clarence P. Oliver, the first director of the Dight Institute, described patient reactions to conditions such as Down syndrome as varied. "Many mothers of mongols," Oliver wrote, "have no children after the defective child, although they may have the physiological ability to produce more children." In other situations, the couple tried again and subsequently produced "normal" children.[95] Geneticists did not have clear understandings of the causes of Down syndrome or whether it was a purely hereditary condition or not. They were aware that it seemed to be influenced by advanced maternal age, but also suspected that women might inherit genetic characteristics that "might cause her to become an abnormal environment" for a fetus.[96]

Oliver's advice to women with relatives who had Down syndrome was to have

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[94] The responses of parents to their disabled children in the post-war era is a topic that deserves additional research. Scholars such as Janice Brockley, Katherine Castles, and Kathleen Jones have made valuable contributions to this historiography. See, for example: Brockley, "Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History"; Castles, "'Nice, Average Americans': Postwar Parents' Groups and the Defense of the Normal Family."

[95] Clarence P. Oliver, "Fifth Annual Report of the Dight Institute for the Academic Year 1945-46," *Bulletin - The Dight Institute of the University of Minnesota*, no. 5 (1947): 14.

[96] Clarence P. Oliver, "Second Annual Report of the Dight Institute for the Academic Year 1942-43," *Dight Institute of the University of Minnesota* (1944): 5.

their children early in life to avoid the increased risk that came along with advanced age. He suggested that, in giving advice to a mother who already had a child with Down syndrome, “it is not possible for anyone to tell her definitely the chance that another child will develop mongolism. She can be told, however, that in cases on record mongolism has occurred in more than one sibling in a family.” Oliver’s implications were clear: such a women should not have additional children.[97] Geneticists like Oliver and Sheldon Reed were careful in their professional writing to explain that it was not the role of the genetic counselor to make decisions for their clients. It is also evident from the literature and case studies, however, that they did possess clear expectations of what constituted a good or a poor decision. They left clients to make the final call on their own, but it is evident that these choices would have been profoundly shaped not only by clients’ prior notions of normality and acceptable levels of difference in their prospective children, but also by the scientific rhetoric employed by geneticists in communicating risk factors.

All of these factors and more complicated would-be parents’ autonomy in counseling encounters, but it is critical to bear in mind that they were not passive bodies in the face of medico-scientific jargon. Many clients clearly had strong personal feelings about what sort of children they wanted. These feelings were also profoundly affected by the powerful emotions attendant to pregnancy and family making. “No one but a mother,” wrote Elizabeth Sturns in a 1949 *Hygeia* article about the loss of her child just after birth,

> can really understand the feeling of closeness one has to the little unborn child in the womb, whose flutters and kicks prove it is getting stronger all the time in preparation for its advent into this world. So no one but a mother can truly appreciate the empty, hopeless feeling which possessed me for many months after my little girl was born February 28, 1943, just three months too soon. She weighed one pound 12 ounces, and lived 30 minutes. Her very tininess even for her prematurity indicated her development had not gone well, and I tried to

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[97] Oliver, “Fifth Annual Report of the Dight Institute for the Academic Year 1945-46,” 14.

> console myself that it was more merciful for her not to live than to survive if she would not have been strong and healthy"[98]

Sturns' heartrending recollection is an important reminder about the felt experience of prospective parents and the influence emotion had on decision-making. When reading the scientific literature and perusing the antiseptic case studies it is easy to forget the "empty, hopeless feeling" that likely came over many prospective mothers and fathers when their newly born children suffered, did not reflect their hopes, or, in the tragic cases such as this one, died shortly after birth. These emotions are crucial to bear in mind when considering the reasons people sought out the services of people like Clarence Oliver, Lee Dice, and Sheldon Reed. It is also important to consider the ways that such emotions were also historically constituted just as notions of normativity and disability were.

Elizabeth Sturn's recollection additionally suggests how affection and notions of desirable children—children that fulfilled expectations for health—could complicate genetic counseling. Sturn attempted to reassure herself that it was preferable for her child to have died in infancy than to have lived a life as anything other than a "strong and healthy" child. This closing line speaks to assumptions that death—or at least non-existence—might have been preferable to disability. But at the same time, her rhetoric suggests that this perspective might have been more of an ideal based on social expectations than personally held belief. Sturn was clear that she "*tried* to console" herself that non-existence was better, but did not indicate that she was necessarily successful in doing so.[99] While she understood, culturally and scientifically, that an atypical life was something to be avoided, it is equally evident that her love for her child

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[98] Elizabeth Daws Sturns, "My 'RH Factor' Baby," *Hygeia* 27, no. 7 (July 1949): 489.

[99] Ibid., 489 (emphasis added).

might have overcome these assumptions. The interactions between genetic counselors and clients were fraught with these complexities and occasional contradictions.

Clients brought these perspectives to genetic counselors and their anxieties, along with genetic counselors' concerns about association with traditional eugenics, helped to shape the developing field into one concerned with birth atypicalities and sensitive to client decision making. Since genetic counselors were reluctant to provide direct advice to clients, anxious prospective parents were left to weigh their own feelings about disability with the predictions geneticists provided them. Under the guidance of geneticists such as Clarence Oliver, Lee Dice, and Sheldon Reed, and through the concerns of clients, genetic counseling took its first steps from an ad hoc practice toward a formal profession. It was through these interactions with clients that geneticists such as Dice came to the conclusion that "every person is interested in his heredity."[100] By the end of the 1940s genetic counseling was still a fledgling field, and one without clear standards of practice, but was garnering enough attention from clients, physicians, and state agencies to make people like Sheldon Reed and Lee Dice start sharing ideas about what constituted good, effective genetic counseling. These were the conversations, guided by client anxieties and scientific developments, that would contribute to the increasing formalization of genetic counseling as a field in the 1950s.

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[100] Dice, "Heredity Clinics," 2.

CHAPTER III

EXPANSION IN THE FIFTIES

In 1957, the *Saturday Evening Post* introduced readers to Bob and Irene Pershing. They were “a healthy farm couple who had every prospect of a happy married life” until the birth of their first two children “crushed” their hopes. Both babies were boys, and both were born with “clubfeet,” a congenital condition wherein the foot is turned up and in and bent towards the heel. “To make matters worse,” the article added, Bob started to blame Irene’s family for the condition, believing they “had ‘tainted blood’ as the result of some dark ancestral sin.” This accusation understandably put great strain the couple’s relationship.[101]

Both the article and genetic counseling publications in general suggested that blaming the mother was not uncommon.[102] Old beliefs about maternal marking, inheritance of anything from hair and eye color to a propensity toward laziness, while falling gradually out of circulation, were still around in the 1950s. “And there is always fear,” the *Saturday Evening Post* author continued, “that the handicap may strike any future children.” The Pershings, to address the guilt, fear, and marital tension these events created, “were persuaded” to see a heredity counselor (another term for genetic counselors).[103]

The counselor made a detailed examination of both Bob’s and Irene’s family histories. He discovered, to the couples’ great disappointment, that the odds were high,

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[101] Irving Freilich and Frances Freilich, “Will Your Baby Be Normal?” *Saturday Evening Post* 230, no. 19 (November 9, 1957): 42.

[102] See, for example, Reed, “Counseling in Human Genetics, Part III,” 15. Reed observed that “there is much quarreling between husband and wife as to who is ‘to blame’ for an abnormality which has appeared in their child.”

[103] Freilich and Freilich, “Will Your Baby Be Normal?” 42.

"at least twenty-five per cent," that they would have another child with clubfoot. The counselor "followed the usual policy" and did not share his own recommendations. He warned that having another child would present a "serious gamble," but also pointed out that a one-in-four chance of having an affected child also meant a three-in-four chance of having a normal child. Bob and Irene were torn: "they wanted more children, but was it worth the risk of bringing handicapped babies into the world?"[104]

In the end, Bob and Irene Pershing's hope and desire for a normal child won out over their fear of the twenty-five percent chance. They decided to "try again," and had "a fine, perfectly formed boy" two years later. A happy ending to an instructive tale. This *Saturday Evening Post* article explained in detail to readers how the relatively new field of heredity counseling took "much of the guesswork and ill-founded fear" out of reproduction.[105] It promised to answer "parenthood's most haunting question": "Will my baby be normal?"[106]

Bob and Irene's experience with genetic counseling reflects some of ways the field was changing in the 1950s. Clients' concerns were still largely similar to those of the 1940s. We can detect in the use of phrases like "followed the usual policy," though, a shift toward thinking of genetic counseling as a more unified field of practice rather than an individual service provided at a few counseling centers and genetics labs scattered across the country. Efforts on the part of genetic counselors to define the best practices of their field represent an early step towards formal professionalization.[107]

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[104] Ibid., 147.

[105] Ibid.

[106] Ibid., 42, 150.

[107] The use of the phrase "best practices" here is my own. People practicing genetic counseling in at this time do not seem to use this phrase, partly because they do not specifically discuss their goals in this

Counseling literature, case studies, and popular media reports were full of stories like Bob and Irene Pershing's. Their stories make up a crucial aspect of the history of genetic counseling. To neglect these voices would be to miss a critical element in the development of genetic counseling. As genetic counselors shared advice, ideas, and case studies, and started trying out rules of good counseling, they did so in the context of client's needs and anxieties.

Genetic counseling in the 1950s dealt with many of the same concerns that clients had in the 1940s about physical and mental atypicalities. The 1950s, however, experienced a significant expansion in geneticists' knowledge of genes, chromosomes, and inheritance, as well as early experiments in prenatal testing, that presented further complications for counseling. The expansion in the scope and reliability of genetic counseling in the 1950s added to an already complicated mixture of science, medicine, and emotion. It fed an increasing expectation—shaped by both genetic counselors and would-be parents—that human geneticists would be remiss not to offer their services to prospective parents to help them have healthy, normal babies that matched the picture of their imagined families. The increasing number of clients seeking advice about childbearing, along with new developments in genetic science, were major factors behind a growing tendency in the 1950s for genetic counselors to work towards standard practices for working with clients.

Human Genetics in the 1950s

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way. There were still no formal organizations representing genetic counselors during the 1950s, and no credentialing mechanisms to control access to the field and delivery of counseling. Nevertheless, I use the phrase to indicate a distinct trend in their professional literature—in academic journals, conferences, and books—towards identifying what went into effective counseling and what made a good counselor. These writings were primarily for each other and for others who might engage in genetic counseling, and so represent an early attempt to recommend certain practices over others. "Best practices," in this case, is shorthand for these activities.

New developments in the science of human genetics contributed in part to the expansion in both the scope and the reliability of genetic counseling in the 1950s. This growth was in keeping with genetic counselors' hopes for their field. Sheldon Reed thought it "conservative" to estimate that there would be at least one hundred genetic counseling centers across the United States, with at least one in every state.[108] The expansion of the genetic counseling field also came with increased expectations. Clients learned from popular and medical sources that genetic counseling could help them have normal, healthy babies, and many clients took these promises to heart. Genetic counselors acknowledged in discussions with each other, though, that while their understanding of human heredity and the biochemical aspects of genetics were increasing, they still had a long way to go. It is less clear whether they communicated these uncertainties to their clients.

In the 1950s, increasing numbers of both PhDs and MDs joined the ranks of American human geneticists. Both groups came to the subject with different specialties and often lacking knowledge of statistics and biochemistry, but, thanks to labs like those at the University of Michigan and to similar labs in Britain, there were plenty of ways to learn. Greater government funding for the sciences in the post-war United States also contributed to the field's expansion.

By 1959 membership in the American Society of Human Genetics (ASHG) had increased to nearly 500 people.[109] It did not exert any formal control over genetic counseling (there were still no significant training programs, licensing bodies, or credentialing mechanisms), but, through its annual meetings and *The American Journal*

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[108] Reed, "Counseling in Human Genetics, Part III," 14.

[109] Kevles, *In the Name of Eugenics*, 231–233.

of Human Genetics, the ASHG did serve as one avenue for those practicing genetic counseling to communicate their ideas, practices, and goals for the field. The field of genetic counseling and the science of human genetics counted many of the same people among their leadership rolls. Developing understandings of human heredity and genetic processes were often quickly applied to counseling efforts to make genetic counseling in the 1950s "more important to physicians, more interesting to ethicists, and more complicated for the genetic counselor."[110]

One of the complicating factors was that genetic counselors still relied on what were called "empiric risk assessments" for many of the more complicated, and less well understood, conditions they predicted for. These assessments were the source of the odds genetic counselors gave clients in cases when inheritance was not believed to follow a pattern of simple Mendelian inheritance. Human geneticists developed these probabilities based on studies of individual families where a trait existed. They compared those figures with what they knew about the general population, and then filtered these results through statistical methods to try to account for outliers and anomalies. Needless to say, these figures were not always accurate. James V. Neel, one of the leading human geneticists in the United States and head of the Heredity Clinic at the University of Michigan after Lee Dice, described empiric risk assessments as "essentially pragmatic probability statements based on accumulated medical statistics," that can always be subject to revision with additional data.[111]

Genetic counselors engaged in discussion throughout the 1950s about the

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[110] Fraser, "Introduction," 7.

[111] James V. Neel, "The Meaning of Empiric Risk Factors," in *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, ed. Helen Hammons (New York: Hoeber-Harper, 1959), 69.

challenges they faced in making accurate predictions, and even suggested that these "pitfalls" had not been "sufficiently emphasized" in the past.[112] It is not clear whether these uncertainties were communicated to clients, but the fact that genetic counselors were engaged in trying to find ways of dealing with them illustrates a trend in the 1950s towards devising best practices for counseling.[113] None of these authors, however, suggested that genetic counseling should be stopped until it was more reliable. Some argued that counselors should be careful in delivering information, and others that counselors needed more training to deal with "emotionally loaded situation[s] without stirring up trouble," but they agreed that, despite the uncertainty, counseling should continue.[114]

Discoveries in other areas of human genetics also contributed significantly to the development of genetic counseling. New understandings and techniques coming out of cytogenetics and prenatal testing would have a huge influence on genetic counseling in later decades.[115] Cytogeneticists had, since the 1920s, believed that humans had 48 chromosomes rather than 46. The development of a technique to culture human cells (to grow them outside the human body), a project promoted by the National Foundation--March of Dimes, made possible the 1956 discovery that humans typically had 46

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[112] James V. Neel, "Problems in the Estimation of the Frequency of Uncommon Inherited Traits," *American Journal of Human Genetics* 6, no. 1 (March 1954): 59.

[113] Neel, "Problems in the Estimation of the Frequency of Uncommon Inherited Traits"; William J. Schull, "Ascertainment and the Study of Discontinuous Characteristics in Man," *American Journal of Human Genetics* 6, no. 1 (March 1954): 124–130; F. C. Fraser, "Heredity Counseling: The Darker Side," *Eugenics Quarterly* 3, no. 1 (1956): 45–51; Neel, "Problems in the Estimation of the Frequency of Uncommon Inherited Traits"; Neel, "The Meaning of Empiric Risk Factors."

[114] Dice, "Heredity Clinics," 6; C. Nash Herndon, "Heredity Counseling," *Eugenics Quarterly* 1, no. 1 (1954): 66.

[115] Cytogenetics is a field of science concerned with the study of inheritance and of cells, and especially the origin and structure of chromosomes and the role they play in the body and in inheritance. "Cytogenetics," *Concise Medical Dictionary*, Oxford Reference Online (Oxford University Press, 2010), http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t60.e2421.

chromosomes. Scientists Ernest H. Y. Chu and Norman H. Giles confirmed the 46-chromosome correction in 1959.[116]

Prenatal testing, which would create a vast expansion in the use and scope of genetic counseling by the 1970s, had its most direct origins in the 1950s with the use of amniocentesis. Doctors used this procedure as early as the 1880s to treat excesses of amniotic fluid, and starting in the 1950s began to use it to test for "erythroblastosis fetalis," a condition arising from blood type incompatibility between a mother and a fetus.[117] In amniocentesis a small quantity of amniotic fluid was withdrawn from the amniotic sac within the uterus, typically through a hollow needle inserted through the mother's stomach.[118] Amniocentesis was first used in prenatal testing starting in 1955, when it was found that the sex of the fetus could be predicted based on indicators in the fetal cells.[119] These tests were initially used to test for male fetuses in cases with a risk of an X-linked condition such as hemophilia. Under these circumstances, genetic counselors predicted, "it should be possible to diagnose both sex-linked and blood-group-linked

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[116] Reed, "A Short History of Human Genetics in the USA," 291; Ernest H. Y. Chu and Norman H. Giles, "Human Chromosome Complements in Normal Somatic Cells in Culture," *American Journal of Human Genetics* 11, no. 1 (March 1959): 63–79.

[117] Erythroblastosis fetalis is currently referred to as "hemolytic disease of the newborn" and is caused by a mother and fetus having different Rh blood types. The mother's blood produces antibodies that attack the fetus' red blood cells. The condition can cause swelling under the surface of the skin (leading some people in the 1940s and 1950s to still refer to the condition as "water head"), jaundice, and in severe cases death shortly before or after birth. In the 1940s and 1950s genetic counselors most frequently encountered this condition in relation to incompatibility of the Rh (Rhesus) factor. "Hemolytic Disease of the Newborn," *A.D.A.M. Medical Encyclopedia*, PubMed Health (U.S. National Library of Medicine, 2012), http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002275/.

[118] F. Fuchs et al., "Antenatal Detection of Hereditary Diseases," in *Proceedings of the First International Congress of Human Genetics*, ed. Tage Kemp, Mogens Hauge, and Bent Harvald (Basel, CH: S. Karger, 1957), 106.

[119] Leo Sachs, David M. Serr, and Mathilde Danon, "Prenatal Diagnosis of Sex Using Cells from the Amniotic Fluid," *Science* 123, New Series (1956): 548.

hereditary diseases at a stage where pregnancy can be safely interrupted."[120] In keeping with their predictions, the first therapeutic abortion based on such results took place in Copenhagen, Denmark, in 1960. Laws limiting abortion, as well as the potential for amniocentesis to accidentally trigger abortion, combined to keep the use of this procedure low in the United States in the 1950s.[121] The scientific discovery that would pioneer the use of prenatal testing for genetic conditions was the isolation of the cause of Down syndrome in 1959.[122] These new scientific developments would further complicate genetic counselors' interactions with patients, by giving them one more technique to help parents have a healthy, normal child, and by bringing genetic counselors and clients in tension with cultural beliefs about abortion.

At the same time, questions about whether the ability to have children, and as many children as one wanted, was a right or a privilege were still highly relevant in American culture. *Time* magazine quoted Nobel Prizewinning geneticist George W. Beadle in a 1959 report on recent discoveries in human genetics. Beadle asked: "Can we go on indefinitely defending as a fundamental freedom the right of individuals to determine how many children they will bear, without regard to the biological or cultural consequences?"[123] Science and medicine in the 1950s continued to weigh in on these questions, and through advice literature, doctors, popular media, and state and local

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[120] Fuchs et al., "Antenatal Detection of Hereditary Diseases," 105.

[121] Fraser, "Introduction," 8; Cynthia M. Powell, "The Current State of Prenatal Genetic Testing in the United States," in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch, Hastings Center Studies in Ethics (Washington, DC: Georgetown University Press, 2000), 44; Ruth Schwartz Cowan, "Women's Roles in the History of Amniocentesis and Chorionic Villi Sampling," in *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, ed. Karen H. Rothenberg and Elizabeth Jean Thomson, Women and Health Series (Columbus: Ohio State University Press, 1994), 36–37.

[122] Prenatal testing, abortion, and genetic counseling will be discussed in more detail in Chapter 3.

[123] "Citizen Genetics," *Time* 73, no. 3 (January 19, 1959): 22.

health programs, they worked to encourage Americans to think carefully about whether to have children and to depend on experts for help.

Medical Planning Meets the Baby Boom

As had been the case in the 1940s, the medical community, state-run organizations, and private institutions interested in maternal and child health encouraged American women to depend on their physicians and obstetricians for prenatal and natal care, and to have their babies in hospitals. These efforts combined with an increasingly pronatalist culture and social programs to contribute to both a higher birth rate and a significantly lower maternal mortality rate. The birth rate, which began to increase around 1940, peaked in 1947 at 26.6 births per 1,000 people, and remained around 25 births per 1,000 people between 1948 and 1953. The nonwhite birthrate continued to rise after 1947 and as of 1953 stood at 34.1 births per 1,000 people.[124]

The decline in maternal mortality that began in the 1930s and 1940s also continued into the 1950s. By 1953, only 4.4 women per 10,000 live births died as a result of childbearing, down from over 60 before 1930. The rate among nonwhite women also dropped, though not as low, from 117 per 10,000 in 1930 to 16.6 in 1953. *Williams Obstetrics* accounted for the decreased number of women dying in childbirth to better education and training of obstetricians, the growth of clinics, the work of state and federal programs like the US Children's Bureau, and to the increased number of births that took place in hospitals.[125] Sheldon Reed remarked that Americans had taken "literally the philosophy that every couple should have a family" and were "growing with joyous planned abandon" with the assistance of fertility clinics. He complained, though, that this

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[124] Nicholson J. Eastman, *Williams Obstetrics*, 11th ed. (New York: Appleton-Century-Crofts, Inc., 1956), 2.

[125] Ibid., 2–3.

“compulsion” to have a family made the work of genetic counseling harder because “no matter how catastrophic the genetic situation may be, the young couple feels compelled to complete their family.”[126]

Parents prioritized healthy, non-disabled babies in all manners of family-making, including adoption. Genetic counselors often recommended that parents at high risk of having a disabled child pursue adoption in order to create the families they hoped for. A 1954 *Saturday Evening Post* article titled, “Babies for the Brave,” reported that “nine out of ten childless couples still ask for a normal healthy infant of good stock,” but that “a surprising number of brave Americans are settling for much less, and finding great joy in their choice.”[127] The fact that this article focused on these “brave” families who could look past physical differences speaks to the prevailing views of disability in the 1950s.[128]

Mid-century perspectives on disability and family played a powerful role in parents’ thinking about family making. Parents in the 1940s and 1950s were frequently encouraged to institutionalize their newborn children with disabilities. Of these parents, half were advised to separate from them “immediately.” Those parents who resisted these recommendations often found out later in life just how much social and emotional support raising a child with special needs demanded. They also discovered the dearth of social, material, and service-related assistance available to them, and many found they eventually had to place their children in an institution for care and education.[129] In these

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[126] Reed, “Counseling in Medical Genetics,” 933. Reed’s mention of fertility clinics raises interesting additional avenues of research into the possible connections between genetic counseling and infertility. There were no evident connections between the fields in this period, but they were both associated with helping Americans make the families they wanted, so there may be some overlap that is not immediately apparent.

[127] Alice Lake, “Babies for the Brave,” *Saturday Evening Post* 227, no. 5 (July 31, 1954): 26.

[128] See also Herman, *Kinship by Design*, especially Part 3.

[129] Reagan, *Dangerous Pregnancies*, 41–67; Castles, “‘Nice, Average Americans’: Postwar Parents’

circumstances it is understandable that mothers and parents of disabled children would react with distress—not only because their imagined family did not materialize as they had pictured it, but also because the challenges and costs of raising a child with disabilities would fall largely on them.[130]

One of the ways prospective parents in the 1950s responded to the likelihood of disability in their future children was to seek abortion. Abortion was illegal in the United States at the time, but many states had therapeutic abortion provisions that allowed a woman to have an abortion if her life was at risk. There was nothing new about married women seeking abortions in the 1950s, but in the post-war atmosphere of greater conservatism and pronatalism it became much more difficult than it had been just two decades earlier. In the 1940s and 1950s police targeted illegal abortion clinics, and hospitals put increased pressure on legal therapeutic abortions. Media in the 1950s portrayed abortion as criminal and mortally dangerous, and the women who sought them as delinquent, sexually deviant, and racially suspect. At the same time, increasing numbers of women who were worried about birth defects pressured obstetricians and hospital abortion committees to approve them.

The standard medical school textbook, *Williams Obstetrics*, reflected the

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Groups and the Defense of the Normal Family"; Brockley, "Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History."

130. On the continuing discussions about disability, reproduction, prenatal testing, and genetic counseling see Parens and Asch, *Prenatal Testing and Disability Rights*; Karen H Rothenberg and Elizabeth Jean Thomson, eds., *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, Women and Health Series (Columbus: Ohio State University Press, 1994); Rapp, *Testing Women, Testing the Fetus*; Wexler, *Mapping Fate*; Katrina Alicia Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Durham: Duke University Press, 2008). Catherine J. Kudlick offers a thorough review of disability history in Kudlick, "Disability History." See also Joseph P. Shapiro, No Pity : People with Disabilities Forging a New Civil Rights Movement, 1st ed. (New York: Three Rivers Press, 1994); Paul K. Longmore and Lauri Umansky, eds., The New Disability History: American Perspectives (New York University Press, 2001). For an excellent look at disability, eugenics, and the media see Pernick, *The Black Stork*.

conflicted status of therapeutic abortion in the United States. It referred to therapeutic abortion as a "greatly abused operation" consistent with "homicide with respect to the fetus" that should only be undertaken in a small number of cases where the life of the mother was in serious jeopardy. At the same time, however, the textbook approved of therapeutic abortion in cases, such as following a German measles infection, when a fetus was expected to be born disabled. The textbook also cited possible injury to "mental health or sanity" as a potential justification for the procedure.[131]

As in other areas of reproduction, the medical community positioned itself in between social and cultural notions of abortion as criminal and immoral in some cases, and as a necessary medical procedure in others. During the 1950s privileged American women and men—white, middle-class, and educated—increasingly lobbied for relaxed therapeutic abortion laws to include situations where birth defects were predicted in the fetus. These concerns would come to play an important role in genetic counseling in the 1960s, but for the 1950s, genetic counselors stayed largely out of the debate because genetic science had not developed to the extent that they could make accurate prenatal diagnoses of disability until, at the very earliest, 1959 or 1960.

Genetic Counseling Clients in the 1950s

By the mid-1950s, interest from doctors and other medical professionals, in addition to publicity in national circulation media, led heredity clinics to become increasingly visible and their services sought after. As of 1955, when Sheldon Reed published one of the first major books on genetic counseling, the young profession had a

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[131] Eastman, *Williams Obstetrics*, 1077; Nicholson J. Eastman, *Williams Obstetrics*, 10th ed. (New York: Appleton-Century-Crofts, Inc., 1950), 707; Eastman, *Williams Obstetrics*, 1077. On abortion in the United States, see Gordon, *Woman's Body, Woman's Right*; Maloy, *Birth or Abortion?*; Solinger, "A Complete Disaster"; Reagan, *When Abortion Was a Crime*; Reagan, *Dangerous Pregnancies*, especially chatper 4.

name and about twenty heredity clinics had been organized across the country.[132] Most of these clinics were in settings like the University of California, Berkeley, the Bowman Gray School of Medicine, in Winston-Salem, North Carolina, and the University of Oklahoma. Others, in the United States and Canada, were located at children's hospitals or in mental health institutions such as the New York State Psychiatric Institute (see Appendix A).[133] As of 1952, the Dight Institute alone reported a total of 1,088 "requests for information," over the course of six years, from people with concerns about genetics or heredity.[134] A "rough-and-ready questionnaire" that genetic counselor F. Clarke Fraser circulated near the end of the decade found that genetic counseling centers met with between one and forty clients every month—the Dight Institute, averaging almost 200 cases per year by that time, fell roughly in the middle of this continuum.[135]

Clients found out about genetic counseling from a variety of sources. Some, having read about genetic counseling or a particular heredity clinic in a newspaper or magazine, sought out a local heredity clinic or wrote to one elsewhere in the country on their own. Other clients were referred by their doctors or by state and private agencies. Adoption agencies, welfare departments, state and local health departments, and other organizations were all sources of referral. Most genetic counselors preferred referrals from physicians because it meant access to detailed patient histories, but they accepted

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[132] Reed, *Counseling in Medical Genetics*.

[133] Ibid., 2.

[134] Reed, "Report of Progress, 1951-1953," 8.

[135] F. Clarke Fraser, "Types of Problems Presented to Genetic Counselors," in *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, ed. Helen Hammons (New York: Hoeber-Harper, 1959), 76–77, quotation on page 76; Sheldon C. Reed, "Report of Progress, 1953-1955," *Bulletin - Dight Institute of the University of Minnesota*, no. 9 (1956): 4; Reed, "Report of Progress, 1955-1957," 5; Reed, "Report of Progress, 1957-1959," 4.

clients from wherever they came.[136] These clients' interests and concerns shaped the direction genetic counseling would take.

Much of the growth in genetic counseling in the 1950s centered around reproductive decision making, in response to genetic counseling clients' worries about their future children. The questions clients asked most frequently dealt with whether or not they should have a baby. These concerns arose either because they already had a child with an atypicality that they or the person who referred them thought was hereditary, or because a condition was present in one or both of their families. The next most common type of question clients asked was whether they or someone close to them should get married. These concerns revolved around either the possible effects of "consanguinity" or of "some genetic disease in one of the families involved." The rest of the time, clients asked about the genetic suitability of a particular child for adoption, for interpretations of specific illnesses, about the likelihood of a relative of an affected person developing a condition, and for help resolving paternity disputes.[137] More than anything else, clients—would-be parents—were anxious and wanted to exert some degree of control over what their future families would be like. They wanted to make sure that their babies would be normal, and genetic counselors seemed to promise just that.

Some clients went to heredity clinics with their decision already made and were only looking for expert confirmation. William Schull argued that "many of the individuals who seek advice shop for it," suggesting that they sought out multiple

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[136] C. Nash Herndon, "Procedures for Referral to Heredity Counselors," in *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, ed. Helen Hammons (New York: Hoeber-Harper, 1959), 72–74; Reed, "Counseling in Human Genetics, Part III," 13; Fraser, "Types of Problems Presented to Genetic Counselors," 77.

[137] Fraser, "Types of Problems Presented to Genetic Counselors," 78.

prognoses looking for the one they wanted.[138] Other clients who sought the advice of genetic counselors had already made their decision and merely wanted to "make sure they had their genetics straight." In one case an older couple with five boys, three of whom had developed a sex-linked type of muscular dystrophy, learned that they were pregnant again. They had already requested a therapeutic abortion, but wanted to make sure they were right in predicting another affected child.[139] This case illustrates the degree to which some patients exercised a degree of autonomy in their interactions with the medical system. Working off of prior knowledge, assumptions, and everyday realities, these clients came to decisions and then depended on experts like those at the Dight Institute to confirm the logic of those decisions.

Clients' voices are difficult to recover, but genetic counseling literature and case studies frequently noted that prospective parents usually found "the chances of producing another defective child" were less than they had feared. Couples in these cases often went on to have more children. Such a decision left genetic counselors somewhat torn between their strong desire to avoid giving direct advice and the fact that it meant a "defective gene" would be reproduced.[140] They often downplayed the risk to the general population of such a couple reproducing by suggesting that the couples' intellect, personal responsibility, and other genetic traits could still be "sufficiently above normal" to counterbalance the dysgenic effect of the atypical gene.[141] As time passed, Sheldon Reed

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[138] Clarence P. Oliver, Harold F. Falls, and William J. Schull, "Discussions: Heredity Counseling," in *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, ed. Helen Hammons (New York: Hoeber-Harper, 1959), 104.

[139] Reed, "Counseling in Medical Genetics," 935.

[140] Reed, "Counseling in Human Genetics, Part III," 16.

[141] Lee R. Dice, "A Panel Discussion: Genetic Counseling," *American Journal of Human Genetics* 4, no. 4 (December 1952): 335.

observed, couples who received counseling often “became more optimistic, and the desire to ‘compensate’ for [an] abnormal child usually overwhelm[ed] their fears.” It was unclear to Reed whether genetic counseling had an overall eugenic or dysgenic effect, but it did clearly have “a beneficial effect upon family harmony” and added to “an understanding of the biology of mankind,” and, Reed observed, “what more could one ask of it?”[142] Genetic counselors’ continued worrying over the population-wide effects of genetic counseling suggests that many of them retained the notion common to the traditional eugenics movement of prior decades that the human race could be improved, if gradually, through rational reproductive decision-making carried out by enough people.

Expansion and Challenges

Genetic counselors hoped that they could help people to make informed reproductive decisions by making their services widely available and educating the public about the real risks of genetic disease in their families. Sheldon Reed, like most genetic counselors in the 1950s, recommended that people with questions or concerns about heredity start with their physicians. He believed that the best way to reach clients was by training graduate and medical students who would then refer clients to heredity clinics or establish clinics of their own. Even though articles in popular media were useful and tended to create a spike in requests for information, these questions often lacked medical data and were difficult to respond to. As a result, genetic counselors like Reed preferred “the steady flow and increase of case load from local physicians” instead.[143]

Many of the geneticists who perceived a role for human genetics in American’s everyday lives envisioned what would eventually be a vast network of easily accessed

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[142] Reed, “Counseling in Human Genetics, Part III,” 17.

[143] Ibid., 13.

heredity counseling centers where people might be educated in human heredity, learn about potential traits they might carry, and receive advice as to the probability of their having healthy children. They were confident that, as interest in genetic counseling spread, and knowledge of human heredity with it, it would only be a matter of time before genetic counseling would "be demanded by communities all over the nation."[144] Responsible prospective parents, they believed, would do everything they could to ensure normal, healthy children. All they had to do was get the word out about genetic counseling and what it offered, and the people would come. This expectation was based on a number of factors. Among these were genetic counselors' experiences with clients, many of whom fit this archetypal picture, and their assumption that physical or mental difference constituted a disease that any normal person would want to avoid.

Lee Dice, in his 1951 presidential address to the American Society of Human Genetics, encouraged "the establishment in every state of a series of heredity clinics . . . in order to provide dependable advice on human heredity."[145] His was just one of a number of voices seeking to promote the benefits of genetic information to the general public. Dice initially trained as a zoologist and a biologist, studied human genetics, and was President of the American Society of Human Genetics for the year 1950 to 1951. He had been a driving force behind the creation of the Heredity Clinic, in Ann Arbor, and was also a force behind recruiting James V. Neel to the University of Michigan, where he later took over for Dice at the Heredity Clinic.[146] Dice was one of many genetic

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[144] Lee R. Dice, "The Structure of Heredity Counseling Services," in *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, ed. Helen Hammons (New York: Hoeber-Harper, 1959), 64.

[145] Dice, "Heredity Clinics," 13.

[146] Kevles, *In the Name of Eugenics*, 225.

counselors who wanted heredity clinics set up all over the United States to help couples make informed decisions about whether or not to have children.

Dice and his peers intended such clinics to meet the needs of clients, but believed they could concurrently solve a problem many geneticists perceived to be threatening modern society. Thanks to modern medicine, Dice explained, "many individuals who carry serious hereditary defects survive to transmit their harmful genes to their offspring," thus increasing the incidence of those genes in the population. "Segregation or sterilization of defective persons," he acknowledged, could be an effective antidote if implemented on a large scale.[147] "No sane geneticist," however, would accept the degree to which such a program would infringe on the "liberties of the people." The decision had to remain with the couples. "Voluntary abstention from reproduction by those persons who carry hereditary defects," Dice argued, "is consequently the only practical method for eliminating any considerable number of harmful genes from the population of a democracy. With only rare exceptions," he continued,

> every person is interested in his heredity. From my experience in giving advice about heredity to families in all walks of life I can affirm that every parent desires his children to be free from serious handicaps and to be physically and mentally well endowed. If there is known to be high probability of transmitting a serious defect, it would be an abnormal person indeed who would not refrain from having children.[148]

This scientifically pragmatic assessment represents the perspective taken by many geneticists working in heredity clinics in the 1950s. The success of this system, Dice noted, would be "dependent upon each family being given dependable advice" from organizations such as his own. Two unspoken assumptions at the heart of this argument

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[147] Dice, "Heredity Clinics," 1.

[148] Ibid., 2.

deserve particular notice. First, Dice relied on a presumably universal definition of normal and abnormal. Second, there was no space in his worldview for a parent who would accept the possibility of a child being born with what he perceived to be an unacceptable genetic difference.

It is likely that most, if not all, of the would-be parents Dice interacted with in his capacity at the Heredity Clinic did desire children "free from serious handicaps." But Dice's assumption that "it would be an abnormal person indeed" who would have children even after being warned of a risk of birth defects reveals as much about him and his colleagues, many of whom shared this perspective, as it suggests about those prospective parents. We are led to wonder how Dice might have responded to those would-be parents that may not have embodied the rationalism he expected to be "normal" of couples seeking his clinic's assistance. The frequency with which counselors referred to the "intelligence and social and moral responsibility" of their clients based on the fact that they sought counseling, however, suggests that a client who consciously rejected these services or ignored a high-risk "prognostication" would have been considered lacking in these qualities.[149] While it would seem that prospective parents' primary concerns were for the imagined futures of their children—futures that they understood would be ruined, or at least significantly altered, by a physical or mental atypicality—genetic counselors seemed to be torn between their human geneticist concerns about the spread of abnormal genes and their counseling desire to withhold prescriptive advice.

Clients were primarily concerned about the health and normality of their prospective children, but these concerns were also influenced by external factors. It was

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[149] Oliver, Falls, and Schull, "Discussions: Heredity Counseling," 99. For similar discussions of the construction of "bad" mothers, see Ladd-Taylor and Umansky, *"Bad" Mothers*.

in the area of religion that genetic counselors might have truly thanked their policy of not giving specific advice. Sheldon Reed argued that it was their very non-directiveness that made them easily compatible with multiple religions. "There is no direct connection," Reed held, "between counseling and religious precepts."[150] While there may not have been a connection from his perspective, though, there was most certainly a connection for many of his clients, and no doubt for other genetic counseling clients across the United States. The times when conflict with religious beliefs surfaced most distinctly were in situations where the need to place some limit on family size was clear, but the client was Roman Catholic.[151]

Religion and Genetic Counseling

By the time Anne walked into the Dight Institute she and her family had already lost their car, a small house, and "their ambition." Anne was "a twenty-four-year-old intelligent Roman Catholic mother" of four. Two of her four children were born with fibrosis of the pancreas. Of these two, one had died and the other was six years old and had spent much of its life in hospitals.[152] These hospital expenses were the reason for Anne's financial trouble. She and her family depended on county relief money to get by, and the county had legal claim to any assets her family might manage to raise.[153]

Anne visited the Dight Institute curious about the likelihood of having another child with fibrosis. The counselor told her that, based on her family pedigree chart and understandings about the inheritance of fibrosis, there was a one-in-four chance. Anne

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[150] Reed, "Counseling in Human Genetics, Part III," 17.

[151] Ibid.

[152] A pseudonym. Ibid.

[153] Ibid., 18.

had actually already decided not to have any more children, but, for her own sake, had wanted an expert to confirm her suspicions about her future childbearing prospects. In a previous conversation with her priest, though, he had recommended that the only way for her to limit her reproduction was to stop living with her husband as man and wife: a suggestion, she pointed out, that "lacked realism."[154]

Anne's final decision is indicative of the ways individual Americans negotiated their sometimes conflicting, but no less intensely held, faiths both in science and in religion. She accepted that contraception would be a sin, and that the church's approved rhythm method would not work for someone with her "proven high fertility," but she also "considered it even a greater sin to risk having further defective children who would suffer and die while also depriving their normal [siblings] of their rightful social and financial position in the community." Anne was in a bind.

Caught between her religious beliefs on the one hand and her understanding of genetics on the other, she decided to be sterilized. Anne reasoned that it was better to sin once through sterilization rather than continuously through contraception. These were the sorts of challenges genetic counseling clients had to face. While Sheldon Reed acknowledged that, "anyone can appreciate her dilemma," he concluded that, no matter how difficult, "no one can decide for her which alternative to accept."[155] The principle that genetic counselors more and more agreed upon—that it was never the counselor's role to provide a direct answer to the question, "should I have a baby?"—protected them from accusations of eugenic engineering, and protected their clients from coercion. It also may have shielded them from the criticism they might otherwise have received from

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[154] Ibid.

[155] Ibid.

groups like the Roman Catholic Church on the one hand, and those opposed to eugenic policies like sterilization on the other. Instead, genetic counseling, and the Dight Institute in particular, actually won the praise of the Vatican, which recommended similar heredity clinics be established everywhere.[156] This sensitivity to client's decisions also meant that genetic counseling was shaped in important ways by the prospective parents coming to them for help.

Clients' questions contributed to the expansion of genetic counseling services, but clients could influence genetic counseling services in ways that limited the availability of testing as well. F. Clarke Fraser, writing in 1959, described how his clinic had for a time provided clients with a test to determine fetal sex. Research in the early 1950s had suggested that the Richardson Pregnancy Test, when given in the sixth or seventh month of pregnancy, could indicate the sex of the fetus: positive if a boy, and negative if a girl.[157] Fraser reported that the test was more than ninety-percent accurate, and that his clinic had "quite a number of requests" for it. In the "few cases that were wrong," however, the parents were so upset that they "far outweighed the minor benefits of the ones that were right" and Fraser stopped offering the test.[158] Client's desires to gain some control over their reproductive decisions led them to rely on genetic counselors' predictions. When a client was unsatisfied with the outcome of the predictions, though, they sometimes brought their complaints back to the clinics. In the context of 1950s reliance on science and medicine, genetic counselors' increasing success in convincing prospective parents to

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[156] Pope Pius XII, "Two Discourses," *Bulletin - Dight Institute of the University of Minnesota*, no. 11 (1959): 12.

[157] Gustav Wm. Rapp and Garwood C. Richardson, "A Saliva Test for Prenatal Sex Determination," *Science* 115, no. 2984, New Series (March 7, 1952): 265.

[158] Fraser, "Types of Problems Presented to Genetic Counselors," 79.

come to them for help with having normal children had the potential to sound more like a promise than a prediction.

As more human geneticists and doctors entered the genetic counseling field, discussions about best practices became more common in their professional literature. One of the most frequent, aside from "do not give your opinion," had to do with avoiding the confusion or misunderstanding about probability statements that could result in angry clients. Sheldon Reed suggested that, even though counseling was free, the counselor's natural desire to please the clients could lead him or her to "under-rate" the risk. He warned counselors who would allow themselves to do this that "there is a reasonable probability that the clients will be back to see you after having produced a second affected child." Counselors should always "tell the truth" to clients, Reed asserted, "not brutally, but in an 'educational' way."[159]

This sort of advice suggests two things about genetic counseling in the 1950s. First, the fact that it was necessary to advise counselors to always be forthright with their clients suggests that this was not standard practice at the time. In fact, even Reed moderated this position and suggested that in some cases it could cause undue stress to tell a client everything.[160] Second, it reflects the ways genetic counselors were starting to apply standards to their practice, through conferences, journal publications, and books, in ways that foreshadowed the move towards professionalization as a distinct health care service during the 1970s.

Genetic counseling clients also shaped the growth of genetic counseling through their expectations of care; specifically, they increasingly expected their doctor's

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[159] Reed, "Counseling in Medical Genetics," 932–933.

[160] Reed's suggestion was to provide just enough information to incite "a little apprehension in every client" in order to protect against more serious distress later. Ibid., 936.

predictions about future children to be correct. “The patient,” Sheldon Reed wrote, “pays the physician for this information and is not getting his money’s worth if only assured that ‘lightning never strikes twice in the same spot.’ In the families that came to us after the lightning had struck twice, the mistaken physician was no longer considered to be a family friend.”[161] Reed warned doctors that they may lose patients as a result of uneducated and unsuccessful genetic counseling, where the measure of success was a “normal” baby. By the 1970s the consequences would become much more costly as patients increasingly sued doctors who had failed to offer testing.

Responsibility and the Specter of Malpractice

By 1959, genetic counselors were more and more often discussing their work in terms of responsibility. Genetic counselors came to describe their relationship with clients as similar to the relationship between physicians and their patients.[162] Counselors perceived their duty to serve their clients and provide the best medical service they could. This reflected both clients’ demands and counselors’ own belief in the potential for genetic counseling to make a very real impact on the health of the population. As such, just as Reed warned physicians that they might be held liable for failing to refer their patients to a genetic counselor, many genetic counselors by the end of the 1950s were conscious of facing similar risks. With expectation came the potential for dissatisfaction, and genetic counseling’s implied promise of healthy, normal babies set up a powerful expectation.

Genetic counselors recommended working with physicians not only for the benefit of their more extensive and accurate patient medical histories, but also as a

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[161] Reed, *Counseling in Medical Genetics*, 13.

[162] Helen Hammons, *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building* (New York: Hoeber-Harper, 1959), 4.

potential shield against malpractice. C. Nash Herndon, at the Bowman Gray clinic in Winston-Salem, warned genetic counselors to “be careful to observe the pattern of medical ethics” and “to avoid any action that could be construed as malpractice.”[163] While this advice seems obvious from a post-1970s perspective, it was evidently not clear how much it applied to genetic counseling in the 1950s. At that time, genetic counseling was still a relatively young field. Without a formal professional structure there was still a lot of uncertainty about what made a good counselor, what sorts of answers a counselor should give, and what responsibilities counselors had to their clients. “I am not certain,” one genetic counselor acknowledged, “to what extent the counselor can be held legally responsible for a mistaken prognosis, but this possibility should be kept constantly in mind.”[164] Genetic counselors’ growing concern about liability is representative of the growth the field experienced in the 1950s, and the responsibilities that went along with helping parents have healthy babies.[165]

By the end of the 1950s, many genetic counselors seem to have been increasingly concerned about making sure that they were all providing the best, most up-to-date information to their clients, and were conscious of the fact that they were working in highly emotional settings where mistakes could potentially result in lawsuits. This marked a shift from the initial decade of genetic counseling in the way genetic counselors began to build a professional community and seek some degree of consensus on the question of what actually constituted their best practices. These shifts came as a result of changing understandings of human genetics that allowed counselors to predict for more

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163. Herndon, “Procedures for Referral to Heredity Counselors,” 73.

164. Oliver, Falls, and Schull, “Discussions: Heredity Counseling,” 101.

165. Issues of malpractice and liability raise interesting avenues for future research, and would become especially relevant into the 1970s with regard to prenatal testing.

traits with greater accuracy. Genetic counselors perceived their work as only becoming more challenging in the face of the still experimental process of prenatal diagnosis and the potential it created to find birth defects in time to end a pregnancy.[166]

For many decades before the 1910s and 1920s American women had been taught that they were responsible for the health and normality of their babies. By the end of the 1950s women and parents increasingly looked to genetic counselors, along with their obstetricians and physicians, for a share of this responsibility. Genetic counselors took part in this process by positioning themselves as experts in heredity and the prediction of abnormality in families. Clients responded to counselors' expert status and many increasingly did come to rely on them for help achieving the families they imagined.

The history of genetic counseling, though, cannot simply be a story of medical progress. Nor is it a story in which power-hungry, prejudiced eugenicists concealed themselves within genetics. Genetic counseling exhibited continuities with the early-twentieth century eugenics movements—continuities human geneticists in the 1950s were still grappling with—but the story is more complicated. Genetic counseling was co-produced by state and medical professionals' interests in improving the health of the human race by detecting and eliminating harmful genes and by would-be parents who wanted the best for their children. In both cases, adjectives such as healthy, harmful, best, and normal suggest qualities that are at once apparently obvious and historically contingent. When reading a mother's account of her child who died shortly after birth of a blood incompatibility, or from an excruciating condition such as Tay Sachs disease, it seems like the acme of academic relativism to question parents' desires for prediction, prenatal diagnosis, and choice. But coming across similar language to describe albinism,

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[166] Fuchs et al., "Antenatal Detection of Hereditary Diseases," 105.

"feeblemindedness," or Down syndrome, raises important questions about where parents, doctors, and scientists drew the line between serious and non-serious conditions. It begs the question: what does it mean to prefer non-existence to conditions like blindness? Genetic counselors, to a large degree, were able to avoid these questions, perhaps intentionally, by relying on their non-directive style of counseling.

These questions would become increasingly relevant in the 1960s, particularly in conjunction with related debates taking place over disability, birth defects, and therapeutic abortion taking place around the German measles epidemic and congenital rubella syndrome. Genetic counseling in the 1950s dealt with many of the same client concerns as the 1940s. Parents were worried about physical atypicalities, mental illness and retardation, and countless other manifestations of difference that might appear or reappear in their future children. What changed in the 1950s was that geneticists' knowledge of genes, chromosomes, and inheritance grew to allow them to predict more traits with gradually increasing levels of reliability. These developments were not lost on their clients or the physicians who referred them. Genetic counselors responded to the growth of their field and the needs and anxieties of clients by sharing best practices and by warning each other about the need to follow them. The changes in the field of genetic counseling in the 1950s were shaped by client anxieties, which they brought to counselors in hopes of answers and guidance, by changes in scientific understandings, and by genetic counselors' desires to help their clients have the normal, healthy families they dreamed of.

CHAPTER IV

CHANGES IN THE SIXTIES

Loretto and James Benson were filled with anxiety as they walked into the heredity clinic of a large medical center in the mid-1960s. Loretto had recently given birth to their first child, a boy who they named David. This should have been a happy time for the Bensons, who "desperately wanted a family," but they were anxious. David had Down syndrome and was "born mentally retarded." The Bensons visited the heredity clinic not for David, but for themselves. Like so many Americans who sought the help of genetic counselors in the mid-twentieth century, they wanted to know whether they could ever "hope to have normal children."[167]

The Bensons met with a genetic counselor who assured them that David's condition was merely the result of an "accident of nature." He had a "misplaced" chromosome, but it was not caused by any genetic condition. Further research into both Loretto's and James' medical histories "revealed no previous incidence of Down syndrome" in their families. On top of that, because Loretto was still in her twenties, she did not fit into the advanced maternal age risk group. The Bensons returned home secure in the genetic counselors' conclusion that, given their medical histories and the lab results, their risk of having another child like David were "only three percent." They resolved to "go ahead" and try again. One year later,they "had a perfectly normal second son."[168]

This story opened a 1968 *Today's Health* feature titled, "Predicting Tomorrow's Children." It was part of a special six-article section called "Protecting the Infant" that

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[167] Dorothy Crane Davis, "Predicting Tomorrow's Children," *Today's Health* 46 (January 1968): 32.

[168] Ibid.

provided readers with information about a number of ways science and medicine were working to help prevent, identify, and treat disability and birth defects in newborns. The author suggested that “less than a decade ago, the Bentons and many like them would have had little to guide them except vague rules of thumb.” Thanks to the “explosive development” of genetic counseling, though, they received more reassuring and concrete guidance.

The story of Loretto and James Benson was adjacent to a photo of a serious-looking genetic counselor in a white lab coat. In the photo he examined a “chromosome chart” to look for missing, misshapen, or otherwise atypical chromosomes that could cause birth defects like David’s.[169] The genetic counselor in the photo conveyed an air of studied reassurance—this was the person to help American families have the normal, healthy families they imagined for themselves and their children. The article’s message was that through the revolutionary new science of chromosome analysis genetic counselors could begin making more concrete diagnoses during pregnancy rather than relying solely on pedigrees, risk estimates, and probabilities. These new techniques came with new complications as well.

If genetic counselors thought they were starting to bring some order to their growing field at the end of the 1950s, the changes that took place over the course of the 1960s complicated them all over again. In the 1940s and 1950s most genetic counseling took place in a few academic departments across the United States, but by the end of the 1960s most counseling took place in medical centers. The expansion of genetic counseling services in the 1960s involved not only an increase in the number of clinics and counselors, but also a change in their professional and educational backgrounds.

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[169] Ibid.

Debate over what specialties were best suited to provide genetic counseling increased over the course of the decade. Most acknowledged, though, that because counseling centers were in short supply family physicians would likely provide most genetic counseling.

New scientific and medical techniques such as amniocentesis and chromosome analysis further contributed both to the growth and to the complexity of genetic counseling. These changes brought a degree of fragmentation to the best practices genetic counselors like Sheldon Reed and James Neel sought to define in the 1950s and complicated the practice of genetic counseling. The changes in the field of genetic counseling in the 1960s continued to be shaped both by clients' hopes for healthy families and by genetic counselors' ideas about disease and disability. In the 1960s, though, these perspectives were further shaped by the possibilities, and the legal and moral challenges, inherent in prenatal genetic testing and therapeutic abortion. New understandings and techniques in human and medical genetics profoundly altered the ways both clients and counselors thought about planning, pregnancy, and reproductive options.

Genetics, Chromosomes, and the Promise of Prenatal Testing

An "exasperating" profusion of blurry photographs and sketches of what looked to one *Lancet* reporter in 1961 "like masses of squashed spiders" flooded scientific and medical journals and books in the late 1950s and through the 1960s.[170] The humble appearance of these early photographs of human chromosomes belied their enormous significance to human genetics in the 1960s. Human genetics had been around for over two decades by the 1960s. It did not get the attention of the larger scientific or medical communities, though, until after the development of a technique to isolate and

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[170] Bernard Lennox, "Chromosomes for Beginners," *The Lancet* 277, no. 7185 (May 13, 1961): 1046.

photograph chromosomes, the promise of amniocentesis to allow testing at the fetal stage, and an expansion in course offerings. These developments enlivened human genetics from what Susan Lindee described as a "medical backwater" into a thriving scientific and medical field.[171] Though some medical schools by 1968 still lacked courses in genetics, they had become the exception rather than the rule.[172]

Mid-century developments in cytogenetics (the study of chromosomes) that allowed more specific investigation into the genetic causes of disease and held the potential for more accurate diagnosis of hereditary conditions profoundly shaped the fields of human and medical genetics. These new understandings were inexorably tied to the diagnosis and prevention of genetic conditions, and thereby closely linked to genetic counseling as well. "The term 'genetic counseling,'" Mihaly Bartalos observed in *Genetics in Medical Practice*, *"*has become commonplace" in journals such as the *American Journal of Obstetrics*, the *American Journal of Diseases in Children*, and *Nursing Outlook*. More and more physicians wanted to learn about these squiggly little images that held so much diagnostic promise, but the learning curve was steep. The "physician's dilemma," Bartalos explained, was that many had completed their education when material on genetics was not part of the curriculum. Many doctors had little knowledge of genetics and experienced difficulty understanding the new academic literature on it.[173] Bartalos' textbook, along with programs like Victor McKusick's Bar Harbor short-course in medical genetics, aimed to help physicians catch up with the

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[171] 171. Susan Lindee, *Moments of Truth in Genetic Medicine* (Baltimore, MD: Johns Hopkins University Press, 2005), 1–5, quotation on page 1.

[172] 172. Davis, "Predicting Tomorrow's Children," 33.

[173] 173. Mihaly Bartalos, ed., *Genetics in Medical Practice* (Philadelphia, PA: J. B. Lippincott Company, 1968), 3.

rapidly changing field.[174]

If one were to choose a single event that triggered the dramatic upsurge of interest in human and medical genetics—as well as in genetic counseling—it would probably be the finding that Down syndrome was caused by a chromosomal atypicality. A French team led by Jerome LeJeune discovered that Down syndrome was a chromosomal variation that occurred when an individual had one additional copy of the twenty-first chromosome (hence its medical name, trisomy 21).[175] Geneticist and counselor Victor McKusick, in an interview with historian Daniel Kevles, recalled how, after the discovery of trisomy-21 disorders, "doctors would notice that disorders ran in families, so they would send the patients over to have us look at their chromosomes."[176] Better understanding of the biochemical and chromosomal causes of hereditary conditions, combined with the promise of prenatal testing, opened the possibility that parents might be able to make determinations as to whether to continue with a pregnancy or not and led an even greater demand for genetic counseling.[177] Cytogenetics was by no means a standardized science before the early 1970s, though, and the genetics community

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[174] Ibid., 5.

[175] Cowan, "Women's Roles in the History of Amniocentesis and Chorionic Villi Sampling," 38; Frederick Hecht, "Jerome Lejeune (1926-94): In Memoriam," *American Journal of Human Genetics* 55 (1994): 201–202; J. Lejeune, M. Gauthier, and R. Turpin, "Les Chromosomes Humains En Culture Des Tissus," *Academie De Sciences* 248 (1959).

Down syndrome, in the 1940s through the 1960s commonly referred to as "mongolism," causes a variety of physical traits, such as low muscle tone, small stature, and an upward slant to the eyes. It can lead to increased risk of medical difficulties such as congenital heart defects, respiratory problems, and thyroid conditions. As of 1983, the life expectancy for people with Down syndrome was approximately 25 years. "Down's Syndrome," *A Dictionary of Nursing*, Oxford Reference Online (Oxford University Press, 2010), http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t62.e2540; "Down Syndrome Fact Sheet," *National Down Syndrome Society*, n.d., http://www.ndss.org/index.php?option=com_content&view=article&id=54&Itemid=74.

[176] Victor McKusick interview with Daniel Kevles, in Kevles, *In the Name of Eugenics*, 254.

[177] Fraser, "Introduction," 8.

struggled to agree on nomenclature and how to classify chromosomes.[178]

New developments in cytogenetics and the use of amniocentesis to collect fetal cells for analysis profoundly influenced the direction of genetic counseling and drew many more people to the field. Reed described that, as early as 1961, chromosome testing often coincided with genetic counseling as another source of information to provide to prospective parents.[179] These changes not only added to genetic counselors' investigative toolkit, but also introduced greater complexity into their burgeoning profession. The addition of previously uninvolved specialists, many of them medical doctors, highlighted again the lack of clear standards of practice. To further complicate the situation, amniocentesis and therapeutic abortion introduced difficult moral, legal, and ethical questions.

The potential for chromosome analysis in genetic counseling became especially evident when combined with amniocentesis. Clinicians and geneticists may have been among the first to notice the diagnostic potential of amniocentesis, but pregnant mothers remained most intimately connected to the procedure. In a 1968 article, Dr. Henry Nadler, from the Northwestern University Medical Schools' Department of Pediatrics, in Chicago, qualified amniocentesis for genetic testing as "experimental in nature." Within two years, though, a *Journal of the American Medical Association* article described the procedure as "one of the most important advances in genetic counselling [*sic*]."[180] Looking back on geneticists' and physicians' predictions about how amniocentesis would

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[178] Lindee, *Moments of Truth in Genetic Medicine*, 90–119.

[179] Sheldon C. Reed, "Report of Progress, 1961-1963," *Bulletin - Dight Institute of the University of Minnesota*, no. 13 (1966): 3.

[180] Henry L. Nadler, "Antenatal Detection of Hereditary Disorders," *Pediatrics* 42, no. 6 (December 1, 1968): 912; "Medical News," 2170.

benefit pregnant women, though, it is all too easy to forget the woman on the other side of the needle.

Amniocentesis required inserting a "20-gauge 5-inch needle on a plastic syringe" into a pregnant woman's stomach, through the uterus, and into the amniotic sac to withdraw between five and ten cubic centimeters of amniotic fluid.[181] Amniotic fluid contains fetal cells, which were separated and incubated in a culture prepared to feed them for approximately three weeks, after which time they were ready for analysis.[182] Cells for culturing could come from a variety of other sources as well, including blood or tissue. This allowed for counselors and clinicians to also test a mother or father for potential chromosomal conditions before the fetus was ready for testing, often in the sixteenth week of pregnancy. After the cells had multiplied enough to be analyzed, they were isolated using a liquid solution and then photographed. The photo was enlarged and then each chromosome cut out and rearranged on a grid from largest to smallest to make a karyotype for easier analysis (see Appendix B).[183] Genetic counselors often used these images to "show" clients the source of their genetic conditions.

The risk to the fetus during this procedure was relatively low with a well-trained clinician, but it is safe to assume that it would have been a highly stressful ordeal for most women nonetheless. The procedure itself breached, in a physical and a psychological sense, the sanctuary of the uterus, and the cells withdrawn might contain

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[181] Nadler, "Antenatal Detection of Hereditary Disorders," 912; Carlo Valenti, Edward J. Schutta, and Tehila Kehaty, "Cytogenetic Diagnosis of Down's Syndrome in Utero," *Journal of the American Medical Association* 207, no. 8 (February 24, 1969): 1513.

[182] Valenti, Schutta, and Kehaty, "Cytogenetic Diagnosis of Down's Syndrome in Utero," 1513.

[183] Cecil B. Jacobson, "Cytogenetic Techniques and Their Clinical Uses," in *Genetics in Medical Practice*, ed. Mihaly Bartalos (Philadelphia, PA: J. B. Lippincott Company, 1968), 117–120; Nadler, "Antenatal Detection of Hereditary Disorders," 915.

evidence of an abnormality. These factors likely combined to make the procedure powerfully affecting.[184] The hypodermic needle, an otherwise relatively everyday object for people with access to medical care, became instead an object of both hope and foreboding. It promised knowledge. It could either confirm prospective parents' hopes that their child would be free of disability, or it could confirm their fears. Amniocentesis also further medicalized so-called normal pregnancies—those with no preexisting factor that created increased risk—by eventually making such testing routine.

Chromosome analysis through amniocentesis was one of the first viable ways to detect some birth defects prenatally. These techniques gave genetic counselors and prospective parents new tools to go about assuring healthy, normal children, but left them in a legally and morally ambiguous gray area. While prenatal testing could be used to get a head start on adjusting to the special needs of a disabled child, it has more often been used as an indicator for abortion. Abortion, however, even therapeutic abortion, was a contentious issue in the 1960s, and highly regulated. In most states, the only time abortion was legally justified was when the life of the mother was at serious risk. Officially, this did not extend to the child. Chromosome analysis and amniocentesis further complicated genetic counseling in the 1960s, just as it did pregnancy and family making in general.

Reproductive Decisions: Abortion and Disability in the 1960s

Many of the social and political changes that gained traction in the 1960s shaped women's—and, perhaps less directly, men's—options when it came to reproductive decision-making. The birth-control pill, the beginnings of the women's liberation

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[184] Rothman, *The Tentative Pregnancy*, especially 78–85. Rothman described these types of reactions to amniocentesis among the women she interviewed for her 1987 book. While this is a different time period than what I am looking at, it seems safe to expect that women in the 1960s encountering this very new, very invasive procedure might have reacted in similar ways.

movement, medical consumerism, and the ways that personal self-fulfillment and experience were caught up in social and political debates all contributed to giving women and prospective parents legal and medical options they had only had at-best illicit access to in the 1940s and 1950s.[185] But in the 1960s these changes were still underway, and even decades later would be by no means fully realized.

Women's and men's approaches to pregnancy were also influenced by new medical studies that linked certain medications and viruses to birth defects. Medical opinion had long held that the placenta formed a barrier to the outside world that protected the fetus. Thalidomide, a rest aid that turned out to interfere with fetal development resulting in babies born with seriously underdeveloped or nonexistent limbs, and an epidemic of rubella, which produced birth defects when pregnant women contracted it early in pregnancy, both overturned these prior theories. Studies also found links between nicotine use and alcohol consumption and developmental problems. Increasingly, the mother's womb seemed much less a place of safely and protection and more a space in need of monitoring and medical management.[186] Genetic counseling provided a collection of pre-conception and prenatal diagnostic tools—family histories, pedigrees, empiric risk statements, and, in the 1960s, amniocentesis and chromosome analysis—that merged both with notions that reproduction should be medically managed

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[185] Ruth Rosen, *The World Split Open: How the Modern Women's Movement Changed America* (New York: Viking, 2000); Wendy Kline, *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave* (Chicago, IL: The University of Chicago Press, 2010); Estelle Freedman, *No Turning Back: The History of Feminism and the Future of Women* (New York: Ballantine Books, 2002); Sara Evans, *Tidal Wave: How Women Changed America at Century's End* (New York: Free Press, 2003); Nancy Tomes, "Merchants of Health: Medicine and Consumer Culture in the United States, 1900-1940," *The Journal of American History* 88, no. 2 (2001): 519–547; Lemus, "'The Maternity Racket': Medicine, Consumerism, and the Modern American Pregnancy, 1876-1960"; Herman, *The Romance of American Psychology*; Davis, *More Perfect Unions*.

[186] Reagan, *Dangerous Pregnancies*; Elizabeth Armstrong, *Conceiving Risk, Bearing Responsibility: Fetal Alcohol Syndrome & the Diagnosis of Moral Disorder* (Baltimore, MD: Johns Hopkins University Press, 2003); Golden, *Message in a Bottle*.

and with increasing pressure from prospective parents for these services.

The development of amniocentesis and chromosome analysis as a potentially viable means of prenatal testing also meant that abortion became a much more relevant issue to genetic counseling. During the 1960s, laws across the United States restricting abortion, especially therapeutic abortion, came under attack from citizens in positions of privilege in response to the situation they saw unfolding as a result of the rubella (German measles) epidemic of the mid-twentieth century. Historian Leslie Reagan traced the growing pressure from white, middle-class, and well-educated women (and men) at risk of having children with congenital rubella syndrome to reform abortion laws. These parents, who occupied the same demographic category as many genetic counseling clients, and who shared similar concerns about the health and normality of their future babies, played an important role in the eventual loosening of therapeutic abortion regulations and in the legalization of abortion in 1973. These outcomes would have important ramifications for genetic counseling, which similarly involved parents in thinking about how best to protect their future children from birth defects.[187]

The debates over therapeutic abortion in cases of likely disability contributed to the eventual decriminalization of abortion, but also included the voices of disabled citizens concerned about what abortion for disability suggested about their place in society. Many of the calls for more liberal access to abortion during the 1960s, because they centered around congenital rubella syndrome, spoke to American's continued focus on normality as the absence of disability. Medical advice, mainstream media, and a variety of other cultural and medical sources had long taught prospective parents that normality was not only desirable, but also achievable through proper maternal behavior

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[187] Reagan, *Dangerous Pregnancies*, 142–179; Reagan, *When Abortion Was a Crime*, chapters 7 and 8.

and dependence upon expert advice. This perspective, however, was not universal.

As early as 1967, a woman from the disability community voiced a concern about therapeutic abortion in response to potential birth defects that highlighted a developing disability rights perspective that would come to play an important role in debates about and within genetic counseling. She wrote that she occasionally felt “anguish” living with even her “mild case” of cerebral palsy, but nevertheless would prefer it all to having been “deprived of the great gift of life.” This woman opposed relaxing abortion laws because she felt not only that was it presumptuous to “play God” with people’s lives, but also that it assumed “so-called ‘defective’ individuals” could contribute nothing to the world.[188] Not all Americans with disabilities fell on this side of the issue. Much like today there were divided opinions about what prenatal testing and abortion said about people’s perceptions of disabled people and their place in society.[189]

In these situations, genetic counselors’ focus on withholding their opinions and not directing clients’ actions might have helped to distance them from the ethical, if not the legal, issues around therapeutic abortion for disability. What is certain, is that amniocentesis and chromosome analysis, and their implied connection to therapeutic abortion, served to further complicate the genetic counseling field. The rough consensus around non-directiveness that the relatively small cohort of genetic counselors managed to build in the 1940s and 1950s began to splinter in the 1960s as new information and techniques attracted more people to the field. The same developments that encouraged

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[188] Betsey Warwick to Sen. Anthony Beilenson, 1 May 1967, quoted in Reagan, *Dangerous Pregnancies*, 161.

[189] Reagan, *Dangerous Pregnancies*; Davis, *Enforcing Normalcy*; Parens and Asch, *Prenatal Testing and Disability Rights*; Rothenberg and Thomson, *Women and Prenatal Testing*. On the question of disability, prenatal testing, and selective abortion today, see Parens and Asch, *Prenatal Testing and Disability Rights*; Rothenberg and Thomson, *Women and Prenatal Testing*.

more people to practice genetic counseling also drew media attention. Popular publications in the 1960s communicated to readers the possibilities presented by genetic counseling at the same time they reinforced notions of health and the tragedy of abnormality.

Genetic Counseling in the News

Throughout the 1960s, articles appeared in national newspapers and magazines with headlines like: "Will the Baby Be Normal?"; "Babies With Defects High"; and "Chances of a Defective Child."[190] These articles, like many others, warned readers about the omnipresent threat of having a disabled child, even if a couple were themselves perfectly "normal." They also advised that the best way to reduce the number of birth defects in the United States was with "heredity counseling and discouraging couples, who carry heritable factors that cause malformations, from having children."[191] These articles quoted similar statistics on the number of birth defects per year and gave similar advice about how to avoid them. One area they were not consistent in, though, was in the possibility, or impossibility, of testing and therapeutic abortion.

Articles on genetic counseling and heredity clinics often characterized reproduction in similar ways. In a 1969 *New York Times Magazine* article, staff writer Robert Stock described the process of having children as a lottery "stacked in our favor" by the remarkable dependability of reproduction. But as in other lotteries, the article made clear, "there are losers." The "losers" Stock referred to were the approximately "200,000 American children . . . born with an inheritance of disabling defects: deaf,

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[190] "Will the Baby Be Normal?" *Time*, 1960; "Babies With Defects High," *Chicago Daily Defender* (Chicago, IL, April 24, 1961); "Chances of a Defective Child," *Time*, March 3, 1967.

[191] "Babies With Defects High," 8.

mentally retarded, physically deformed."[192] Other articles quoted similar numbers and similar "defects." Two others, one in 1961 and one in 1968 quoted the number at closer to 250,000.[193] Another explained that "200,000 babies [were] born in the U.S. each year with deformed bodies, impaired minds and possibly fatal abnormalities in body chemistry—often because of defective genes or chromosomes." The same article predicted that this number could be "reduced dramatically" if only there was a way "to 'test' routinely the genes of prospective married couples" much as couples were already tested for syphilis. This, it concluded, was what genetic counseling was trying to do.[194]

"It is little wonder," another article began, "that some women are afraid to have children." Would-be mothers read "agonizing details of the birth and death of quintuplets." They had friends whose children had Down syndrome, or they remembered that "Cousin Willie" had harelip and they "dread[ed] the thought of bearing a hairlipped [*sic*] baby." What was a couple to do? Fortunately this article, like others, provided an answer after bombarding readers with laundry lists of anxiety: couples could find "help in genetic counseling."[195] Like most articles on genetic counseling, this one pulled readers in—and likely made some prospective parents at least a little anxious—with statistics and anecdotes about babies born with disabilities, and then provided them with a solution.

Media stories reassured readers that it was no longer necessary to live in fear or to simply accept the fact that some people were born disabled. Thanks to genetic counselors, the "space-age counterpart of the old matchmaker," prospective parents could exert some

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[192] Robert W. Stock, "Will the Baby Be Normal? The Genetic Counselor Tries to Find the Answer," *New York Times Magazine* (March 23, 1969): 25.

[193] "Babies With Defects High," 8; Davis, "Predicting Tomorrow's Children," 33.

[194] "How Are Your Genes? Genetic Counseling Centers," *Newsweek* 73 (February 10, 1969): 90.

[195] Faye Marley, "Who Should Bear Children?," *Science News* 90, no. 26 (December 24, 1966): 537.

control.[196] Geneticists could “probe the depths of the human cell” to ascertain hereditary conditions or birth defects in order to “control the lottery” of reproduction. A *New York Times Magazine* article described the genetic counselor as “the man whose task it is to translate” the genetic revolution into “human terms.”[197] Readers were assured that the “explosive development” of genetic counseling would help them protect their prospective families from birth defects.[198] Media in the 1960s seems to have responded in part to concern about birth defects and also to have fanned the flames. At the same time, though, the tone of these articles was not one of doom and resignation, but of hope and promise. Readers may have been reminded of the constant threat of birth defects in their future children, but they were also given a way to avoid them.

Readers were also reminded that the threat applied to everyone. Anyone might be a carrier, so everyone should go to see a genetic counselor. “Carriers” were people who had a “defective” gene that did not manifest itself in symptoms because of a dominant “normal” gene. One article about genetics and genetic counseling cited Dr. Kurt Hirschhorn, at Mount Sinai School of Medicine in New York, to further underline the point that everyone should inspect their extended families for disability and should arrange to visit a genetic counselor if they had any doubts. Even people without a history of defective genes, it warned, might be a carrier of a recessive defective gene that would show up in one's offspring if combined with the same gene in one’s spouse.[199] Carrier status, though, was not what the majority of genetic counseling clients were concerned

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[196] “Of Miracles and Medicine,” *Today’s Health* 46, no. 1 (January 1968): 30.

[197] Stock, “Will the Baby Be Normal?,” 25.

[198] Davis, “Predicting Tomorrow’s Children,” 33.

[199] “How Are Your Genes?,” 90.

about. Many clients sought the assistance of a genetic counselor only after having had a child with an abnormality.[200]

If one of the functions of articles about genetic counseling was to explain to readers why they should be aware of the service and consider seeing a counselor if they were anxious for their future children, a second goal was to explain to readers what to expect once there. These types of stories might have had two effects, first, they described to clients what sorts of questions many other clients had, and second, they may have helped to reinforce the kinds of questions clients were expected to ask.

The first most common question clients reportedly asked was, "why did this happen to our child?" Responding to this counselors were expected to dispel blame and any confusion couples might have about how genetics worked. After that was clear, "the next question is usually, 'what are the chances of our having another child with the same defect?'" These young couples, concerned about disability in their families and having just received a rapid course in basic genetics, often asked outright if they should "risk having another child." The response, in keeping with the best practices of early genetic counselors like Sheldon Reed and James V. Neel, was that counselors "cannot play God"; that the decision was up to the parents. "All the counselor can or should do," one genetic counselor was quoted as saying, "is to inform the parents or prospective parents of the facts, state the risks clearly, and be sure they understand all facets of the problem."[201] Given the often emotional nature of counseling meetings, and the fact that clients often had only just learned the basics of genetics, it may have been an irritating experience for some to then be told to go home and make up their own minds. For others, though, the

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[200] Davis, "Predicting Tomorrow's Children," 35.

[201] Ibid., 37.

counseling experience brought relief from worry, blame, or exaggerated fears about the recurrence of birth defects in future children.

Popular media articles told a remarkably consistent story about the need for genetic counseling and what to expect from a consultation with a geneticist. One place where their coverage diverged was on the topic of therapeutic abortion. The March 23, 1969 issue of the *New York Times Magazine*, arrested the reader's attention with a full-page photo of a nine-week-old fetus. Alone on a black background, hands, feet, and individual toes easily discernible, the photo was taken just fifteen minutes after a therapeutic abortion, and the fetus was still in the amniotic sac (see Appendix D). The photo caption on the inside page announced that "by being able to detect many inbred birth defects, scientists are giving parents grave new options."[202] It is difficult to know why this image was chosen for the cover, but it seems likely to have sold magazines. It is also impossible to know what readers thought of it; though, if nothing else, it represents the degree to which therapeutic abortion for birth defects had become part of popular discourse.

Not all articles presented the same information on whether therapeutic abortion in the case of fetal atypicality was an option in the United States. One article described how amniocentesis and chromosome analysis, employed when other factors warranted it, could "establish whether or not the [fetus'] chromosomes are damaged." If tests showed definitively that the fetus was disabled in some way then a client could seek a therapeutic abortion. "Unfortunately," this *Science News* article concluded, "therapeutic abortion in cases of expected mongolism is not legal in the United States."[203] The fact that this article

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[202] Stock, "Will the Baby Be Normal?," magazine cover, quotation on 22.

[203] Marley, "Who Should Bear Children?," 537.

cited such procedures as illegal and other publications did not represents the sharp divide —not to mention confusion—over these issues at the time, and just what constituted valid grounds for a therapeutic abortion.

A *Time* magazine article, for example, presented amniocentesis as a "boon" to couples with "a history of pregnancy mishaps" or whose families were "known to harbor inheritable defects." The piece described Nadler's work at the Children's Memorial Hospital in Chicago, where his department "managed" 150 pregnancies with chromosome analysis using amniocentesis. Nadler's clinic "recommended" abortion in fourteen of these cases. Thirteen clients had an abortion, and one did not. The one mother who did not have an abortion already had one "mongoloid child" and preferred to have another rather than go through with an abortion, "and she did." Nadler's clinic, the article suggested, could prevent the spread of "defective" genes if only his clients cooperated.[204] Another inconsistency in this report is the description that Nadler "recommended" fourteen abortions. There is little way to know whether he suggested that these women have abortions, or if Nadler merely confirmed his clients' own desires for abortion and made his recommendation instead to the hospital in charge.

A *Newsweek* article provided perhaps the clearest message to would-be parents about the possibilities presented by amniocentesis and chromosome analysis. The article also quoted Nadler that this type of testing added "a new dimension to genetic counseling." He told of a 39-year-old client who he found carried a chromosomal condition that caused Down syndrome. A subsequent amniocentesis and karyotype showed the fetus also had this additional chromosome. She had a therapeutic abortion, became pregnant again, and when Nadler tested this fetus he was able to say "that she

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[204] "New Concern for the Unborn," *Time*, 1969, 58.

would give birth to a normal child. He was right."[205] This story showed readers in no uncertain terms the potential that lay in amniocentesis, chromosome analysis, and therapeutic abortion. Therapeutic abortions carried out for these reasons may have been of ambiguous legality, but they meshed with representations of disability and health at the time. Further, it is not clear from this case study whether the client acted on her own initiative or on Nadler's recommendations, but the fact that she returned to him after her first therapeutic abortion, though, suggests how she and genetic counseling clients like her had the power to shape genetic counselor's approaches to these morally and legally ambiguous issues.

These new procedures also raised important questions about the relationship between prenatal testing and a social programs. The *New York Times Magazine* quoted Kurt Hirschhorn, then president of the American Society of Human Genetics, that if Americans were willing to abort fetuses that had, or were carriers for, diseases like cystic fibrosis, then it would be possible to "eradicate [the disease] from the American scene." Hirschhorn was not "enthralled" by this course of action, but noted that these "eugenic programs" were becoming increasingly feasible. A *Today's Health* article similarly reported that some specialists advocated mandatory premarital genetic counseling "to determine whether prospective newlyweds are likely to have children with serious defects." These specialists did not advocate preventing them from marrying, or even from having children, but believed that getting the information was too valuable to not be required.[206] Genetic counselors, the *New York Times Magazine* predicted, would be on the

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[205] "How Are Your Genes?," 90–91.

[206] Davis, "Predicting Tomorrow's Children," 37. A *Science News* article similarly clarified to readers the difference between genetic counseling and eugenics: "Not to be confused with eugenics, which includes sterilization and birth control procedures," the article explained, "genetic counseling aims to tell worried people what is known about genes and chromosomes and lets them decide for themselves

front lines of future debates over national policies for dealing with issues like these.[207]

By the 1970s and 1980s this prediction came true in a variety of ways, but in the 1960s genetic counselors were already engaged with these questions at a more individual level. On a personal level, when anxious clients came to them with hopes for a child free of disability, genetic counselors in the 1960s were already engaging with these issues and helping clients make their own decisions. The expectation of non-directiveness, largely agreed-upon in the 1940s and 1950s, became further complicated by changes in the 1960s. The expansion of the genetic counseling into a variety of specialties influenced how the beginnings of a consensus on best practices formed in the 1950s drifted apart again in the 1960s. Some of the new participants, particularly from the medical community, felt differently about the place of advice in genetic counseling than people like Sheldon Reed.

Growth and Professional Diversification

One news writer described genetic counseling in the late 1960s as "something of a stepchild" in the family of science and medicine.[208] This was an apt description for a field that started in academic departments and moved into medical centers. Starting in the late 1950s, and increasing dramatically in the 1960s, the practice of genetic counseling shifted from academic departments to primarily medical centers. This process sped up as the field of medical genetics gained popularity among doctors. This new interest developed out of better understandings of chromosomes and the ability to photograph them, analyze them, and make diagnoses with them.

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whether they want to take a calculated risk": Marley, "Who Should Bear Children?," 537.

[207] Stock, "Will the Baby Be Normal?," 26.

[208] Ibid., 25.

In 1955 there were approximately twenty genetic counseling centers in the united states.[209] By the latter half of the 1960s, that number had increased to over 100. Another source cited over eighty "so-called heredity clinics" across the United States by 1968, and over 100 birth-defect clinics operated by the National Foundation-March of Dimes that also offered genetic counseling (see Appendix A).[210] Three-fourths of these centers were located in medical settings like hospitals or medical schools. Lee Dice suggested in the early 1950s that every genetic counseling clinic ought to have a someone on staff with a medical degree, and Sheldon Reed was confident that most counseling would be done by physicians eventually, but significant numbers of medical doctors were not attracted to the field until after techniques like chromosome analysis became viable.[211]

Some states also began to get involved in genetic counseling efforts. The State of Minnesota's Human Genetics Unit of the State Board of Health took on a portion of the Dight Institute's counseling load between 1959 and 1961.[212] Dr. Lee Schacht, a Dartmouth graduate and former researcher and genetic counselor at the Dight Institute, led the Human Genetics Unit.[213] Other states experimented with different models for bringing genetic counseling services to their populations. The Health Department of Contra Costa County, California, believed that the "ideal genetic counselor, being an expert in many different disciplines at once," could exist in reality "only as concept." Most counseling was performed either by geneticists or by physicians with a range of

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[209] Reed, *Counseling in Medical Genetics*, 3.

[210] Davis, "Predicting Tomorrow's Children," 33, 72.

[211] Dice, "Heredity Clinics," 7–8; Sheldon Reed, *Parenthood and Heredity*, 2d ed. (New York: Wiley, 1964), 229–230.

[212] Sheldon C. Reed, "Report of Progress, 1959-1961," *Bulletin - Dight Institute of the University of Minnesota*, no. 12 (1962): 4–5.

[213] Ibid., 1.

specialties. The Contra Costa County Health Department was confident that family physicians did most of the day-to-day counseling, and that they were not adequately trained to do so.[214] A solution health officials came up with to address this problem was for health departments to help physicians in their roles as the primary genetic counselors.

The Contra Costa County Health Department in Martinez, California, piloted their program between 1963 and 1965. They provided physicians with genetic information about their clients in order to help them better serve as genetic counselors. The health department's first step in each case was to send public health nurses to collect detailed family pedigrees. This pedigree then went to a specialist at the Health Department, who interpreted it and sent both the chart and interpretation to the client's physician for use in counseling. They reported that physicians were enthusiastic about the service, but it was still too early for them to have clear data on the efficacy of the program.[215]

Awareness of genetic counseling services and what they offered prospective parents contributed significantly to the field's growth in the 1960s. Nadler argued that "the increasing awareness of the scope of genetic disorders has made it incumbent upon physicians to provide the most precise genetic counseling possible."[216] Scientists and doctors interested in medical practice observed that most of the "present-day killing diseases" seemed to "have a significant genetic component" involved. They believed that as more physicians and individuals learned about these discoveries the need for genetic

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[214] Elizabeth Jolly and Henrik L. Blum, "Genetic Counseling—A Health Department Service to Physicians," *California Medicine* 103, no. 5 (November 1965): 331.

[215] Ibid., 332. As of 1968 there was a Genetics Consultation and Counseling Service associated with the Health Department in Martinez, California.

[216] Nadler, "Antenatal Detection of Hereditary Disorders," 916.

counseling would continue to increase.[217] This growth introduced genetic counseling into a variety of new specialties, medicine in particular. It meant not only increased availability for clients, but also a greater degree of divergence in counselors' skills, training, and exposure to the early standards developed in the 1940s and 1950s.

Physicians and counselors in the 1960s disagreed over who best should provide genetic counseling. Some believed that practicing physicians were the best placed to provide it, often because they knew the individual or couple already and because they had experience with the interpersonal requirements of working with patients.[218] Others, however, argued that medical geneticists (who could, certainly, also be medical doctors, if not practicing physicians) made ideal counselors when assisted by other specialists. Most acknowledged, though, that in many cases it would be necessary for the family physician to provide genetic counseling because of the short supply of counseling centers.[219]

Sheldon Reed argued that the genetic counselor "must be a competent geneticist" first and foremost because of the wide range of cases he or she was likely to encounter. He believed that while backgrounds in anthropology or medicine would be beneficial, it would be more likely that a genetic counselor would have to rely on colleagues for these opinions.[220] Even sources that acknowledged that only those with training in human genetics could adequately counsel in the more complex cases noted that the most everyday genetic counselors would be physicians. Many sources described the "typical"

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[217] Bartalos, *Genetics in Medical Practice*, 3–4.

[218] Henry T. Lynch, "Family Centered Genetic Counseling: Role of the Physician and the Medical Genetics Clinic," *The Nebraska State Medical Journal* 50 (April 1965): 155–159.

[219] Robert F. Murray, "Genetic Counseling in Clinical Medicine," in *Genetics in Medical Practice*, ed. Mihaly Bartalos (Philadelphia, PA: J. B. Lippincott Company, 1968), 143.

[220] Reed, *Parenthood and Heredity*, 9.

genetic counselor as a physician with an interest in genetics.[221]

Reed also argued that genetic counselors, perhaps most importantly, needed to "have a deep respect for the sensitivities, attitudes and reactions of the client" as well as a desire to teach.[222] A common argument that surfaced more frequently in the 1960s in professional discourse was that genetic counseling, if done properly, would take into account patient attitudes, anxieties, and confusion, and could have a broad, beneficial effect by working through other family tensions at the same time.[223] Genetic counselors observed that clients often responded to data about hereditary disease in their families with "responses such as guilt, anxiety, hostility, impotence, frigidity, reduced reproductive performance, marriage disruption, and divorce." The authors of one study went so far as to warn physicians against referring cases to "non-medically oriented laboratory or agency personnel who may be deficient in the understanding of such emotional problems." In these settings clients were expected to receive "cold, stereotyped, mathematical" advice.[224] These debates over who was best qualified to provide genetic counseling were integral to the professionalization of the field, and would be revisited in the mid-1970s. The question of who should do genetic counseling was also closely caught up with similar questions about what genetic counselors should actually entail.

As the previous source indicated, many genetic counselors were concerned with the emotional well-being of their clients as much as in presenting genetic data. Reed

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[221] Stock, "Will the Baby Be Normal?," 26.

[222] Reed, *Parenthood and Heredity*, 11.

[223] Robert L. Tips and Henry T. Lynch, "The Impact of Genetic Counseling Upon the Family Milieu," *The Journal of the American Medical Association* 184, no. 3 (April 20, 1963): 120.

[224] Lynch, "Family Centered Genetic Counseling," 158.

argued that counselors should be on the lookout for signs of tension between parents or attempts to assign "blame" for a condition that appeared in their child. He also suggested that counselors were likely to encounter clients who were ashamed of the fact that they possessed atypical genes. He advised explaining to these clients that simply carrying such a gene did not make him or her "defective," and that most people probably carried such genes.[225] Much of what took place in genetic counseling sessions, though, was initiated by the clients. Their concerns, anxieties, and confusions went a long way toward shaping the services they received.

In the 1964 version of *Counseling in Medical Genetics,* retitled *Parenthood and Heredity* and geared towards a larger audience, Sheldon Reed reiterated his impression that the clients he counseled were largely self-selected. Describing them, he gauged that "there must be a fair amount of intelligence, insight and educational background behind the motivation that actually gets the client to the counseling center." His impression was that his clients were typically in good mental health, were often from the middle or upper class with good incomes, and were fairly well educated. Reed also noted that the counselors often came from the same social classes, which allowed them to better communicate with their clients.[226] Genetic counseling clients were, by these descriptions, members of a privileged group of Americans that also had more access to regular medical care. Their privilege and access to medical services also meant that, as mothers and prospective parents, they were perceived as respectable, responsible, "good" mothers, who were taking all the right steps to look out for the health and normality of their

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[225] Reed, *Parenthood and Heredity*, 11–12.

[226] Ibid., 8.

children.[227]

Though the Dight Institute was still a no-fee clinic in the 1960s, it is less clear that newer genetic counseling centers followed the same practice. In some cases clients began to pay at least the cost of hospital admission in order to access genetic counseling services in medical centers. What is more clear is the effect that the increased viability of cytogenetic testing had on genetic counseling costs. One source reported that it cost $100 per test to cover the cost of a chromosome analysis performed using a sample of blood as $100, and the same test using a tissue culture (skin or organ cells) cost $150.[228] Even the Dight Institute, which resisted charging for its services, began to require clients to pay at most $60 out of the $400 it cost to do a chromosome analysis.[229]

Most people who sought out the services of a genetic counselor in the 1960s, like in the 1950s, had already had an “abnormal” child and wanted to know the risk of having another. Other clients might be couples with a history of “hereditary abnormality” in one side of their family and curious about whether their children might be affected. Another client might be “a mother with one or more abnormal offspring” looking for information because she was contemplating sterilization or therapeutic abortion[230] Out of all of these types of cases, the first was the most common. Many people who sought the assistance of genetic counselors had already experienced a problem of one kind or another while trying to make a normal family.

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[227] Issues of how expectations—both women’s (and men’s) expectations of service from genetic counselors and expectations that responsible mothers sought the assistance of genetic counselors—will form an important part of my future work on genetic counseling. As will questions of access to health care, direct and indirect costs, and how these factors played in the same expectations discussed above.

[228] Jacobson, “Cytogenetic Techniques and Their Clinical Uses,” 105.

[229] Reed, “Report of Progress, 1961-1963,” 3.

[230] Murray, “Genetic Counseling in Clinical Medicine,” 136.

Clients often experienced both love for their affected child and an intense hope not to have another at the same time. “They show great affection for their abnormal child and give it more than its ordinary share of attention,” Reed observed, “but the parents are unhappy both for the defective child and for themselves. We have never seen parents who wished to repeat their misfortune.” He continued that it was necessary to help such parents by providing them with the best possible probability of “another abnormality” so that they could make an informed decision. He stressed, however, that counselor should not give in to clients’ questions about whether or not to have another child. “This question,” Reed argued, “is one that we do not answer because we cannot.”[231] While Reed was still adamant in the 1960s that the genetic counselor should not give direct advice to clients, other, often newer genetic counselors, were not as consistent.

The Counseling Encounter in the 1960s

The question, then, is just what did genetic counselors in the 1960s tell their clients, and how much did they abide by Sheldon Reed’s advice, born out of the 1940s and 1950s, in their own practice? By the 1960s there was more evident variation in genetic counselors’ approach to counseling, particularly with regard to giving or not giving advice. This suggests that their on-the-ground encounters with clients possibly varied more widely than their writings suggest. Nevertheless, these records are valuable for exploring the ways genetic counselors tried to create a shared template for genetic counseling, and for considering what those guidelines said to do.

The initial steps in a 1960s genetic counseling session were not significantly different from those of the previous decades. They varied in length, number, and duration, but counselors seemed to agree, at least on paper, that they did their best “not to ‘push’

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[231] Reed, *Parenthood and Heredity*, 12–13.

information at a rate faster than" clients could understand." In some situations, one counselor remarked, the counseling "may take several sessions."[232] In other cases, the initial counseling session might last for about three and a half hours, with follow-up sessions each about one and a half hours long. In this clinic the entire process of counseling one client took about sixty days.[233] The addition of amniocentesis would also add time to the counseling process, since client and counselor would have to wait while the fetal cells divided.

As in the 1950s, counseling in the 1960s began with taking a detailed medical history. The move to medical facilities also facilitated making a physical examination. Counselors encouraged making family histories as detailed as possible, including ages, health, and sex of all family members, as well as siblings, parents, children, and close relatives of the affected person.[234] Geneticists often used questionnaires, medical records, death certificates, and the services of state and county welfare agencies to uncover all they could about the client and his or her family.[235] In most cases this information was then organized into a pedigree chart, as in the past. One counselor, having gone over pedigree charts with clients, was "impressed at how readily they understand the symbols and comprehend the particular mode of inheritance."[236] By 1968, there was an addition to the counseling process. Physical examinations and family histories could be supplemented by chromosome analyses or biochemical studies. Counselors, however,

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[232] Davis, "Predicting Tomorrow's Children," 35.

[233] Tips and Lynch, "The Impact of Genetic Counseling Upon the Family Milieu," 185.

[234] Murray, "Genetic Counseling in Clinical Medicine," 144.

[235] Lynch, "Family Centered Genetic Counseling," 155–157.

[236] Ibid., 158.

continued to stress the need for family history analysis in conjunction with cytogenetic testing to form the best picture of the client's prospects for a normal family.[237]

At this stage in a genetic counseling session it was time to convey information to the client—to finally start answering their questions and providing recurrence estimates. Some counselors tried to put off discussion of genetic data and risk figures until later visits after the clients had grown more comfortable.[238] This is does not seem to have been the case in all, or even most clinics, though. Many counselors still agreed that "acceptable genetic counseling allows the individual to arrive at his own decisions without persuasion in any personal issues that arise."[239] But the language used to communicate risk figures to clients could have almost as much influence over their decisions as direct advice could. At least a few counselors started giving clients risk figures in different ways in the 1960s that raised issues of directiveness.

The presentation of the recurrence risk statement was the "climax" of the counseling meeting and should be "stated as confidently as possible" one textbook recommended. It suggested giving the recurrence probability as both a percentage and numerical figure; that is, telling a client the changes were 25 percent, or one in four. These risk estimates were often lower than anxious clients had feared.[240] Counselors were also encouraged to make certain that clients understood that the risk figure applied to each subsequent pregnancy, not to the total number of children.[241] All of these elements of

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[237] Murray, "Genetic Counseling in Clinical Medicine," 144; Tips and Lynch, "The Impact of Genetic Counseling Upon the Family Milieu," 184.

[238] Tips and Lynch, "The Impact of Genetic Counseling Upon the Family Milieu," 184.

[239] Jolly and Blum, "Genetic Counseling—A Health Department Service to Physicians," 331.

[240] Davis, "Predicting Tomorrow's Children," 37.

[241] Murray, "Genetic Counseling in Clinical Medicine," 146.

information delivery were consistent with prior notions of non-directiveness.

In the mid-1960s genetic counselors started also recommending the use of groupings to communicate risk to clients, but these groups were not consistent. “High” risk according to some counselors was a ten-percent chance or greater, while “low” risk was ten-percent or lower. Others, such as Arno Motulsky at the University of Washington, in Seattle, suggested three categories. “High” would be a fifty-percent chance or more, “moderate,” was between twenty-five and fifty percent, and “low” was a five percent or less.[242] There does not seem to have been a significant amount of discussion about the impression such language might have had on clients, but at least one textbook did recommend that physicians could provide probabilities in different ways to influence outcomes. The author of *Genetic Counseling in Clinical Medicine* suggested that clients who seemed like they wanted another child could be told that their risk was, for example two percent, whereas a couple that seemed like they did not want any more children could be told, instead, that their risk was forty times higher than usual. The same quantitative risk presented in two qualitatively different ways.[243]

This presentation of data, while perhaps not in keeping with prior counseling (though it is difficult to be sure, since earlier counselors did not discuss this sort of communication bias) was in keeping with a medical perspective that was more used to encouraging patients to take certain courses of action. In any event, the textbook that suggested this might be done made it clear that risk figures should never be presented in

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[242] C. O. Carter, “Comments on Genetic Counseling,” in *Proceedings of the Third International Congress of Human Genetics*, ed. J. F. Crow and J. V. Neel (Baltimore, MD: Johns Hopkins University Press, 1967), 97–100; Murray, “Genetic Counseling in Clinical Medicine,” 147.

[243] Murray, “Genetic Counseling in Clinical Medicine,” 147.

this way for clients with moderate (25%) to high (50%) risks.[244] This textbook suggested that the goal of genetic counseling, at least from this medical doctor's point of view, was to "influence high risk families not to have further children" and to give low risk families the reassurance needed to have more.[245] This perspective stands out when placed adjacent to the carefully non-directive nature of genetic counseling in the 1940s and 1950s, but it was not necessarily out of step with prior genetic counselors' assumptions about their clients' decisions. Even Sheldon Reed, who continued to oppose counselors giving direct advice to clients, assumed that these were the sorts of decisions clients would make on their own if properly informed and rationally minded.[246]

Client's responses to these risk figures and probabilities are difficult to access, but some data started to appear in the 1960s about their decisions following genetic counseling. In a study reported at the *Third International Congress of Human Genetics*, one counselor presented a study of 169 families. One hundred and fifty of them sought help because they had previously had a child with a birth defect. Thirty-two percent of these 150 families that were given a recurrence risk of ten percent or greater chose to have more children anyway. In the low risk group, seventy-five percent went on to have more children.[247]

The report cited these data as confirmation that clients did in fact make the decisions counselors hoped they would make. Low-risk couples, relieved of their unnecessary anxieties, went ahead with having children, and high-risk couples, warned of

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[244] Ibid.

[245] Ibid., 149.

[246] Reed, *Parenthood and Heredity*, 85.

[247] Murray, "Genetic Counseling in Clinical Medicine," 149.

the potential consequences, either found other ways of making a family or went on with their lives without children.[248] But this conclusion reads thirty-two percent as a small percentage. Another reading of these data reflects not only how much genetic counseling clients considered genetic risk factors when making important life decisions, but also how they sometimes read them differently than geneticists and occasionally dismissed the risks altogether. Clients went to genetic counselors with a wide variety of prior assumptions, expectations, hopes, and fears. All of these factors could influence the way they answered counselors' questions, the decisions they made about genetic information, and the demands they placed on genetic counselors. These interactions became particularly fraught in the 1960s with the addition of amniocentesis, chromosome analysis, and therapeutic abortion.

Amniocentesis: Promises and Decisions

Susan Taylor's family doctor thought she should have a therapeutic abortion. He referred Susan to an obstetrician for the "interruption of pregnancy" because she had a previous child with Down syndrome and she was only 28, not in the age range that would put her in the commonly accepted risk pool. The obstetrician Susan met with took a sample of her blood for analysis. Testing showed that her chromosomes were atypical in a manner consistent with Down syndrome, much as her physician had suspected.[249]

Susan returned to the obstetrician in the tenth week of her pregnancy for an amniocentesis. The fetal cells from the amniotic fluid were then cultured, isolated, and photographed. The photograph was enlarged and cut into a karyotype for analysis. The fetal cells unexpectedly had a full 46 chromosomes even though Susan had only 45.

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[248] Ibid.

[249] Nadler, "Antenatal Detection of Hereditary Disorders," 915.

Susan underwent another amniocentesis six weeks later that showed the same results. There was no evidence of Down syndrome in the fetus.[250] Based on these findings, Susan decided not to go through with the therapeutic abortion her doctor had recommended. About five months later, Susan delivered a “normal, 6 lb., 11 oz.” baby girl.[251] This is just one example of how genetic counseling came to play another role in women’s reproductive decisions. For two decades genetic counselors had positioned themselves as experts to be consulted prior to becoming pregnant. They specialized in predicting the odds of an atypicality occurring or recurring. Starting in the 1960s, though, these expectations expanded to include prenatal testing and an increasing impression that genetic counselors were responsible for guaranteeing healthy, normal babies.

A case somewhat similar to Susan’s, but with a different ending, appeared in the *Journal of the American Medical Association*. At the beginning of spring in 1968, twenty-nine year old Laurie was sixteen weeks pregnant and had been referred to the Department of Obstetrics and Gynecology at Downstate Medical Center in Brooklyn, New York. Her pedigree chart showed multiple relatives with the chromosomal translocation type of Down syndrome, including three of her siblings, who had had children with Down syndrome.[252] After an amniocentesis and time for the cells to grow in culture, a karyotype showed chromosomal formation consistent with this rare type of Down syndrome. Laurie

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[250] Ibid.

[251] Ibid., 916.

[252] Translocation occurs when part of a chromosome is transferred to another chromosome or a different part of the same chromosome. In translocation Down syndrome, part of chromosome 21 attaches to another chromosome. Today, this is known to be the only form of Down syndrome that can be inherited, but only about 4 percent of people with Down syndrome have this type. “Translocation,” *Concise Medical Dictionary*, Oxford Reference Online (Oxford University Press, 2010), http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t60.e10269; Mayo Clinic, “Down Syndrome: Causes,” *Mayo Clinic*, April 7, 2011, http://www.mayoclinic.com/health/down-syndrome/ds00182/dsection=causes.

had a therapeutic abortion ten days after the diagnosis.

Laurie maintained her relationship with the clinic after the abortion. She still wanted a non-Down baby. The doctors at the clinic explained to her that the "probability of carrying a defective child" were at least one in five, but the risks posed by amniocentesis small. Laurie indicated that she would like to become pregnant again and to have the clinic monitor her fetus through testing. The article proposed that if amniocentesis was performed early in the second trimester, karyotyping could take place between three and six weeks later, leaving time for the "interruption of pregnancy, if indicated."[253] This case, appearing at a time of intense debate over access to therapeutic abortion, tells the story of a prospective mother who intended to rely quite directly on genetic counselors to help her have the normal baby she was hoping for.

Had she visited the clinic ten or twenty years earlier, she would have been given her risk figures—one in five—and probably gone home. There is no way of knowing what decision she would have made, but it would have involved a significant degree of chance. The availability of prenatal testing and therapeutic abortion, however, meant that she could have a baby with greater confidence that her baby would be normal. It was still impossible to control for a variety of other genetic conditions, environmental disease, or injuries, but women like Lauri, along with increasing numbers of other Americans and physicians, gradually came to rely on genetic counselors and the data they could provide for help.

Genetic counselors were conscious of the fact that they could not simply wait for other groups to resolve the ambiguity of amniocentesis and therapeutic abortion. Henry Nadler argued that "despite the moral, legal, and ethical questions" involved, "attempts at

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[253] Valenti, Schutta, and Kehaty, "Cytogenetic Diagnosis of Down's Syndrome in Utero," 1513–1514.

prenatal detection and management are warranted if we are to significantly modify the natural history of these disorders."[254] Though he noted that these techniques "should be considered experimental in nature," Nadler nevertheless suggested, like others in his field, that this new procedure would improve "the precision of genetic counseling."[255]

Predictions about the future expansion of prenatal testing and genetic counseling would prove to be quite accurate. In a 1968 article Nadler listed three conditions he could test for: Down syndrome, galactosemia, and mucopolysaccharidosis.[256] By 1970 that number had increased to thirty.[257] In this atmosphere, though, it was still not especially common for physicians, obstetricians, or gynecologists to recommend prenatal testing with amniocentesis, because of there were not a lot of testing centers, and medical opinion had not yet coalesced around the expectation of testing.

The fact that abortion laws varied from state to state in the late 1960s, and the primary function of prenatal testing was to determine whether to proceed with a

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[254] Nadler, "Antenatal Detection of Hereditary Disorders," 917.

[255] Ibid., 912.

[256] Ibid. Galactosemia is a hereditary metabolic condition in which a person cannot metabolize galactose, a simple sugar and component of milk. People with galactosemia must refrain from all milk products and other foods that contain galactose. Untreated, it can impede mental development and contribute to cataracts and an number of other conditions. Alexander G. Bearn, John M. Last, and George Dunea, "Inborn Errors of Metabolism," ed. Stephen Lock, The Oxford Companion to Medicine, Oxford Reference Online (Oxford University Press, 2010), http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t185.e256; "Galactosemia," A.D.A.M. Medical Encyclopedia, PubMed Health (U.S. National Library of Medicine, 2012), http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001405/.

Mucopolysaccharidosis is another hereditary metabolic condition that complicates the storage of complex carbohydrates. The two most common varieties are Hurler's syndrome and Hunter's syndrome, which can interfere with mental development, cause enlargement of the spleen and liver, and can affect facial features. "Mucopolysaccharidosis," Concise Medical Dictionary, Oxford Reference Online (Oxford University Press, 2010), http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t60.e6437; "Hunter's Syndrome," Concise Medical Dictionary, Oxford Reference Online (Oxford University Press, 2010), http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t60.e13133.

[257] "Medical News," 2170; Aubrey Milunsky, "Prenatal Genetic Diagnosis and the Law," in *Genetics and the Law II*, ed. Aubrey Milunsky and George J. Annas (New York: Plenum Press, 1980), 61.

pregnancy or not, also complicated the use of the procedure.[258] These new procedures and tests, one magazine article explained, not only gave genetic counselors and doctors new information, but also meant "forcing grave ethical decisions upon his patients and, in the last resort, upon the society as a whole."[259] Nevertheless, doctors in 1969 were willing to assert that "amniocentesis performed early in pregnancy opens a promising avenue to genetic counseling for chromosome defects."[260] A "Medical News" article in a 1970 edition of *The Journal of the American Medical Association*, reported that an estimated twenty-five percent of medical conditions could be traced to genetic factors, and that the "public [was] also reading and hearing frank discussions of genetic disorders in the popular press and then demanding more information from physicians," an argument perhaps supported by the increase in malpractice claims over the course of the 1970s.[261]

Genetic counselors did not present a unified approach to therapeutic abortion or to voluntary abortion in general, but some did address it with varying specificity. A textbook chapter that described the process of conducting cytogenetic tests like chromosome analysis stood out as an example of sources that chose not to weigh in. The author provided a useful diagram illustrating the prenatal testing process from the withdrawal of amniotic fluid to incubation, to imaging of the separated chromosomes. After the "prepare karyotype" step, however, readers were presented with two options: "Reassure patient if *normal*," or "? if *abnormal*." This was probably not a particularly useful conclusion for many physicians and genetic counselors wondering how to address

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[258] "Medical News," 2171.

[259] Stock, "Will the Baby Be Normal?," 26.

[260] Valenti, Schutta, and Kehaty, "Cytogenetic Diagnosis of Down's Syndrome in Utero," 1514.

[261] "Medical News," 2167. Fraser also recalled some years later that prenatal diagnosis became a key area for genetic counselors by the end of the 1960s: Fraser, "Introduction," 8.

mothers and couples whose fetus turned out "abnormal."[262]

The same textbook, in a later chapter, did provide a little bit more help to wondering genetic counselors. In the chapter on genetic counseling, it described the potential usefulness of amniocentesis as a testing technique that "would allow one to be more selective in choosing cases for therapeutic abortion." The author noted that there was still "strong sentiment" against therapeutic abortion, but he was confident that opposition was "gradually lessening." As the general public learned that doctors could be more certain about only aborting "abnormal" fetuses, it predicted, "much of the current opposition to therapeutic abortion is likely to lessen."[263] The perspective here was that amniocentesis and chromosome analysis would find more acceptance among a general public conditioned to expect normality and avoid abnormality at all costs. Prenatal testing and therapeutic abortion added an additional level of complexity to genetic counseling in the 1960s. At the same time it promised women and couples greater control over their reproductive decision making, it also limited that freedom, in a sense, to situations in which an abnormal baby was predicted.

Reed had confidence that "the desire for a happy family of normal children" was one of American couples' strongest desires. "In civilized countries," he observed, "responsible parents no longer leave reproduction to the vagaries of chance."[264] If physicians had the power to help infertile parents have children and medicine allowed fertile parents to limit the number of children they chose to have, Reed asked, why should genetic counselors and physicians not also help parents choose what kind of children they

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[262] Jacobson, "Cytogenetic Techniques and Their Clinical Uses," 102. Emphasized in original with an underline that I have replaced with italics. See Appendix B.

[263] Murray, "Genetic Counseling in Clinical Medicine," 150.

[264] Reed, *Parenthood and Heredity*, 228.

wanted? Geneticists like Reed expected that genetic counseling would give parents the power to "avoid the appearance of abnormal children."[265]

The desire to have normal, healthy children was certainly not new to the 1960s, nor to genetic counseling. American women had learned for years that they were responsible for the health and normality of their babies. By the mid-twentieth century, though, these responsibilities relied less on notions of religious morality and avoiding the dangers of "marking," and more on ideas of what might be termed medical morality. By the and of the 1960s women and parents had been thoroughly exposed to the message that responsible mothers and parents put a great deal of thought into the quality of their children prior to conception, and relied on physicians and medical specialists for help. By the end of the 1960s, thanks to developments in genetic science and genetic counselors' success in raising awareness about their services, women and parents increasingly looked to genetic counselors to share the responsibility of having children free of abnormality.

Genetic counseling in the 1960s offered an array of pre-conception and prenatal diagnostic tools, including family histories, pedigrees, empiric risk statements, amniocentesis, and chromosome analysis. These tools, like any other, meant little on their own. When combined with doctors' and clients' notions of disability, normality, and disease prevention, though, they had a profound influence on reproductive decision making. Genetic counselors participated in these changes by positioning themselves as experts in heredity and the prediction of abnormality. Clients responded to counselors' status as experts and many increasing did come to rely on them for help making the families they hoped for.

As the field of genetic counseling experienced the expansion early counselors like

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[265] Ibid., 229.

Reed and Dive had hoped for, it also encountered greater variation. Genetic counselors had achieved some measure of success in creating standards of practice in the 1950s, but these standards—represented primarily by the policy of non-directiveness—began to fragment in the 1960s as many new practitioners began offering genetic counseling services, particularly medical doctors. New techniques such as prenatal testing also contributed to the growth and to the complexity of genetic counseling.

These changes in the field of genetic counseling in the 1960s were consistently shaped by clients' hopes for their future families, genetic counselors' ideas about disease prevention and disability, and by both groups' notions of health and normality. In the 1960s these perspectives were further complicated by the possibilities, and the moral and legal questions, posed by prenatal genetic testing and therapeutic abortion. New genetic understandings and techniques, with attendant social changes that gave a louder voice to alternate perspectives on disability and medicine, profoundly affected the ways both clients and counselors thought about the role of science and the individual in reproductive decision making.

CHAPTER V

CONCLUSION

In 1971 the first cohort of genetic counselors graduated from Sarah Lawrence College. This group was new in that they did not have doctoral degrees in science like the people who established the field in the 1940s and 1950s, and they did not have medical degrees like the people who took up genetic counseling in the 1960s. Instead, this group of Sarah Lawrence College graduates had Master's degrees specifically in genetic counseling. A group led by biology professor Melissa L. Richter developed the Sarah Lawrence curriculum between 1968 and 1969 with input from physicians and genetic counselors from around the country.[266]

Melissa Richter had written a letter to one of the Deans of the college in 1968 about the need for such a program. She argued that a Master's-level program in genetic counseling was needed to help the "hundreds of thousands" in the United States with "manifestations of inherited disease," few of whom could find counseling and information as to the likelihood of passing these traits to their children. The administration was convinced, and Sarah Lawrence enrolled the first cohort in 1969. The Master's program sought to train "assistants to physicians."[267] This approach would be particularly interesting later in the 1970s as genetic counselors, many of them trained in specialty programs like the one at Sarah Lawrence, sought to form a professional organization and encountered friction from the medical community who perceived them as paraprofessionals rather than as independent specialists.[268]

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[266] Marks, "The Training of Genetic Counselors: Origins of a Psychosocial Model."

[267] Melissa L. Richter, Letter to the Dean of Sarah Lawrence College, 1968, quoted in Ibid., 16.

[268] Heimler, "An Oral History of the National Society of Genetic Counselors."

A Babcock Foundation grant funded the first year of the program, in 1969-1970, which included a semester of Mendelian molecular genetics, probability and elementary statistics, and human genetics, and then another semester of coursework in human physiology, social psychiatry, cytogenetics, and medical conferences at Mt. Sinai Hospital.[269] The second year of the program included human physiology, human genetics, social psychiatry, laboratory techniques, cytogenetics, developmental biology, and clinical and medical conferences at either (or both) the Mt. Sinai and the Einstein Clinics.[270] This program was also supported by two five-year grants from the Allied Health Manpower Training Division of the National Institutes of Health. Eight students graduated from the Sarah Lawrence program in 1971. Seven of them soon had positions as genetic associates (a competing term for genetic counselors in the 1970s) and one enrolled in a doctoral program.[271]

The genetic counseling field underwent a significant transformation in the 1970s, largely as a continuation of the fragmentation it experienced beginning in the 1960s. In 1972, the National Genetics Foundation held a meeting in Washington, DC, to respond to the "demand for more and better counseling services," and to the "growing realization" on the part of genetic counselors that they still felt unsure of the "present extent of, and need for, counseling services and the optimal methods for delivering counseling."[272] Out of this workshop, some of the leading genetic counselors in North America came up with the following definition of their field:

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[269] Marks, "The Training of Genetic Counselors: Origins of a Psychosocial Model," 17.

[270] Ibid., 18.

[271] Ibid., 17–18.

[272] F. Clarke Fraser, "Genetic Counseling," *American Journal of Human Genetics* 26 (1974): 636.

> Genetic counseling is a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family (1) comprehend the medical facts, including the diagnosis, the probable cause of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk of recurrence; (4) choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision; and (5) make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder.[273]

This definition shares a lot in common with Reed's 1957 characterization of genetic counseling as "a type of social work carried out by the geneticist or family physician" that was "intended to develop intellectual security and peace of mind for each couple, and to help them gain the happiness to which we all aspire."[274] The 1974 definition reflected the increasing process of professionalization and standardization of the field, but also left certain questions unresolved. Like genetic counselors in previous decades, it was still unclear to many in the 1970s how to go about helping a couple "choose the course of action which seem[ed] appropriate to them" without also letting their own opinions into the discussion. It is also unclear from the 1972 consensus what actually constituted an "appropriately trained" genetic counselor.

The graduation of this first cohort of Master's trained genetic counselors marked a turning point in the provision of genetic counseling and contributed to its formal professionalization in the 1970s. This process started to address the questions left unanswered by the National Genetics Foundation workshop. Other factors included the decriminalization of first- and second-trimester abortion in the 1973 *Roe v. Wade*

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[273] Ibid., 637.

[274] Reed, "Counseling in Medical Genetics," 938.

decision, the continued expansion of genetic science and prenatal testing capabilities, and the formation of the National Society of Genetic Counselors in 1979. These developments, like those in the 1940s, 1950s, and 1960s, brought not only greater recognition, demand, and professionalization to the field of genetic counseling, but also increased complexity and debate.

A series of medical malpractice suits in the 1970s helped to bring questions of expectations and responsibilities in genetic counseling and genetic testing to the fore. Two cases in particular, *Gleitman v. Cosgrove* and *Berman v. Allan*, are representative of some of the changes involving genetic testing that influenced the development and expansion of genetic counseling. In 1979, in the case of *Berman v. Allan*, the Supreme Court of New Jersey partially overturned a key decision it made over a decade earlier in *Gleitman v. Cosgrove* that parents could not collect damages for the birth of a child that they would have aborted if they had more information.[275] The *Berman* decision represented the result of a decade of shifting legal and medical opinion regarding prenatal testing. Taken together, *Gleitman* and *Berman* speak to the ways the legal and medical professions, pushed by the needs and wishes of their clients and patients, sought workable solutions to the difficult questions raised by advances in prenatal genetic testing in the 1960s and 1970s. Two important developments—the legalization of first- and second-trimester abortion with *Roe v. Wade*, and significant improvements in prenatal testing and diagnostic science—left health care providers in largely unknown legal territory. The situation was indicative of the ways that medicine can quickly outpace the standards of care depended upon for legal decision making, and the ways that patients,

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[275] *Berman V. Allan*, 404 A. 2d 8 (Supreme Court of New Jersey 1979); *Gleitman V. Cosgrove*, 227 A. 2d 689 (Supreme Court of New Jersey 1967).

through their expectations of care, and the legal claims they create, can serve as catalysts for change.

In *Gleitman* a husband and wife sued their physician on behalf of themselves and their son, who was born with birth abnormalities. The trial judge dismissed both complaints against the doctors, Robert Cosgrove, Jr. and Jerome Dolan, and the case went before the Supreme Court of New Jersey on November 21, 1966. On November 25, 1959, Sandra Gleitman had given birth to her son Jeffrey, who appeared to have no atypical characteristics. Some weeks later, though, it became evident that Jeffrey had "substantial defects" in sight, hearing, and speech.[276] Sandra had contracted German measles during her pregnancy and claimed that her physician did not warn her of the potential for birth defects in her child as a result. She sued, claiming that had she known about the potential for birth abnormalities she would have terminated the pregnancy.

The *Gleitman* court upheld a lower court's decision to reject both the claim of the infant for damages resulting from "wrongful life," and the claims of the parents for damages, emotional and financial, based on "wrongful birth" of a disabled child. The court's reasons for rejecting their claims, despite finding the doctors negligent, became standard until well into the 1970s. In dismissing the claims of the infant Jeffrey, the court ruled that, because there was no way for the doctors to treat his birth defects, his only claim could be that he should not have been born at all. The majority opinion concluded they could not measure compensatory damages in such a case because the "Court cannot weigh the value of life with impairments against the nonexistence of life itself."[277] The court's rejection of the parents' claims that the birth of this child caused them significant

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[276] *Gleitman V. Cosgrove*, 227:25.

[277] Ibid., 227:28.

emotional and financial damage relied on similar arguments. The court argued it was "impossible" to assess "the denial to them of the intangible, unmeasurable, and complex human benefits of motherhood and fatherhood and weigh these against the alleged emotional and money injuries" of having a child with a medical condition.[278]

The Supreme Court of New Jersey dealt with similar issues when it heard the case of *Berman v. Allan* in 1979. The crux of the Bermans' case rested on Shirley Berman's assertion that, had she been informed of the availability of prenatal testing, she would have undergone the test, learned of the likelihood that her fetus would be born with Down syndrome, and would have terminated the pregnancy. Instead, Sharon, Shirley Berman's daughter, was born and diagnosed with Down syndrome. For approximately seven months prior to Sharon's birth, Shirley's pregnancy had been under the supervision of Doctors Ronald Allan and Michael Attardi. Almost a year after Sharon's birth, on September 11, 1975, Shirley Berman and her husband Paul brought a malpractice suit against Allan and Attardi on behalf of themselves and as legal guardians of their infant daughter, Sharon. The Bermans alleged two related causes of action. The first, brought by Paul Berman on behalf of his daughter Sharon, was a claim for damages based on the "wrongful life" principle. The second, based on "wrongful birth," was brought by the parents and claimed a right to damages in compensation for their own suffering. The trial judge in the case, in 1977, ruled in favor of Doctors Allan and Attardi, and based his ruling on the *Gleitman* decision. Two years later, the case was heard by the Supreme Court of New Jersey.[279] The New Jersey court rejected the infant's "wrongful life" claim, but upheld the parents' "wrongful birth" claim and awarded damages.

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[278] Ibid., 227:29.

[279] *Berman V. Allan*, 404:423, 425.

In *Gleitman* the court used, in part, the argument that both life and parenthood conveyed an array of intangible and unmeasurable benefits to reject both the child's and the parents' malpractice claims. Though the *Berman* court persisted in viewing the question of life versus non-life as incalculable, in terms of birth and abortion they reversed course and determined that courts had a duty to assess, for compensatory purposes, the difference between giving birth to a disabled child and terminating a pregnancy. By the end of the 1970s, legal opinion had shifted significantly, and was clearly caught up in a process of giving greater credence to parents' (and to a lesser extent children's) malpractice claims brought against doctors who were negligent in providing access to prenatal testing. These changes are indicative not only of this shift, but also of the ways that medical technology and science, and public knowledge of, and demand for access to, these services can outpace legal opinion. The dramatic pace of genetic science and prenatal testing in the 1950s, 1960s, and 1970s played a crucial role—perhaps greater than legal decisions like *Roe v. Wade*—in driving litigation and pushing the courts to change precedent like that set in *Gleitman*. In many ways one can see the results of tort suits in the 1970s as something of a catalyst for increased prenatal testing, as doctors and counselors increasingly worried about legal liability.

By the mid-to-late 1970s, with abortion law on more standardized footing after the decision in *Roe v. Wade*, geneticists, genetic counselors, and physicians increasingly came to agree on the importance of accurate prenatal testing, though judicial opinions were not as consistent. "It can be fatally damaging to a family," argued one *JAMA* article, "when the second abnormal child arrives in the face of optimistic statements."[280]

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[280] Kurt Hirschhorn, "Human Genetics," *The Journal of the American Medical Association* 224, no. 5 (April 30, 1973): 604.

Increasingly, the medical community shaped a standard of care based on the importance of prenatal genetic studies in medical care. An article in *JAMA* in 1974 by Aubrey Milunsky, one of the leading medical voices on genetic testing, suggested that every obstetrician should offer prenatal testing to expecting parents when any doubt was present. "It is no longer reasonable," Milunsky concluded, "to withhold these studies from mothers at risk for having babies with genetic disease that could be prevented."[281] This sort of unequivocal statement of medical expectation from the professional community played a significant role in guiding the shift in legal precedent from *Gleitman* to *Berman*.

The medical community's enthusiasm for prenatal testing, and its assertion, by 1974, that testing should be a part of the reasonable standard of care expected of obstetricians and physicians working with at-risk mothers, somewhat outpaced legal opinion. In some ways legal theory in the 1970s was a step or so behind medical science and patients' desires, but to a great extent the medical and legal communities charted their way through this unknown legal and ethical territory together.

In examining the ways that judicial decisions changed regarding prenatal testing and damages in wrongful birth and wrongful life cases between *Gleitman* and *Berman*, it is critical to not take the tort cases by themselves, but to also acknowledge the ways that the medical, legal, and lay communities interpreted these cases. On a certain level, it mattered less whether these cases opened doctors to significantly greater liability, and more that people perceived them that way and modified their behavior accordingly. Legal theory, and moreover judicial decision making, was a step behind medical technology and

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[281] Aubrey Milunsky and Leonard Atkins, "Prenatal Diagnosis of Genetic Disorders," *The Journal of the American Medical Association* 230, no. 2 (October 14, 1974): 235.

patients' wishes in the 1970s.

These changes in the 1970s were only the beginning. Over the next few decades the genetic counseling profession grew dramatically in response to greater and greater demand for prenatal testing and diagnosis. The expectations of care that had their origins in the 1940s, 1950s, and 1960s culminated, in way, in the 1970s under the influence of additional social, political, and legal factors. Since that time people involved in thinking about disability, medical ethics, health care, reproductive rights, and patient autonomy have grappled with questions of choice, abortion, and the degree to which people should be able to select for their children using prenatal tests and other genetic technologies.[282]

Genetic counseling's position between medicine and the people it serves is increasingly important at a time when the potential for what genetic science and medicine can do is so high, and continues to grow. Genetic counselors today, just as they were in the 1940s, 1950s, and 1960s, are sandwiched in between scientific and medical notions of disease and disability and clients' hopes for their future families. There have been many changes in the areas of patient autonomy, informed consent, reproductive freedom, the costs of health care, and other social, political, and cultural areas, but abortion, normality, and disability remain intensely debated subjects. Genetic counselors today are central to helping individuals and couples interpret complex genetic information to help them make important decisions about the lives of themselves and their families. It is crucial to

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282. Stories like the following, for example, appear with some frequency in the news: Darshak M. Sanghavi, "Wanting Babies Like Themselves, Some Parents Choose Genetic Defects," *The New York Times*, December 5, 2006, sec. Health, http://www.nytimes.com/2006/12/05/health/05essa.html?emc=eta1. For more discussion on these and other issues relating to genetic counseling today, see: Kenen, "Genetic Counseling"; Charles Bosk, "The Workplace Ideology of Genetic Counselors," in *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, ed. Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan (New York: Aldine De Gruyter, 1993), 25–37; Meredith, "Genetic Counselor Attitudes Towards Fetal Sex Identification and Selective Abortion"; Samerski, "Genetic Counseling and the Fiction of Choice." And on debates surrounding disability rights and selective abortion: Parens and Asch, *Prenatal Testing and Disability Rights*.

consider the complex history of genetic counseling to better understand the assumptions and expectations that form the foundations of genetic counseling today.

Genetic counseling developed out of the belief that science and medicine could help women and parents manage their pregnancies and make rational decisions about their family making. The field contributed to efforts in other areas of science, medicine, and public policy to encourage women in particular to depend on medical specialists to help them have safe pregnancies and normal, healthy babies. Genetic counseling built upon these efforts and combined them with the assumption that genetic science could help prospective parents have children that matched their hopes of normality. Parents' desires for healthy children free of abnormality powerfully shaped the development of genetic counseling by motivating them to seek out the services of genetic counselors. Would-be parents, by bringing their hopes and anxieties to the offices of genetic counselors, helped define to the types of services genetic counseling would provide and the ways they would provide it. Genetic counseling developed out of counselors' and clients' understandings of human genetics and normality, their interests in exerting greater control over the outcomes of their reproductive decisions, and particularly parents' desires for normal, healthy children.

APPENDIX A

LOCATIONS OF HEREDITY CLINICS, 1955 AND 1968

Heredity Clinics, 1955

Source: Reed, Sheldon. Parenthood and Heredity. 2d ed. New York: Wiley, 1964, p. 2 table 1.

Location	Institution	Counselor
Berkely, California	University of California	Curt Stern
Salt Lake City, Utah	Laboratory of Human Genetics, University of Utah	F. E. Stephens
Austin, Texas	The Genetics Foundation, University of Texas	C. P. Oliver
Norman, Oklahoma	University of Oklahoma	L. H. Snyder
Minneapolis, Minnesota	Dight Institute, University of Minnesota	S. C. Reed
New Orleans, Louisiana	Tulane University	H. W. Kloepfer
Ann Arbor, Michigan	Heredity Clinic, University of Michigan	J. V. Neel
Columbus, Ohio	Institute of Genetics, Ohio State University	D. C. Rife
Toronto, Ontario	Hospital for Sick Children	N. F. Walker
Winston-Salem, North Carolina	Department of Medical Genetics, Bowman Gray School of Medicine	C. N. Herndon
Montreal, Quebec	Department of Medical Genetics, Children’s Memorial Hospital	F. C. Fraser
New York, New York	New York State Psychiatric Institute	F. J. Kallmann
Boston, Massachusetts	Children’s Cancer Research Foundation, Harvard University	A. G. Steinberg

Genetic Counseling Providers in the United States and Canada, c. 1968

Source: Davis, Dorothy Crane. “Predicting Tomorrow’s Children.” *Today’s Health* 46 (January 1968): 32–37; table on page 72, and Reed, Sheldon. *Parenthood and Heredity*. 2d ed. New York: Wiley, 1964, p. 2 table 1.

	State or Province	**City**	**Organization**	**Department(s) / Lead Figure**
1	Alabama	Birmingham	University of Alabama Medical Center	Laboratory of Medical Genetics
2	Alberta (Canada)	Edmonton	Heredity Counseling Service, University of Alberta	Dr. Margaret W. Thompson
3	Arizona	Tempe	Arizona State University	Zoology, Dr. C. M. Woolf
4	California	Berkeley	University of California, Berkeley	Zoology, Genetics, Dr. Curt Stern
5	California	Los Angeles	Children’s Hospital	Pediatrics, Medicine
6	California	Martinez	Genetics Consultation and Counseling Service	Health Department
7	California	Oakland	Children’s Hospital Medical Center	Birth Defects
8	California	Palo Alto	Stanford University School of Medicine	Medicine
9	California	Palo Alto	Palo Alto Stanford Hospital	Pediatrics
10	California	San Bernardino	St. Bernadine Hospital	Pediatrics
11	California	San Francisco	University of California	Pediatrics
12	California	San Francisco	University of California Medical Center	Pediatrics
13	Colorado	Denver	University of Colorado Medical Center	Pediatrics, Biophysics
14	Connecticut	Hartford	Connecticut Twin Registry	Health
15	Connecticut	New Haven	Yale University School of Medicine	Medicine
16	Connecticut	New Haven	Yale University School of Medicine	Pediatrics
17	Connecticut	Ridgefield	New England Institute for Medical Research	Cytogenetics

18	Washington, DC	District of Columbia	Children's Hospital	Neurology
19	Washington, DC	District of Columbia	Georgetown University Hospital	Obstetrics, Pediatrics
20	Washington, DC	District of Columbia	George Washington University Hospital	Genetics Counseling Research Center, Dr. N. C. Myrianthopoulos
21	Florida	Coconut Grove	University of Miami Child Development Center	Pediatrics
22	Georgia	Atlanta	Georgia Mental Health Institute	Psychiatry
23	Georgia	Augusta	Medical College of Georgia	Endocrinology
24	Illinois	Chicago	Children's Hospital	Biochemistry, Dr. David Y-Y. Hsia
25	Illinois	Chicago	Illinois State Psychiatric Institution	Mental Health, Pediatrics
26	Illinois	Chicago	Medicine Blood Center	Pediatrics, Cytogenetics
27	Illinois	Evanston	Evanston Hospital	Research
28	Illinois	Springfield	Department of Public Health	Preventive Medicine
29	Kansas	Kansas City	Kansas University Medical Center	Medicine
30	Kentucky	Lexington	University of Kentucky Medical Center	Pediatrics
31	Kentucky	Louisville	Child Evaluation Center	Pediatrics
32	Kentucky	Louisville	University of Louisville School of Medicine	Pediatrics
33	Louisiana	New Orleans	Genetic Counseling Center	Anatomy, Dr. H. W. Kloepfer (Tulane University)
34	Manitoba (Canada)	Winnipeg	Hospital for Sick Children	Dr. Irene Uchida
35	Maryland	Baltimore	Johns Hopkins Hospital	Medicine, Dr. V. A. McKusick
36	Maryland	Baltimore	Sinai Hospital	Pediatrics

37	Massachusetts	Boston	Birth Defects Center	Pediatrics
38	Massachusetts	Boston	Children's Hospital Medical Center	Clinical Genetics
39	Massachusetts	Boston	Massachusetts General Hospital	Medicine
40	Massachusetts	Boston	Massachusetts General Hospital	Pediatrics
41	Massachusetts	Boston	Boston University Medical School	Department of Immunochemistry, Dr. W. C. Boyd
42	Michigan	Ann Arbor	University of Michigan	The Heredity Clinic, Dr. James V. Neel
43	Michigan	Detroit	University of Detroit	Biology
44	Michigan	Lansing	Michigan State University	Zoology, Dr. J. V. Higgins
45	Michigan	Northville	Plymouth St. Home & Training School	Mental Health
46	Minnesota	Minneapolis	Minnesota Department of Health	Human Genetics Unit, Dr. Lee. E. Schacht
47	Minnesota	Minneapolis	University of Minnesota	Dentistry
48	Minnesota	Minneapolis	University of Minnesota	Genetics, Dr. Sheldon C. Reed
49	Minnesota	Rochester	Mayo Clinic	Dr. J. S. Pearson
50	Missouri	Columbia	University of Missouri Medical Center	Pediatrics
51	Missouri	St. Louis	Children's Hospital	Pediatrics
52	Missouri	St. Louis	St. Louis University; Cardinal Glennon Memorial Hospital for Children	Pediatrics
53	Missouri	St. Louis	Washington University Medical School	Medicine
54	Nebraska	Omaha	Children's Memorial Hospital	Birth Defects
55	Nebraska	Omaha	Creighton University School of Medicine	Preventive Medicine
56	New Hampshire	Hanover	Dartmouth Medical School	Pathology, Medicine

57	New Jersey	Newark	New Jersey College of Medicine	Pediatrics
58	New Mexico	Albuquerque	University of New Mexico School of Medicine	Pathology
59	New York	Albany	Birth Defects Institute	Health Department
60	New York	Buffalo	Buffalo General Hospital	Medicine
61	New York	Buffalo	Roswell Park Memorial Institute	Pediatrics
62	New York	Buffalo	State University of New York at Buffalo	Pediatrics
63	New York	Jamaica	Creedmoor State Hospital	Psychobiologic
64	New York	New York (Bronx)	Albert Einstein College of Medicine	Medicine
65	New York	New York	Albert Einstein College of Medicine of Yeshiva University	Genetics, Dr. S. G. Waelsch, Dr. Helen Ranney
66	New York	New York	Cornell University Medical College	Pediatrics
67	New York	New York	Mount Sinai School of Medicine	Pediatrics
68	New York	New York	New York State Psychiatric Institute	Medical Genetics, Dr. F. J. Kallmann
69	New York	New York	Rockefeller Institute	Dr. A. G. Bearn
70	North Carolina	Durham	Duke Medical Center	Obstetrics, Gynecology
71	North Carolina	Morganton	Western Carolina Center	Birth Defects, Evaluation Clinic
72	North Carolina	Winston-Salem	Bowman Gray School of Medicine, Wake Forest University	Dr. C. N. Herndon
73	Ohio	Cincinnati	Children’s Hospital Research Foundation	Pediatrics
74	Ohio	Cleveland	Cleveland Metropolitan General Hospital	Pediatric Neurology
75	Ohio	Cleveland	Cleveland Psychiatric Institute	Medical Genetics
76	Ohio	Cleveland	Western Reserve University	Department of Biology, Dr. A. G.

				Steinberg
77	Ohio	Columbus	University Hospital	Medicine
78	Ohio	Dayton	Barney Children's Medical Center	Birth Defects, Evaluation Center
79	Oklahoma	Norman	University of Oklahoma	Department of Zoological Sciences, Dr. P. R. David
80	Ontario (Canada)	Toronto	Hospital for Sick Children	Dr. N. F. Walker
81	Oregon	Beaverton	Oregon Regional Primate Center	Genetics
82	Oregon	Eugene	Sacred Heart Hospital	Pediatrics
83	Oregon	Portland	University of Oregon Medical School; Crippled Children's Division	Genetics Clinic
84	Oregon	Salem	Fairview Hospital and Training Center	Medical Research
85	Quebec (Canada)	Montreal	Children's Memorial Hospital	Dr. F. C. Fraser
86	Pennsylvania	Philadelphia	Children's Hospital	Pediatrics
87	Pennsylvania	Philadelphia	Hahnemann Medical College	Anatomy
88	Pennsylvania	Philadelphia	Jefferson Hospital	Medicine, Obstetrics, Gynecology
89	Rhode Island	Providence	Rhode Island Hospital	Pediatrics, Pathology
90	Rhode Island	Providence	Brown University	Department of Biology, Dr. G. W. Hagy
91	Tennessee	Knoxville	University of Tennessee Memorial Research Center and Hospital	Birth Defects Evaluation Center
92	Tennessee	Nashville	Vanderbilt Hospital	
93	Texas	Austin	The University of Texas, The Genetics Foundation	Human Genetics Research, Dr. Clarence P. Oliver
94	Texas	Fort Sam Houston	Brooke Army Medical Center	Pediatrics

95	Utah	Logan	Utah State University	Zoology
96	Utah	Salt Lake City	Primary Children’s Hospital	Birth Defects Clinic
97	Utah	Salt Lake City	University Medical Center	Internal Medicine
98	Vermont	Burlington	Mary Fletcher Hospital	Pediatrics
99	Virginia	Charlottesville	University of Virginia Hospital	Preventive Medicine, Internal Medicine
100	Virginia	Charlottesville	University of Virginia School of Medicine	Chromosome Research Lab, Dr. R. F. Shaw
101	Virginia	Richmond	Medical College of Virginia	Biology, Genetics
102	Washington	Seattle	Mason Clinic	Pathology
103	Washington	Seattle	University of Washington	Medicine, Dr. Arno Motulsky
104	West Virginia	Morgantown	Wast Virginia University Hospital	Pediatrics
105	Wisconsin	Madison	University of Wisconsin Medical School	Department of Medical Genetics, Dr. J. F. Crow

APPENDIX B

SAMPLE KARYOTYPE

Source: Davis, Dorothy Crane. “Predicting Tomorrow’s Children.” *Today’s Health* 46 (January 1968): 36.

APPENDIX C

AMNIOCENTESIS AND CHROMOSOME ANALYSIS DIAGRAM

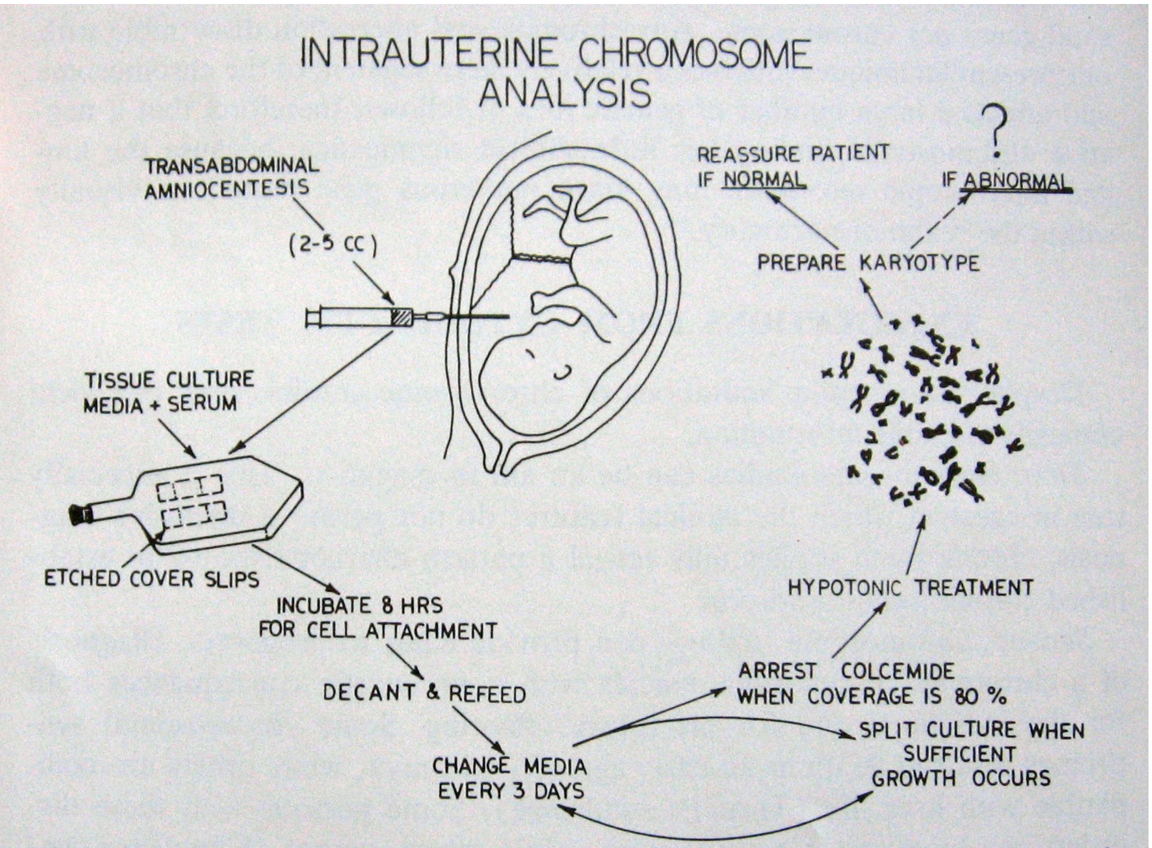

FIG. 9-1. Intrauterine chromosome analysis. Fetal cells obtained by amniocentesis can be cultivated *in vitro,* and cytogenetic, histochemical, and biochemical studies of genetic significance completed.

Source: Bartalos, Mihaly, ed. *Genetics in Medical Practice*. Philadelphia, PA: J. B. Lippincott Company, 1968, 102.

APPENDIX D

NEW YORK TIMES MAGAZINE COVER IMAGE, MARCH 23, 1969

Source: Stock, Robert W. “Will the Baby Be Normal? The Genetic Counselor Tries to Find the Answer.” New York Times Magazine (March 23, 1969): cover.

REFERENCES CITED

Adams, Rachel. *Sideshow U.S.A: Freaks and the American Cultural Imagination*. Chicago: University of Chicago Press, 2001.

American Social Hygiene Association. “Youth and Life: What Kind of Children?” Image. *Social Hygiene Posters*, 1922. http://special.lib.umn.edu/swha/exhibits/hygiene/youth_and_life/index.htm.

Anderson, V. Elving. “Sheldon C. Reed, Ph.D. (November 7, 1910–February 1, 2003): Genetic Counseling, Behavioral Genetics.” *American Journal of Human Genetics* 73, no. 1 (July 2003): 1–4.

Apple, Rima D. *Mothers and Medicine: A Social History of Infant Feeding, 1890-1950*. 1st ed. Madison: University of Wisconsin Press, 1987.

———. *Perfect Motherhood: Science And Childrearing in America*. New Brunswick, NJ: Rutgers University Press, 2006.

Armstrong, Elizabeth. *Conceiving Risk, Bearing Responsibility: Fetal Alcohol Syndrome & the Diagnosis of Moral Disorder*. Baltimore, MD: Johns Hopkins University Press, 2003.

“Babies With Defects High.” *Chicago Daily Defender*. Chicago, IL, April 24, 1961.

Bartalos, Mihaly, ed. *Genetics in Medical Practice*. Philadelphia, PA: J. B. Lippincott Company, 1968.

Bartels, Dianne M., Bonnie S. LeRoy, and Arthur L. Caplan, eds. *Prescribing Our Future: Ethical Challenges in Genetic Counseling*. New York: Aldine De Gruyter, 1993.

Berman V. Allan, 404 A. 2d 8 (Supreme Court of New Jersey 1979).

Black, Edwin. *War Against the Weak: Eugenics and America’s Campaign to Create a Master Race*. New York: Four Walls Eight Windows, 2003.

Borst, Charlotte G. *Catching Babies: The Professionalization of Childbirth, 1870-1920*. Cambridge, Mass: Harvard University Press, 1995.

Bosk, Charles. “The Workplace Ideology of Genetic Counselors.” In *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, edited by Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan, 25–37. New York: Aldine De Gruyter, 1993.

Brockley, Janice. “Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History.” In *Mental Retardation in America: A Historical Reader*, edited by Steven Noll and James W. Trent, Jr., 130–164. New York: New York University Press, 2004.

Brown, Alan A. “What Do You Know About Heredity?” *Hygeia* 25, no. 6 (June 1947): 454, 456.

Bundesen, Herman Niels. “Heredity.” *Ladies' Home Journal* 58 (December 1941): 142–144.

“Career Profiles: Genetic Counselor.” *National Human Genome Research Institute*, n.d. http://www.genome.gov/genomiccareers/career.cfm?id=19.

Carter, C. O. “Comments on Genetic Counseling.” In *Proceedings of the Third International Congress of Human Genetics*, edited by J. F. Crow and J. V. Neel, 97–100. Baltimore, MD: Johns Hopkins University Press, 1967.

Caspari, Rachel. “From Types to Populations: A Century of Race, Physical Anthropology, and the American Anthropological Association.” *American Anthropologist* 105, no. 1. New Series (March 1, 2003): 65–76.

Castles, Katherine. “‘Nice, Average Americans’: Postwar Parents’ Groups and the Defense of the Normal Family.” In *Mental Retardation in America: A Historical Reader*, edited by Steven Noll and James W. Trent, Jr., 362–63. New York: New York University Press, 2004.

Celello, Kristin. *Making Marriage Work: A History of Marriage and Divorce in the Twentieth-Century United States*. Chapel Hill: University of North Carolina Press, 2009.

“Chances of a Defective Child.” *Time*, March 3, 1967.

Childs, Barton. *Genetic Medicine: A Logic of Disease*. Baltimore, MD: Johns Hopkins University Press, 1999.

Chu, Ernest H. Y., and Norman H. Giles. “Human Chromosome Complements in Normal Somatic Cells in Culture.” *American Journal of Human Genetics* 11, no. 1 (March 1959): 63–79.

“Citizen Genetics.” *Time* 73, no. 3 (January 19, 1959): 22.

“Clinic for Ancestors.” *Newsweek* 28 (December 23, 1946): 54.

Cowan, Ruth Schwartz. "Women's Roles in the History of Amniocentesis and Chorionic Villi Sampling." In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, edited by Karen H. Rothenberg and Elizabeth Jean Thomson. Women and Health Series. Columbus: Ohio State University Press, 1994.

Curry, Lynne. *Modern Mothers in the Heartland: Gender, Health, and Progress in Illinois, 1900-1930*. Columbus: Ohio State University Press, 1999.

"Cytogenetics." *Concise Medical Dictionary*. Oxford Reference Online. Oxford University Press, 2010. http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t60.e2421.

Davis, Dorothy Crane. "Predicting Tomorrow's Children." *Today's Health* 46 (January 1968): 32–37.

Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. New York: Verso, 1995.

Davis, Rebecca L. *More Perfect Unions: The American Search for Marital Bliss*. Cambridge, MA: Harvard University Press, 2010.

Davis, Rebecca Louise. "'The Wife Your Husband Needs': Marriage Counseling, Religion, and Sexual Politics in the United States, 1930-1980". Dissertation, Yale University, 2006. http://search.ebscohost.com/login.aspx?direct=true&db=ahl&AN=45917909&site=ehost-live&scope=site.

Dice, Lee R. "Heredity Clinics: Their Value for Public Service and for Research." *American Journal of Human Genetics* 4, no. 1 (March 1952): 1–13.

———. "The Buildings and Lands: Heredity Clinic Building." Edited by Walter A. Donnelly. *The University of Michigan: An Encyclopedic Survey*. Ann Arbor: University of Michigan Press, 1958. http://quod.lib.umich.edu/u/umsurvey/AAS3302.0004.001/1:2.8.3?rgn=div3;sort=occur;subview=detail;type=simple;view=fulltext;q1=Heredity+Clinic+Building.

———. "The Structure of Heredity Counseling Services." In *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, edited by Helen Hammons, 60–64. New York: Hoeber-Harper, 1959.

"Down's Syndrome." *A Dictionary of Nursing*. Oxford Reference Online. Oxford University Press, 2010. http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t62.e2540.

"Down Syndrome Fact Sheet." *National Down Syndrome Society*, n.d. http://www.ndss.org/index.php?option=com_content&view=article&id=54&Itemid=74.

Eastman, Nicholson J. *Williams Obstetrics*. 10th ed. New York: Appleton-Century-Crofts, Inc., 1950.

———. *Williams Obstetrics*. 11th ed. New York: Appleton-Century-Crofts, Inc., 1956.

Edwards, A. W. F. "R. A. Fisher's 1943 Unravelling of the Rhesus Blood-Group System." *Genetics* 175, no. 2 (February 1, 2007): 471–476.

Evadene Burris Swanson. "Biographical Sketch of Charles Fremont Dight, M.D." *Bulletin - Dight Institute of the University of Minnesota*, no. 1 (1943): 9–22.

Evans, Francis C. "Lee Raymond Dice, (1887-1977)." *Journal of Mammalogy* 59, no. 3 (1978): 635–644.

Evans, Sara. *Tidal Wave: How Women Changed America at Century's End*. New York: Free Press, 2003.

Fasten, Nathan. "Sex-linked Factors in Heredity." *Hygeia* 25, no. 8 (August 1947): 590–591, 641.

Fisher, R. A. "The Rhesus Factor a Study in Scientific Method." *American Scientist* 35, no. 1 (January 1, 1947): 95–113.

Fraser, F. C. "Heredity Counseling: The Darker Side." *Eugenics Quarterly* 3, no. 1 (1956): 45–51.

Fraser, F. Clarke. "Genetic Counseling." *American Journal of Human Genetics* 26 (1974): 636–59.

———. "Introduction: The Development of Genetic Counseling." *Birth Defects Original Article Series* 15, no. 2 (1979): 5–15.

———. "Types of Problems Presented to Genetic Counselors." In *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, edited by Helen Hammons, 76–79. New York: Hoeber-Harper, 1959.

Freedman, Estelle. *No Turning Back: The History of Feminism and the Future of Women*. New York: Ballantine Books, 2002.

Freilich, Irving, and Frances Freilich. "Will Your Baby Be Normal?" *Saturday Evening Post* 230, no. 19 (November 9, 1957): 42, 147–150.

Fuchs, F., E. Freiesleben, E. E. Knudsen, and P. Riis. “Antenatal Detection of Hereditary Diseases.” In *Proceedings of the First International Congress of Human Genetics*, edited by Tage Kemp, Mogens Hauge, and Bent Harvald, 105–107. Basel, CH: S. Karger, 1957.

“General Program of the Meeting of Biological Societies.” *AIBS Bulletin* 1, no. 4 (1951): 3–61.

“Genetics: Young Science Studies Continuity of Life.” *Life*, March 17, 1947.

Gerodetti, Natalia. “Rational Subjects, Marriage Counselling and the Conundrums of Eugenics.” *Studies in History and Philosophy of Biological and Biomedical Sciences* 39, no. 2 (June 2008): 255–262.

Gleitman V. Cosgrove, 227 A. 2d 689 (Supreme Court of New Jersey 1967).

Golden, Janet. *Message in a Bottle: The Making of Fetal Alcohol Syndrome*. Cambridge: Harvard University Press, 2005.

Gordon, Linda. *Woman’s Body, Woman’s Right: Birth Control in America*. New York, NY: Penguin Books, 1990.

Hammons, Helen. *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*. New York: Hoeber-Harper, 1959.

Hecht, Frederick. “Jerome Lejeune (1926-94): In Memoriam.” *American Journal of Human Genetics* 55 (1994): 201–202.

Heimler, Audrey. “An Oral History of the National Society of Genetic Counselors.” *Journal of Genetic Counseling* 6, no. 3 (1997): 315–336.

“Hemolytic Disease of the Newborn.” *A.D.A.M. Medical Encyclopedia*. PubMed Health. U.S. National Library of Medicine, 2012. http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002275/.

Herman, Ellen. *Kinship by Design: A History of Adoption in the Modern United States*. Chicago, IL: University of Chicago Press, 2008.

———. *The Romance of American Psychology: Political Culture in the Age of Experts*. Berkeley: University of California Press, 1995.

Herndon, C. Nash. “Heredity Counseling.” *Eugenics Quarterly* 1, no. 1 (1954): 64–66.

———. “Procedures for Referral to Heredity Counselors.” In *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, edited by Helen Hammons, 70–75. New York: Hoeber-Harper, 1959.

Himes, Norman. *Your Marriage: A Guide to Happiness*. New York: Farrar & Rinehart, Inc., 1940.

Hirschhorn, Kurt. “A Short History of the American Society of Human Genetics.” *The American Journal of Human Genetics* 83, no. 3 (September 12, 2008): 307–310.

———. “Human Genetics.” *The Journal of the American Medical Association* 224, no. 5 (April 30, 1973): 597 –604.

Hodges, Fred J. “University of Michigan Medical Center.” Edited by Ferol Brinkman. *The University of Michigan: An Encyclopedic Survey*. Ann Arbor: The University of Michigan Bentley Historical Library, 1977. http://quod.lib.umich.edu/u/umsurvey/AAS3302.0005.001/1:19.1?rgn=div2;sort=occur;subview=detail;type=simple;view=fulltext;q1=Department+of+Human+Genetics.

“How Are Your Genes? Genetic Counseling Centers.” *Newsweek* 73 (February 10, 1969): 90.

Igo, Sarah. *The Averaged American: Surveys, Citizens, and the Making of a Mass Public*. Cambridge, MA: Harvard University Press, 2007.

Jacobson, Cecil B. “Cytogenetic Techniques and Their Clinical Uses.” In *Genetics in Medical Practice*, edited by Mihaly Bartalos, 101–122. Philadelphia, PA: J. B. Lippincott Company, 1968.

Jolly, Elizabeth, and Henrik L. Blum. “Genetic Counseling—A Health Department Service to Physicians.” *California Medicine* 103, no. 5 (November 1965): 330–333.

Karkazis, Katrina Alicia. *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Durham: Duke University Press, 2008.

Kenen, Regina H. “Genetic Counseling: The Development of a New Interdisciplinary Occupational Field.” *Social Science & Medicine* 18, no. 7 (1984): 541–549.

Kenny, Michael G. “Toward a Racial Abyss: Eugenics, Wickliffe Draper, and the Origins of the Pioneer Fund.” *Journal of the History of the Behavioral Sciences* 38, no. 3 (Summer 2002): 259–283.

Kevles, Daniel J. *In the Name of Eugenics: Genetics and the Uses of Human Heredity*. Berkeley: University of California Press, 1985.

Kline, Wendy. *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave*. Chicago, IL: The University of Chicago Press, 2010.

———. *Building a Better Race: Gender, Sexuality, and Eugenics from the Turn of the Century to the Baby Boom*. Berkeley: University of California Press, 2005.

Kudlick, Catherine J. "Disability History: Why We Need Another 'Other'." *The American Historical Review* 108 (June 2003): 763–793.

Kudlick, Catherine. "The Blind Man's Harley: White Canes and Gender Identity in America." *Signs* 30, no. 2 (January 1, 2005): 1589–1606.

Ladd-Taylor, Molly. "Eugenics, Sterilisation and Modern Marriage in the USA: The Strange Career of Paul Popenoe." *Gender & History* 13, no. 2 (2001): 298–327.

———. *Raising a Baby the Government Way: Mothers' Letters to the Children's Bureau, 1915-1932*. New Brunswick, NJ: Rutgers University Press, 1986.

———. "Toward Defining Maternalism in U.S. History." *Journal of Women's History* 5, no. 2 (Fall93 1993): 110.

Ladd-Taylor, Molly, and Lauri Umansky. *"Bad" Mothers: The Politics of Blame in Twentieth-Century America*. New York: New York University Press, 1998.

Lake, Alice. "Babies for the Brave." *Saturday Evening Post* 227, no. 5 (July 31, 1954): 26–65.

Lejeune, J., M. Gauthier, and R. Turpin. "Les Chromosomes Humains En Culture Des Tissus." *Academie De Sciences* 248 (1959).

Lemus, Cheryl K. "'The Maternity Racket': Medicine, Consumerism, and the Modern American Pregnancy, 1876-1960". Dissertation, Northern Illinois University, 2011.

Lennox, Bernard. "Chromosomes for Beginners." *The Lancet* 277, no. 7185 (May 13, 1961): 1046–1051.

Lewis, Carolyn. *Prescription for Heterosexuality Sexual Citizenship in the Cold War Era*. Chapel Hill: University of North Carolina Press, 2010.

Lindee, M. Susan. *Moments of Truth in Genetic Medicine*. Baltimore, MD: Johns Hopkins University Press, 2005.

Lindee, Susan. *Moments of Truth in Genetic Medicine*. Baltimore, MD: Johns Hopkins University Press, 2005.

Lindenmeyer, Kriste. *"A Right to Childhood": The U.S. Children's Bureau and Child Welfare, 1912-46*. Urbana: University of Illinois Press, 1997.

Lombardo, Paul A., and Gregory M. Dorr. "Eugenics, Medical Education, and the Public Health Service: Another Perspective on the Tuskegee Syphilis Experiment." *Bulletin of the History of Medicine* 80, no. 2 (2006): 291–316.

Longmore, Paul K., and Lauri Umansky, eds. *The New Disability History: American Perspectives*. New York University Press, 2001.

"Lottery of the Genes." *Newsweek* 22 (September 13, 1943): 86–87.

Lovett, Laura. *Conceiving the Future: Pronatalism, Reproduction, and the Family in the United States, 1890-1938*. Chapel Hill: University of North Carolina Press, 2007.

Lynch, Henry T. "Family Centered Genetic Counseling: Role of the Physician and the Medical Genetics Clinic." *The Nebraska State Medical Journal* 50 (April 1965): 155–159.

Maloy, Kate. *Birth or Abortion?: Private Struggles in a Political World*. New York: Plenum Press, 1992.

Marks, Joan H. "The Training of Genetic Counselors: Origins of a Psychosocial Model." In *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, edited by Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan, 15–24. New York: Aldine De Gruyter, 1993.

Marley, Faye. "Who Should Bear Children?" *Science News* 90, no. 26 (December 24, 1966): 537.

Marsh, Margaret, and Wanda Ronner. *The Empty Cradle: Infertility in America from Colonial Times to the Present*. Baltimore, MD: Johns Hopkins University Press, 1999.

Mayo Clinic. "Down Syndrome: Causes." *Mayo Clinic*, April 7, 2011. http://www.mayoclinic.com/health/down-syndrome/ds00182/dsection=causes.

"Medical News." *The Journal of the American Medical Association* 213, no. 13 (September 28, 1970): 2167 –2180.

Meredith, Burke. "Genetic Counselor Attitudes Towards Fetal Sex Identification and Selective Abortion." *Social Science & Medicine* 34, no. 11 (June 1992): 1263–1269.

Milunsky, Aubrey, and Leonard Atkins. “Prenatal Diagnosis of Genetic Disorders.” *The Journal of the American Medical Association* 230, no. 2 (October 14, 1974): 232 –235.

Milunsky, Aubrey. “Prenatal Genetic Diagnosis and the Law.” In *Genetics and the Law II*, edited by Aubrey Milunsky and George J. Annas, 61–68. New York: Plenum Press, 1980.

Mohr, James. *Abortion in America: The Origins and Evolution of National Policy, 1800-1900*. New York: Oxford University Press, 1978.

Muller, H. J. “Our Load of Mutations.” *American Journal of Human Genetics* 2, no. 2 (June 1950): 111–176.

Muravchik, Stephanie Natalya. *American Protestantism in the Age of Psychology*. New York: Cambridge University Press, 2011.

———. “Came to Believe: American Faith in an Age of Psychology”. Dissertation, University of Virginia, 2007.

Murray, Robert F. “Genetic Counseling in Clinical Medicine.” In *Genetics in Medical Practice*, edited by Mihaly Bartalos, 143–155. Philadelphia, PA: J. B. Lippincott Company, 1968.

Myers-Shirk, Susan E. *Helping the Good Shepherd: Pastoral Counselors in a Psychotherapeutic Culture, 1925-1975*. Baltimore, MD: Johns Hopkins University Press, 2009.

Nadler, Henry L. “Antenatal Detection of Hereditary Disorders.” *Pediatrics* 42, no. 6 (December 1, 1968): 912 –918.

Neel, James V. “Problems in the Estimation of the Frequency of Uncommon Inherited Traits.” *American Journal of Human Genetics* 6, no. 1 (March 1954): 51–60.

———. “The Meaning of Empiric Risk Factors.” In *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, edited by Helen Hammons, 65–69. New York: Hoeber-Harper, 1959.

“New Concern for the Unborn.” *Time*, 1969.

“Of Miracles and Medicine.” *Today’s Health* 46, no. 1 (January 1968): 29–88.

Oliver, Clarence P., Harold F. Falls, and William J. Schull. “Discussions: Heredity Counseling.” In *Heredity Counseling: A Symposium Sponsored by the American Eugenics Society and Held at the New York Academy of Medicine Building*, edited by Helen Hammons, 93–106. New York: Hoeber-Harper, 1959.

Oliver, Clarence P. “Fifth Annual Report of the Dight Institute for the Academic Year 1945-46.” *Bulletin - The Dight Institute of the University of Minnesota*, no. 5 (1947): 1–19.

———. “Report on the Organization and Aims of the Dight Institute and Its Accomplishments for the Year Ending June 30, 1942.” *Bulletin - Dight Institute of the University of Minnesota*, no. 1 (1943): 1–7.

———. “Second Annual Report of the Dight Institute for the Academic Year 1942-43.” *Dight Institute of the University of Minnesota* (1944): 1–9.

———. “The Collection of Records in the Study of Human Heredity.” *Bulletin - Dight Institute of the University of Minnesota*, no. 2 (1945): 1–34.

Ordover, Nancy. *American Eugenics: Race, Queer Anatomy, and the Science of Nationalism*. Minneapolis: University of Minnesota Press, 2003.

Parens, Erik, and Adrienne Asch, eds. *Prenatal Testing and Disability Rights*. Hastings Center Studies in Ethics. Washington, DC: Georgetown University Press, 2000.

Paul, Diane. “Eugenic Origins of Medical Genetics.” In *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature-Nurture Debate*, edited by Diane Paul, 133–156. Albany: State University of New York Press, 1998.

Pernick, Martin S. *The Black Stork: Eugenics and the Death of “Defective” Babies in American Medicine and Motion Pictures Since 1915*. New York: Oxford University Press, 1996.

Pernick, M S. “Eugenics and Public Health in American History.” *American Journal of Public Health* 87, no. 11 (November 1, 1997): 1767–1772.

Pius XII, Pope. “Two Discourses.” *Bulletin - Dight Institute of the University of Minnesota*, no. 11 (1959): 9–21.

Powell, Cynthia M. “The Current State of Prenatal Genetic Testing in the United States.” In *Prenatal Testing and Disability Rights*, edited by Erik Parens and Adrienne Asch, 308–333. Hastings Center Studies in Ethics. Washington, DC: Georgetown University Press, 2000.

Rapp, Gustav Wm., and Garwood C. Richardson. “A Saliva Test for Prenatal Sex Determination.” *Science* 115, no. 2984. New Series (March 7, 1952): 265.

Rapp, Rayna. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge, 1999.

Lee R. Dice. “A Panel Discussion: Genetic Counseling.” *American Journal of Human Genetics* 4, no. 4 (December 1952): 332–346.

Reagan, Leslie. *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in America*. Berkeley: University of California Press, 2010.

Reagan, Leslie J. *When Abortion Was a Crime: Women, Medicine, and Law in the United States, 1867-1973*. Berkeley: University of California Press, 1997.

Reardon, Jenny. *Race to the Finish: Identity and Governance in an Age of Genomics*. Princeton University Press, 2004.

Reed, Sheldon C. “A Short History of Genetic Counseling.” *Social Biology* 21, no. 4 (1974): 332–9.

———. “A Short History of Human Genetics in the USA.” *American Journal of Medical Genetics* 3 (1979): 282–295.

———. “Counseling in Human Genetics.” *Bulletin - Dight Institute of the University of Minnesota*, no. 6 (1949): 7–21.

———. “Counseling in Human Genetics, Part II.” *Bulletin - Dight Institute of the University of Minnesota*, no. 7 (1951): 6–17.

———. “Counseling in Human Genetics, Part III.” *Bulletin - Dight Institute of the University of Minnesota*, no. 8 (1953): 10–19.

———. *Counseling in Medical Genetics*. Philadelphia, PA: W. B. Saunders Company, 1955.

———. “Counseling in Medical Genetics.” In *Proceedings of the First International Congress of Human Genetics*, edited by Tage Kemp, Mogens Hauge, and Bent Harvald, 931–938. Basel, CH: S. Karger, 1957.

———. “Reactivation of the Dight Institute.” *Bulletin - Dight Institute of the University of Minnesota*, no. 6 (1949): 1–6.

———. “Report of Progress, 1949-1951.” *Bulletin - Dight Institute of the University of Minnesota*, no. 7 (1951): 1–5.

———. “Report of Progress, 1951-1953.” *Bulletin - Dight Institute of the University of Minnesota*, no. 8 (1953): 1–9.

———. “Report of Progress, 1953-1955.” *Bulletin - Dight Institute of the University of Minnesota*, no. 9 (1956): 1–5.

———. “Report of Progress, 1955-1957.” *Bulletin - Dight Institute of the University of Minnesota*, no. 10 (1957): 1–6.

———. “Report of Progress, 1957-1959.” *Bulletin - Dight Institute of the University of Minnesota*, no. 11 (1959): 1–5.

———. “Report of Progress, 1959-1961.” *Bulletin - Dight Institute of the University of Minnesota*, no. 12 (1962): 1–5.

———. “Report of Progress, 1961-1963.” *Bulletin - Dight Institute of the University of Minnesota*, no. 13 (1966): 1–4.

———. “Report of Progress, 1963-1966.” *Bulletin - Dight Institute of the University of Minnesota*, no. 13 (1966): 5–10.

Reed, Sheldon. *Parenthood and Heredity*. 2d ed. New York: Wiley, 1964.

Resta, Robert G. “Eugenics and Nondirectiveness in Genetic Counseling.” *Journal of Genetic Counseling* 6, no. 2 (1997): 255–258.

———. “Historical Aspects of Genetic Counseling: Why Was Maternal Age 35 Chosen as the Cut-Off for Offering Amniocentesis?” *Medicina Nei Secoli* 14, no. 3 (2002): 793–811.

———. “In Memoriam: Sheldon Clark Reed, PhD, 1910-2003.” *Journal of Genetic Counseling* 12, no. 3 (June 2003): 283–285.

———. “The Historical Perspective: Sheldon Reed and 50 Years of Genetic Counseling.” *Journal of Genetic Counseling* 6, no. 4 (1997): 375–377.

Roberts, Elmer. “Biology and Social Problems.” *Bulletin - The Dight Institute of the University of Minnesota*, no. 4 (1946): 13–21.

Rosen, Ruth. *The World Split Open: How the Modern Women’s Movement Changed America*. New York: Viking, 2000.

Rothenberg, Karen H, and Elizabeth Jean Thomson, eds. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Women and Health Series. Columbus: Ohio State University Press, 1994.

Rothman, Barbara. *Encyclopedia of Childbearing: Critical Perspectives*. Phoenix, AZ: Oryx Press, 1993.

Rothman, Barbara Katz. *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. New York, NY: Penguin Books, 1987.

Sachs, Leo, David M. Serr, and Mathilde Danon. “Prenatal Diagnosis of Sex Using Cells from the Amniotic Fluid.” *Science* 123. New Series (1956): 548.

Samerski, Silja. “Genetic Counseling and the Fiction of Choice: Taught Self-Determination as a New Technique of Social Engineering.” *Signs* 34, no. 4 (June 1, 2009): 735–761.

Sanghavi, Darshak M. “Wanting Babies Like Themselves, Some Parents Choose Genetic Defects.” *The New York Times*, December 5, 2006, sec. Health. http://www.nytimes.com/2006/12/05/health/05essa.html?emc=eta1.

Scheinfeld, Amram. “How Much Do You Know About Heredity?” *Ladies’ Home Journal* 58 (November 1941): 121–123.

Schull, William J. “Ascertainment and the Study of Discontinuous Characteristics in Man.” *American Journal of Human Genetics* 6, no. 1 (March 1954): 124–130.

Shapiro, Joseph P. *No Pity : People with Disabilities Forging a New Civil Rights Movement*. 1st ed. New York: Three Rivers Press, 1994.

Solinger, Rickie. *Abortion Wars: A Half Century of Struggle, 1950-2000*. Berkeley: University of California Press, 1998.

———. “‘A Complete Disaster’: Abortion and the Politics of Hospital Abortion Committees, 1950-1970.” *Feminist Studies* 19, no. 2 (July 1, 1993): 241–268.

———. *Wake up Little Susie*. New York: Routledge, 2000.

Sorenson, James R. “Genetic Counseling: Values That Have Mattered.” In *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, edited by Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan, 3–14. New York: Aldine De Gruyter, 1993.

“States Issuing Licenses for Genetic Counselors.” *National Society of Genetic Counselors*, April 26, 2012. http://www.nsgc.org/Advocacy/StatesIssuingLicensesforGeneticCounselors/tabid/347/Default.aspx.

Stehney, Michael. “Legacy of the American Eugenics Movement: Implications for Primary Care.” *Primary Care* 31, no. 3 (September 2004): 525–541, ix.

Stern, Alexandra. *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America*. Berkeley: University of California Press, 2005.

———. “Rejecting and Reinscribing Racial Differences.” In *Telling Genes: The Story of Genetic Counseling in America*. Manuscript Chapter in Possession of Author. Baltimore: Johns Hopkins University Press, 2012.

Stock, Robert W. “Will the Baby Be Normal? The Genetic Counselor Tries to Find the Answer.” *New York Times Magazine* (March 23, 1969): 25.

Sturns, Elizabeth Daws. “My ‘RH Factor’ Baby.” *Hygeia* 27, no. 7 (July 1949): 458–459, 489–491.

Tharp, Julie. *This Giving Birth: Pregnancy and Childbirth in American Women’s Writing*. Bowling Green, OH: Bowling Green State University Popular Press, 2000.

Theriot, Nancy M. “Women’s Voices in Nineteenth-Century Medical Discourse: A Step Toward Deconstructing Science.” In *Gender and Scientific Authority*, edited by Barbara Laslett, Sally Gregory Kohlstedt, Helen Longino, and Evelynn Hammonds, 124–154. 1st ed. University of Chicago Press Journals, 1996.

Tips, Robert L., and Henry T. Lynch. “The Impact of Genetic Counseling Upon the Family Milieu.” *The Journal of the American Medical Association* 184, no. 3 (April 20, 1963): 183–186.

Tomes, Nancy. “Merchants of Health: Medicine and Consumer Culture in the United States, 1900-1940.” *The Journal of American History* 88, no. 2 (2001): 519–547.

Tone, Andrea. *Controlling Reproduction: An American History*. Wilmington, DE: SR Books, 1997.

“Translocation.” *Concise Medical Dictionary*. Oxford Reference Online. Oxford University Press, 2010. http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t60.e10269.

Trent, James. *Inventing the Feeble Mind: A History of Mental Retardation in the United States*. Berkeley: University of California Press, 1994.

Tucker, William. *The Funding of Scientific Racism: Wickliffe Draper and the Pioneer Fund*. Urbana: University of Illinois Press, 2002.

Valenti, Carlo, Edward J. Schutta, and Tehila Kehaty. “Cytogenetic Diagnosis of Down’s Syndrome in Utero.” *Journal of the American Medical Association* 207, no. 8 (February 24, 1969): 1513 –1515.

Wailoo, Keith. *The Troubled Dream of Genetic Medicine: Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease*. Baltimore, MD: Johns Hopkins University Press, 2006.

Weinstein, Deborah F. “Culture at Work: Family Therapy and the Culture Concept in Post-World War II America.” *Journal of the History of the Behavioral Sciences* 40, no. 1 (2004): 23–46.

Wertz, Dorothy C., and John C. Fletcher. “Communicating Genetic Risks.” *Science, Technology, & Human Values* 12, no. 3/4 (July 1, 1987): 60–66.

Wertz, Richard W., and Dorothy C. Wertz. *Lying-In: A History of Childbirth in America*. New Haven: Yale University Press, 1989.

Wexler, Alice. *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*. 1st ed. New York: Times Books: Random House, 1995.

Wilcox, Allen. *Fertility and Pregnancy: An Epidemiologic Perspective*. New York: Oxford University Press, 2010.

“Will the Baby Be Normal?” *Time*, 1960.

Wilson, Philip. *Childbirth: Changing Ideas and Practices in Britain and America 1600 to the Present*. New York: Garland Pub., 1996.