

Third Edition

A Guide to
**Genetic
Counseling**



Edited by

Vivian Y. Pan • Jane L. Schuette
Karen E. Wain • Beverly M. Yashar

WILEY Blackwell

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Counseling*

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Contents

List of Contributors	xi
Preface	xv
Acknowledgment	xvii
1 The Practice and Profession of Genetic Counseling	1
<i>Robert G. Resta</i>	
Genetic Counseling—A Clinical Activity and a Profession / 1	
Defining Genetic Counseling / 2	
Historical Overview of Genetic Counseling / 5	
The Genetic Counseling Profession / 8	
Other Providers of Genetic Counseling / 15	
Philosophy and Ethos of Genetic Counseling / 16	
The Practice of Genetic Counseling / 22	
The Many Roles of Genetic Counselors / 27	
Professional Growth and Skill Acquisition / 31	
Concluding Remarks / 32	
Appendix 1 / 33	
Appendix 2 / 35	
References / 38	
2 Building a Working Alliance Through Culturally Conscious Interviewing	43
<i>Gayun Chan-Smutko</i>	
Introduction / 43	
Building and Maintaining a Working Alliance: Key Attributes / 44	

Creating a Welcoming and Affirming Environment / 52
Developing Mutual Goals of a Session / 57
Promoting Shared Understanding Through Inquiry: Specific Interviewing
Techniques / 63
Growing Your Clinical Interviewing Process / 71
Concluding Guidance / 78
Acknowledgements / 79
Resources / 79
References / 80

3 Family History: An Essential Tool 85

Jane L. Schuette and Diane R. Koeller

Introduction / 85
The Evolution of the Pedigree / 86
Family History Basics / 89
Gathering the Information and Constructing a Pedigree / 92
Interpreting the Family History and Pedigree Analysis / 109
Psychosocial Aspects of Obtaining a Family History / 115
Summary / 117
References / 117

4 Understanding the Counseling in Genetic Counseling Practice 123

Luba Djurdjinovic

Introduction / 123
Psychological Framework of Our Practice / 125
Theories that Support Psychological-Based Discussions / 130
Appreciating Dynamics that can Enhance and/or Disrupt a Session / 132
Discussing Difficult Issues and Giving Bad News / 135
Coping Styles / 140
Supervision: An Opportunity to Further Explore and Understand
Ourselves and Self-Care / 141
Conclusion / 142
References / 142

**5 Patient-Centered Communication and Providing Information
in Genetic Counseling 147**

Jehannine (J9) Austin

Introduction / 147
What is Patient-Centered Communication? / 149
Deciding What Information to Provide in the Context of Patient-Centered
Genetic Counseling / 151
Principles of Providing Patient-Centered Information / 152
The process of Providing Information in Patient-Centered
Genetic Counseling / 157

The Process of Developing Patient-Centered Communication Skills / 167	
Summary / 171	
References / 171	
6 Evaluating and Using Genetic Testing	175
<i>Natasha Strande and Karen E. Wain</i>	
Introduction / 175	
Clinical Genetic Testing / 176	
Testing Methodologies / 179	
Test Parameters / 184	
Genetic Test Quality and Development / 189	
Genomic Variant Interpretation / 196	
Putting It into Practice / 206	
Conclusion / 215	
References / 215	
7 The Medical Genetics Evaluation	221
<i>Shane C. Quinonez</i>	
Components of the Medical Genetics Evaluation / 222	
Physical Examination / 229	
Tools Utilized in a Medical Genetics Evaluation / 233	
Future Care Consideration following a Genetic Diagnosis / 234	
Patient Follow-up When a Diagnosis is not Established / 235	
Summary / 236	
References / 236	
8 Thinking It all Through: Case Preparation and Management	239
<i>Lauren E. Hipp and Wendy R. Uhlmann</i>	
Introduction / 239	
Case Preparation / 240	
Performing a Risk Assessment / 248	
Contracting: Turning Case Preparation into Reality / 252	
Logistical Components of Case Management / 254	
Case Documentation / 259	
Case Follow-up and Care Coordination / 263	
Summary / 266	
References / 270	
9 Inclusion, Inclusivity, and Inclusiveness in Genetic Counseling: On Being an Authentic and Collaborative Community of Providers	271
<i>Annie K. Bao, Deanna R. Darnes, and Liann H. Jimmons</i>	
Introduction / 272	
Authors' Positionality / 273	

Phases of Inclusion: Principles for Practice / 278	
Context: Genetic Counseling Community Stories and Narratives / 289	
Reflective Exercises / 309	
Conclusion / 310	
Acknowledgements: Contributors and Allies / 311	
References / 312	
10 Health Disparities and Opportunities for Equity in Genetic Counseling	319
<i>Nadine Channaoui, Altovise T. Ewing-Crawford, Barbara W. Harrison, and Vivian Y. Pan</i>	
Introduction / 319	
Equality, Equity, and Justice / 320	
A Patient's Lived Journey: Centering the Experiences of Patients from Marginalized Communities / 323	
Pre-Appointment / 328	
Appointment Day / 332	
Post-Appointment / 336	
Epilogue / 338	
A Public Health Approach to Genetic Counseling / 340	
Summary / 344	
Key Definitions / 347	
References / 348	
11 Genetic Counselors in the Healthcare Ecosystem: Navigating Policies, Payment and Professional Advocacy	355
<i>Gillian W. Hooker and Katie Lang</i>	
Introduction / 355	
Health Care Ecosystems Around the World / 356	
The US Health Care Ecosystem / 356	
Federal Policies / 359	
Health and Human Services / 362	
Private Payers / 364	
The Integration of Genetic Counselors into the Health Care Ecosystem / 368	
Genetic Counselor Certification, Licensure, and Credentialing / 368	
Coding and Billing for Genetics Services in the US / 376	
Clinical Practice Challenges / 378	
Genetic Counseling Service Delivery Models / 379	
Improving Access to Services / 379	
New Service Delivery Models / 381	
Arguing the Business Case for Genetic Counseling / 383	
Conclusions / 386	
References / 386	

- 12 Ethical Genetic Counseling Practice** 391
Curtis R. Coughlin II and Kelly E. Ormond
- Introduction / 391
 - Morality, Ethics, and the Law: Some Definitions / 394
 - Ethical Foundations / 398
 - Ethical Analysis / 403
 - Informed Consent as a Foundational Concept in Genetic Counseling / 405
 - Clinical Examples of Ethical Issues in Genetic Counseling / 409
 - Resources for Ethical Dilemmas / 416
 - Research Ethics / 418
 - Conclusions / 419
 - References / 419
- 13 Genetic Counseling Research: Understanding the Basics** 427
Sarah Scollon and Beverly M. Yashar
- Why Do Research? / 428
 - What Makes Scientific Knowledge Different? / 430
 - The Research Process / 432
 - Data Collection and Analysis / 454
 - The Human Side of the Equation: Ethical Research / 458
 - Sharing Your Research with Others / 461
 - Seeing it Through to the End / 462
 - Research as a Career: Thinking Beyond Graduate School / 463
 - Conclusion / 464
 - References / 465
- 14 Clinical Supervision: Strategies for Receiving and Providing Direction, Guidance, and Support** 469
Monica Marvin
- Introduction / 469
 - Defining Clinical Supervision and Its Goals / 470
 - Setting the Stage for Growth and Learning: Guidance for Students / 471
 - Transitioning from Student to Supervisor / 479
 - Establishing a Working Alliance with Students / 481
 - Providing Ongoing Feedback and Support for Students / 486
 - Other Responsibilities of Supervisors / 490
 - Additional Considerations in Supervision / 492
 - Clinical Supervision Agreements / 495
 - Working with Graduate Programs / 495
 - Concluding Thoughts / 499
 - Acknowledgement / 499
 - References / 499

15 Professional Identities, Evolving Roles, Expanding Opportunities 503

Erica Ramos

Introduction / 503

The Benefits and Challenges of Professional Identity, Conduct,
and Professionalism / 504

Professional Development, Fulfilment, and Advancement / 511

Managing Professional Challenges / 526

Looking to the Future / 534

Acknowledgements / 535

References / 535

16 Examining Our Work through Case Presentations 541

Richard Dineen, Logan B. Karns, Matthew J. Thomas, and Barry S. Tong

Introduction / 541

The Things We Don't See: Prenatal Genetic Counseling
(Logan B. Karns) / 542

Case Example (GANAB PKD): Addressing Multiple Evolving Genetic
Counseling Issues in a Pediatric Polycystic Kidney Disease Case
(Rich Dineen) / 562

Cardiovascular Genetic Counseling: Supporting a Family Following
a Sudden Unexplained Death (Matthew J. Thomas) / 572

Supporting Patients' Decisions in a Cancer Setting: Family Matters
(Barry S. Tong) / 590

References / 605

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Preface

Welcome to the newest edition of *A Guide to Genetic Counseling*. The third edition of this textbook provides learners with a comprehensive overview of genetic counseling and explains the fundamental principles applicable to its practice. We emphasize the patient-care process, highlighting theoretical frameworks, technologies, and contextual realities that impact care. Our goal is to help learners appreciate the diverse perspectives, approaches, and areas of expertise that embody the genetic counseling profession and build knowledge and skills for success as practitioners. Using the American Board of Genetic Counseling core competencies as a scaffold, the book's content covers the genetic counseling process from case initiation to completion, addresses critical professional issues, and considers the profession's historical journey, current advances, and future challenges. This book is designed to serve as a foundational and introductory text for genetic counseling students and as a comprehensive reference for anyone seeking to understand the practice of genetic counseling.

Our goal has remained the same as the first two editions—to codify the knowledge in the field of genetic counseling and facilitate academic instruction. You may ask: “Has the practice of genetic counseling really changed?” The short answer is both yes and no. Many of the chapters in this edition have a similar focus to that of the second edition; however, all the content has been updated and new chapters have been added to reflect current principles and practices in clinical care, the expanded landscape of genetic counseling practice, and to directly address the topics of inclusivity and health disparities. The chapters are organized to help learners focus on the development of counseling skills, envision practical aspects of working as a genetic counselor, and foster contextual self-awareness and professional development as one considers the role of the individual, society, and the profession.

In embarking on this third edition, it became evident that the practice of genetic counseling has grown more complex than it was when the first edition was published in 1998 and the second edition in 2009. Beyond technological advances, the profession is reckoning with how to respond to social injustices, inequities, and health disparities. This is hard work (and heart work); we encourage readers to engage and re-engage with this textbook throughout their education and their career. Creating and editing the third edition was a learning journey for each of us as we worked to understand and learn from the unique perspectives we held about the practice of genetic counseling. Our intentional approach to this textbook extends to decisions on content, approach, and language. We acknowledge that practices evolve and what might be considered acceptable today, may change tomorrow. This necessitates constant reflection and adaptation. We firmly believe that words matter and that understanding the nuances of language is a crucial aspect of effective communication. We encourage readers to reflect on why and in what context specific terminologies are used. We humbly acknowledge that no textbook can include all relevant content, perspectives, or clinical approaches, and as editors, we do not represent all views, knowledge, and experiences. We have therefore sought to engage authors who bring diversity across personal characteristics, perspectives, and expertise. Consequently, we hope that learners and educators will appreciate the importance of curiosity and openness to differing perspectives as important aspects of learning, applying, and mastering the provided content. We urge all users of this text to embrace the value of being a life-long learner, a key skill in maintaining competence and growing professionally.

Finally, we dedicate this third edition of *A Guide to Genetic Counseling* to genetic counseling students and all who strive to teach, mentor, support, and affirm them. You are the future of genetic counseling. May this text provide you with a framework for developing your skills, your professional self, and your dedication to the provision of high-quality genetic counseling services for all people.

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As we sought to make the textbook more inclusive, we extend special appreciation to Annie Bao, Deanna Darnes, and Liann Jimmons. They engaged in critical discussions with us around author compensation and the DEIJ-factors that lead to the exclusion of marginalized individuals in efforts like this textbook, including the altering or erasing of authentic voices, input, and truths. Annie, Deanna, and Liann pushed us to advocate for a more just arrangement. We thank them for raising their voices, maintaining unwavering integrity, and challenging the oppressive norms and inertia that prevent progress. We would also like to convey gratitude and acknowledgement specifically to Ginger Tsai, whose suggestion of using sensitivity reading introduced a novel and important aspect of enhancing the quality of this text. This new editorial process helps to ensure the content is not only accurate but also sensitive and inclusive. Deepti Babu, Nadine Channaoui, Gayun Chan-Smutko, Altovise Ewing, Barbara Harrison, Erica Ramos, Michelle Takemoto, and Vivian Ota Wang offered invaluable guidance and feedback to individual editors early in the process, which shaped our approach to inclusivity

related content. We also express appreciation to Wiley for their openness, curiosity, and collaborative approach in navigating these contractual arrangements.

Finally, we deeply appreciate the groundwork laid by contributors to the first and second editions. Without their pioneering efforts, our current work would not have been possible, and we recognize the lasting impact of their scholarship on the field. Sincere thanks to these predecessors, as our endeavors stand firmly on the solid foundation they established.

1

The Practice and Profession of Genetic Counseling

Robert G. Resta¹

GENETIC COUNSELING—A CLINICAL ACTIVITY AND A PROFESSION

Change, if you will, is in the DNA of genetic counseling. The *clinical activity* of genetic counseling began in the early decades of the twentieth century. It then continued to evolve in response to advances in the understanding of the principles of genetics and the expansion of biomedical technology and bioinformatics. This in turn led to a greater understanding of genetic disease etiology, manifestations, variability, and treatment, along with new genetic testing capabilities such as genomic analysis, prenatal testing, and pre-implantation genetic diagnosis. Equally important advances occurred in the study of human behavior and psychology, public health policy, ethical analysis, and counseling theory. These have occurred in the context of shifting social and ethical norms, reproductive patterns

¹ This chapter is adapted from an earlier edition of this book, authored by Ann Walker.

like the decades long unwavering trend in delayed child-bearing in many Westernized countries, and new philosophies of medical care such as patients assuming greater responsibility for their health care management and owning their medical records.

It is only since the 1970s, however, that the *profession* of genetic counseling has arisen. The education and practice of genetic counseling professionals involves expertise in all the above elements, enabling them to function as members of genetics health care teams and working with diverse specialists. Beyond medical clinics, genetic counselors work in genetic testing laboratories, educational institutions, research, private practice groups, and health insurance companies, to name a few. Today's genetic counselor provides a unique service, distinct from the contributions of other specialists, for patients and families who seek to understand, adapt to, and cope with the genetic, medical, and—most critically—psychological aspects of conditions they confront.

Fifty years after the first master's degrees were awarded in genetic counseling, genetic counselors have achieved a prominent place in genetic health care delivery, education, laboratory services, and public policy development. Around the globe they have formed professional organizations and developed mechanisms for accrediting genetic counselors and creating training programs.

The definition, goals, and scope of genetic counseling are tied to time and place. What constituted genetic counseling a century ago appears quite different than it does in 2023, and contemporary genetic counseling can look and sound different across the globe. There is no one "right way" to practice genetic counseling, some Platonic ideal against which all comers are to be measured. Instead, the practice of genetic counseling is continually shaped and reshaped by its regional, social, economic, scientific, medical, historical, and ethical context. Today's "best practices" and professional codes of ethics are tomorrow's discarded approaches and ethical shortcomings. The measures of success in genetic counseling in the UK or US might be different than the measures in Saudi Arabia or China or India.

In order to understand how genetic counseling arrived where it is we must understand what it is and where it has come from. This chapter provides an overview of defining genetic counseling, the history of genetic counseling as a practice and as a profession, its ethos and philosophy, and the current practice of genetic counseling. Because of the historical focus of this chapter, some terms are used that were common or considered appropriate at the time that they were written but are now considered offensive. I have set these terms in quotation marks to alert the reader that they are being used strictly for historical context.

DEFINING GENETIC COUNSELING

The term "genetic counseling" was coined in 1947 by Sheldon Reed, a PhD geneticist at the Dight Institute for Human Genetics at the University of Minnesota and one of the first clinical geneticists. He defined it quite tersely as "a kind of genetic

social work without eugenic connotations.” (Resta, 1997b). While this definition is lacking in specifics, it does capture the general essence of the idealized concept of genetic counseling.

The American Society of Human Genetics 1975 Definition

Various authors proposed their own brief definitions of genetic counseling in the 1950s and 1960s, but it was not until the early 1970s that a more formal definition was proposed by a committee of the American Society of Human Genetics (ASHG), and was subsequently adopted by ASHG in 1975:

Genetic counseling is a communication process which deals with the human problems associated with the occurrence or 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 to: (1) comprehend the medical facts including the diagnosis, probable course 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 alternatives for dealing with the risk of recurrence, (4) choose a course of action which seems to them appropriate in their view of their risk, their family goals, and their ethical and religious standards and act in accordance with that decision, and (5) to make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. (ASHG, 1975)

This definition held up quite well for several decades, articulating as it does several central features of genetic counseling. The first is the two-way nature of the interaction—quite different from the “advice-giving” of the eugenic period or the supposedly neutral and objective information-based counseling characteristic of the mid-twentieth century. The second is that genetic counseling is a *process*, ideally taking place over a period of time and across the lifespan so the client can gradually adapt to and assimilate complex or distressing information regarding diagnosis, prognosis, and risk and formulate age-appropriate decisions or clinical and social strategies. The third is the emphasis on the client’s autonomy in decision-making related to reproduction, testing, or treatment, and the recognition that such decisions will appropriately be different depending on the personal, family, and cultural contexts in which they are made. The fourth acknowledges that the occurrence or risk for a genetic disorder can have a family-wide impact different from that of other kinds of diseases and indicates that there should be a psychotherapeutic component of genetic counseling to help people explore and manage the implications of often rare disorders. Implicit in the words “appropriately trained persons” is the admonition that genetic counseling requires special knowledge and skills distinct from those needed in other medical and counseling interactions.

No master's level genetic counselors were on the committee that crafted this definition. This was primarily the result of the profession being so new; the first class of genetic counselors graduated in 1972, just as the ASHG committee was first convening. But the lack of genetic counselor input may also have been partially due to the fact that genetic counselors, who were often called genetic associates in the 1970s, were initially regarded as having an ancillary role in the genetics clinic (Heimler, 1997).

2006 NSGC Definition of Genetic Counseling

Because genetic counseling has continued to evolve, in 2003 the National Society of Genetic Counselors (NSGC) appointed a task force to re-visit the definition of genetic counseling. Recognizing that many types of professionals provide genetic counseling, the group's charge was to define *genetic counseling*, rather than to describe various *professional roles* of genetic counselors (Resta et al., 2006). In reviewing the literature, the task force found 20 previous definitions of genetic counseling. They also considered the purposes for which a genetic counseling definition might be used. Among these are marketing the profession, not only to potential clients but also to insurance companies, hospital administrators, and health maintenance organizations; increasing public, professional and media awareness of genetic counseling; developing practice guidelines and legislation for licensure; and providing a basis for research in genetic counseling. They settled on a succinct definition that would be readily understandable, broad enough to apply to the variety of settings in which genetic counseling may be practiced, and that acknowledges the increasing importance of genetic counseling for common and complex diseases. As approved by the NSGC Board of Directors, the definition reads:

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

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

Note that the definition does not include references to eugenics, the health of the gene pool, or assessing reproductive decisions. Of course, this is the way that just one branch of a profession has chosen to define its core clinical activity. Genetic counselors from other geographic locales or other genetic professionals might define it differently, though none has done so formally and the NSGC definition is still widely cited.

HISTORICAL OVERVIEW OF GENETIC COUNSELING

The commonly told origin story often begins in August of 1947 when Sheldon Reed coined the term genetic counseling. But 1947 is more of a historical pivot point that shifted genetic counseling on its current trajectory rather than a true origin. The groundwork for Reed's vision was laid down nearly a century before.

Eugenic Roots of Medical Genetics and Genetic Counseling

A convenient historical starting point for the story of genetic counseling can be somewhat arbitrarily assigned to 1883 when the British polymath Francis Galton, Charles Darwin's half-first cousin, coined the word *eugenics* and defined it somewhat abstrusely as “a brief word to express the science of improving stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognizance of all influences that tend in however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had” (Galton, 1883).

Eugenics did not emerge out of the blue in 1883 from the head of Galton, however. For example, in 1872, John Humphrey Noyes described what he called a science of “rational reproduction” for the religious Oneida Community that he founded in New York State (Noyes and Noyes, 1872). Another source of eugenic thought in the mid-nineteenth century were the asylums for the “insane.” Directors of these institutes in North America and Europe were alarmed by the surge in the patient populations of these institutions and began suggesting that people with a family history of insanity should refrain from reproduction because of what they perceived to be the social, economic, and human costs of psychiatric conditions (Porter, 2018). Concerns about the economic and social “threat” of the growing numbers of lower socioeconomic status people during the Industrial Revolution were not limited to just a few intellectuals. Think of Ebenezer Scrooge's attitude toward the poor in Charles Dicken's *A Christmas Carol* from 1843: “If they [the poor] would rather die,” said Scrooge, “they had better do it, and decrease the surplus population.” Galton provided focus and scientific legitimacy to ideas and beliefs that had been voiced by others in the prior decades.

In the United States, the focal point of eugenics was the Eugenics Record Office (ERO) at Cold Spring Harbor in New York, headed by Charles Davenport, a well-respected PhD geneticist, and Harry Laughlin who served as its Superintendent. The ERO staff collected pedigrees in an effort to demonstrate what they felt was the Mendelian inheritance of physical, psychological, and behavioral traits. The pedigrees were intended to distinguish between “good families” and “dysgenic families,” the latter characterized by undesirable traits such as low IQ, poverty, alcoholism, unemployment, and “loose” sexual behavior. The pedigrees used by today's genetic counselors are direct descendants of, and nearly indistinguishable in format from, the ERO pedigrees.

The ERO advocated for anti-miscegenation and mandatory sterilization laws, along with immigration restriction to protect the “true” American racial stock, which largely implied people of Northern and Western European origin. Fear of immigration and replacement of “native” American stock (as distinct from Native Americans) was viewed as a threat to society a century ago, just as it is often viewed by some today. Ultimately, mandatory sterilization laws targeting socially and genetically undesirable individuals were passed in more than 30 states and resulted in more than 60,000 legally mandated sterilizations that continued well into the second half of the twentieth century.

A common misconception about eugenics is that it was identified primarily with ultra-conservative and racist viewpoints. While it is certainly true that eugenics was used as both a justification and tool of racist policies, eugenics was embraced to varying degrees across the sociopolitical spectrum (Paul, 1984). Eugenics was often viewed as a policy that could help people who were socioeconomically deprived. Progressives may have been opposed to some eugenic goals and policies, but they were not necessarily critical of all eugenic policies, particularly those that could help achieve what they thought of as more positive and helpful outcomes; for example, reducing poverty and undesirable social behaviors such as criminality and alcoholism. Eugenics was a global phenomenon, although it manifested differently in different countries depending on local circumstances. Advocacy of eugenics was not confined to upper middle class White Western Europeans and Americans; support for eugenics could be found across Asia, Latin America, African Americans, and Jews (Bashford and Levine, 2010).

The most extreme and reprehensible application of eugenic measures took place in Nazi Germany during the 1930s and 1940s, measures which borrowed directly from, and with the support of, prominent American and English eugenicists (Kühl, 1994). The result was the horrific treatment and deaths of millions across Europe, including Jews, Roma, Sinti, people with disabilities, homosexuals, and criminals, among others. The moral revulsion at these profound abuses and misapplications of genetic principles contributed to the demise of classical eugenics. It also led many geneticists to reject eugenics, though not as completely and clearly as is typically claimed (Paul, 1997).

The seeds of the specialty of medical genetics—and the clinical practice of genetic counseling—were sown in this field of eugenics. The genetic counseling that took place in the early genetics clinics was shaped by a conscious and stated rejection of classical eugenics and its overt racism and abuses. The post-World War II story of genetic counseling pivots to its modern trajectory in 1947 when Sheldon Reed coined the term *genetic counseling*. Reed and nearly all the other medical geneticists were highly educated, financially secure white males whose social and economic status and biases were reflected in how they formulated the developing ethos of genetic counseling. They shifted the focus of genetic counseling from race- and class-based eugenics to the goal of protecting the health of the human gene pool and to nondirective parental education about reproductive risks as one way of protecting the gene pool. Implicit in this approach is an

assumption that the lives of some people with genetic conditions were somehow a threat to the future of humanity. At the same time that they were espousing nondirectiveness, geneticists felt that properly counseled parents would make the “right” decisions and refrain from reproduction if they were at increased risk of having a child with a genetic condition (Paul, 1997). The tension between these seemingly conflicting approaches is illustrated in the contrasts between these two quotations from Sheldon Reed from the 1950s (note that some of vocabulary in these quotes that are out of place with current perspectives):

We try to explain thoroughly what the genetic situation is but the decision must be a personal one between the husband and wife, and theirs alone.

(Sheldon Reed, cited in Resta (1997a))

If our observation is generally correct, that people of normal mentality will behave in the way that seems correct to society as a whole, then an important corollary follows. It could be stated as a principle that the mentally sound will voluntarily carry out a eugenics program which is acceptable to society if counseling in genetics is available to them.

(Sheldon Reed, cited in Resta (1997a))

This idea of genetic counseling as a sort of informed and voluntary eugenics continued to shape the practice up until the 1970s. Many ASHG presidents during this time gave vocal and strong support to “protecting” the human gene pool through reproductive and other measures (Resta, 2020). James Neel, an ASHG president and a towering early figure in the field of medical genetics, even titled his autobiography *Physician to the Gene Pool* (Neel, 1994). By the 1970s, geneticists started to subtly switch the focus of genetic counseling from protecting the gene pool to “disability prevention” through counseling about reproductive decisions. Nearly every study that assessed the effectiveness of genetic counseling, whether performed by physicians or master’s level genetic counselors, from the 1960s to the 1990s, looked at its impact on disability and reproduction (Resta, 2019).

Genetic Testing Technology and Genetic Counseling Grew Hand in Hand

Up until 1956, few diagnostic tests were available. Knowledge of the physical structure of DNA was only three years old; there was no means of prospectively identifying unaffected *carriers* of genetic conditions; and given that it was still thought that there were 48 chromosomes in the human genome, the basis for chromosomal syndromes was unknown. Even with the goal of preventing genetic disorders, there was little for genetic counseling to offer families beyond information, sympathy, and the option to avoid childbearing.

The capabilities of genetics changed dramatically over the next 10 years as the correct human diploid complement of 46 chromosomes was reported by Tjio and

Levan (Tjio and Levan, 1956) and the cytogenetic basis of Down syndrome (Lejeune et al., 1959), Klinefelter syndrome (Jacobs and Strong, 1959), Turner syndrome (Ford et al., 1959) and trisomies 13 (Patau et al., 1960) and 18 (Smith et al., 1960; Edwards et al., 1960) were elucidated. Over this decade it also became possible to identify carriers for alpha or beta thalassemia (Kunkel et al., 1957; Weatherall, 1963); a host of abnormal hemoglobins; and metabolic diseases such as galactosemia (Hsia et al., 1958), Tay-Sachs disease (Volk et al., 1964), and G6PD deficiency (Childs et al., 1958), among others. Amniocentesis was first utilized for prenatal diagnosis—initially for sex determination using Barr body analysis (Serr et al., 1955)—and then for karyotyping (Steele and Breg, 1966). In 1968 Henry Nadler reported the first diagnosis of a fetal chromosome condition—Down syndrome as the result of an inherited D/G chromosomal translocation—as well as galactosemia and mucopolysaccharidoses (Nadler, 1968).

These advances in genetics meant that families had more options to better assess their risks and possibly avoid having a child with a genetic condition if they so desired. But the choices were by no means straightforward. Tests were not always informative. Prenatal diagnosis was novel and its potential pitfalls were incompletely understood. Explaining the technologies and the choices was time-consuming. However, clinical genetics' tenet of nondirective counseling was echoed elsewhere as medicine began to shift from its paternalistic approach toward promoting patient autonomy in decision-making. The emphasis in genetic counseling shifted too, from simply providing information that families would presumably use to make "rational" decisions (thereby preventing genetic disorders), towards a more interactive process in which individuals were not only educated about risks, but also helped with the difficult tasks of exploring issues related to the disorder in question, and of making decisions about reproduction, testing, or management that were consistent with the needs, resources, and values of patients and their families. To achieve this, genetic counselors needed to acquire the skills to understand the psychological meaning of their patients' beliefs, words, and actions (Tips and Lynch, 1963; Kessler, 1997). This environment helped to create the need for a dedicated genetic counseling profession and the development of post-graduate training programs to teach the necessary counseling skills and technical knowledge to work with patients. Equally important, this training needed to instill a clinical self-confidence in the value of a genetic counselor that newly minted counselors would need to advocate for themselves in creating employment opportunities and a professional identity separate from medical geneticists.

THE GENETIC COUNSELING PROFESSION

The professional non-MD trained genetic counselor emerged in the United States in the early 1970s. A profession typically has multiple components, including certified training programs, professional certification of individuals to assure competency, a professional organization to advocate for the profession's interests, a means to

obtain licensure or registration, employment opportunities, a scope of practice and a clearly defined core skill set. This section discusses these components.

Genetic Counseling Training Programs in The United States

The first graduate program to educate master's level professionals in human genetics and genetic counseling was established at Sarah Lawrence College in 1969 and graduated its first class in 1972 (Stern, 2012). By the end of that decade, there were 10 such training programs, though some were short-lived (Stern, 2012).

It is somewhat surprising that Sarah Lawrence College would serve as the birthplace of the profession. Located about a half hour north of New York City, Sarah Lawrence is a small liberal arts college that had no formal affiliations with medical centers or a vigorous genetics research program. No medical geneticists were on its faculty. The genetic counseling training program grew out of the vision of two people: Melissa Richter and Joan Marks. Richter was a former riveter and welder at a machine plant, and a sergeant in the Women's Army Corps. She went on to obtain a doctorate in psychology and eventually served as Dean of Graduate Studies at Sarah Lawrence. She claimed to have developed the idea of a genetic counseling training program after reading Sheldon Reed's book *Counseling In Medical Genetics* (Reed, 1955; Stern, 2012). Joan Marks, a psychiatric social worker, assumed directorship of the Sarah Lawrence program in 1974 after Richter's untimely death from breast cancer. Marks was responsible for incorporating a significant psychosocial component into genetic counseling training.

The number of genetic counseling training programs has increased regularly, with a notable rise in the last five years. In 2023 in the United States there are over 50 genetic counseling graduate training programs. Most training programs take about two years to complete, with some variation among programs. The curriculum combines clinical training involving rotations at clinics, laboratories, and other relevant institutions along with coursework in the principles of human genetics/genomics, genetic counseling, and clinical genetics; basic counseling skills; ethical, legal, and social issues; research methodology; principles and basics of some common medical specialties such as oncology, pediatrics, neurology, and obstetrics; laboratory methods; client education, communication and counseling; health care delivery systems and principles of public health; and professional development.

Accreditation for genetic counseling training programs is the responsibility of the Accreditation Council for Genetic Counseling (ACGC) (www.gceducation.org). Collaboration between program directors is coordinated by the Genetic Counselor Educators Association (formerly known as the Association of Genetic Counseling Program Directors), whose mission is "to promote collaborative interactions between individuals involved in genetic counseling graduate education and to support the highest standards of practice" (<https://educategc.org>).

In 1994, the newly created American Board of Genetic Counseling (ABGC) sponsored a meeting that included directors of all existing genetic counseling

programs, the ABGC Board, and consultants from outside the genetic counseling field who had expertise in clinical supervision and accreditation. The goal was to develop consensus about what new graduates should be able to do. By analyzing the counselor's role in various clinical scenarios, participants identified areas of required knowledge and skills (Fine et al., 1996) and from these analyses, 27 "competencies" were described. These were revised in 2015 and 2023. Since helping students to develop these competencies is what this book is all about, the 2023 version of this description is appended to this chapter.

Genetic Counseling Training Around the Globe

Global expansion of the genetic counseling training programs began in the 1980s, starting with Canada (1985), South Africa (1989), the UK and the Netherlands (1992), Australia (1995), and then spread to the rest of the world. In 2023, outside of the US, more than 20 countries on five continents offer more than 60 programs of advanced training in genetic counseling (Abacan et al., 2019). Not all countries offer a master's degree in genetic counseling specifically and instead may offer alternative degrees or certificate programs. In the Netherlands, for example, experienced genetic counselors can earn a master's degree as a Physician Assistant. Programs in India offer a master's degree as well as one-year diploma and certificate programs (Abacan et al., 2019).

Directors of many of these programs met as a group for the first time in Manchester, England in May 2006 to learn about each other's curricula and experiential training, genetics service delivery models, and mechanisms for genetic counselor credentialing. A Transnational Alliance of Genetic Counseling (with the clever acronym TAGC) was born at this meeting, and one outcome is that information about training programs around the world can now be found on the TAGC website (https://sc.edu/study/colleges_schools/medicine/centers_and_institutes_new/transnational_alliance_for_genetic_counseling/index.php).

Professional Organizations

A milestone in the evolution of any profession is the formation of its own society. For genetic counselors, this came in 1979 when the NSGC was incorporated. The goals of the new society were "to further the professional interests of genetic counselors, to promote a network of communication within the genetic counseling profession and to deal with issues related to human genetics" (Heimler, 1997). In 1980, the newly formed NSGC—then numbering only about 200 members—lobbied successfully for genetic counselors to be included among subspecialties that would be certified by the newly created American Board of Medical Genetics (ABMG) (starting in 1993, certification fell to the American Board of Genetic Counseling; refer to below discussion). NSGC has helped achieve representation by genetic counselors on the Boards of Directors and on numerous committees of the ASHG, the American College of Medical Genetics