THE GENETIC COUNSELOR WORKFORCE

Training Programs, Professional Practice, and Issues Affecting Supply and Demand

Illinois Center for Health Workforce Studies

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Executive Summary

The demand for genetic services is expected to increase significantly as the Human Genome Project and other research yield scientific advances with clinical applications. At this relatively early stage in the new genetics revolution, the issues involved with genetic testing and counseling have stimulated professional and public policy discussions. A key concern is the state of readiness of health professionals to provide genetic counseling and testing services. From the perspective of the health professions workforce, the growth in genetic testing presents two challenges 1) that clinicians (physicians, nurses, and others) be adequately trained and informed of the scientific advances and appropriate clinical applications; and 2) that there be a sufficient supply of genetic specialists to provide specialty services and manage referrals from other clinicians.

The number of clinicians trained as genetic specialists is small and includes physicians, non-physician clinical geneticists, nurses trained in genetics, and genetic counselors. This report describes the genetic counselor workforce – a professional group specifically trained to counsel individuals and families about genetic risks. The report includes a description of the number, distribution and composition of the profession, the training programs, certification, work setting and professional practice, the job market, and factors expected to influence the future supply and demand.

There are about 1,800 master's trained genetic counselors, with most working as clinicians within medical teams in urban academic medical centers and hospitals. Genetic counselors provide information and counseling to individuals and families at risk for genetic conditions. While counselors have traditionally worked in prenatal and pediatrics clinical areas, in recent years, their practice has expanded into adult medicine and specialty areas such as cancer centers and neurology, and into commercial genetic testing laboratories. The profession is relatively young, with the first graduates in 1971, and a steady increase in programs and graduates since that time. Currently 24 programs, usually based in academic medical centers, provide a two-year training program, with 120 to 130 graduates per year. The American Board of Genetic Counselors offers certification for genetic counselors, and although no state requires licensure, California has legislation pending that would require state licensure.

The National Society of Genetic Counselors conducts surveys of members biennially. The 1998 survey of over 800 counselors reported that 95% were women and 93% Caucasian; most were active clinicians with a mean patient load of 350 patients per year. Counselors also reported conducting public and professional educational programs on human genetics and testing. Professional job satisfaction was rated high with some concerns about professional advancement and earnings potential. A major concern of the profession has been with the difficulties obtaining recognition and payment for their services from health insurance groups and managed care plans.

The geographic distribution of counselors tends to be uneven, probably related to the training and employment locations in selected urban areas. In recent years, the growing, the growing number of counselors has helped increase geographic distribution, such that many states that lacked any counselors, now have at least a small number of counselors (often less than five per state). The lack of available counselors was noted in several clinical studies reviewed for this report. Another important issue related to the composition of the workforce is the lack of ethnic and racial minority representation. The profession has discussed ways to try to address this.

The rapid pace of genetic discoveries and their translation into clinical practice has led to expectations in many sectors that public demand for testing and counseling will increase; although early studies have found mixed levels of interest among those at risk for testing for specific adult onset conditions. In general, expansions in genetic testing would be expected to increase the demand for services by genetic counselors.

This report ends with several recommendations. The first is that the current training programs be maintained, with monitoring of the growth in clinical genetic testing and demand for genetic counselors' services. The strong applicant pool, the growing job market, and the expressed sense of a shortage of genetic counselors, all suggest that the existing training programs and numbers of trainees should be maintained. Expansions of existing training programs may require external financial support since existing programs report limited institutional budgets and strains on their clinical faculty. New training program starts may require external start-up funding as most academic medical centers currently face constricting revenue streams and this may limit their ability to add new programs with limited clinical revenue generating potential.

It is very difficult to assess this single profession in isolation from other genetic specialists and other professions that provide genetic counseling services, notably physicians and nurses. Thus a comprehensive assessment of both genetic specialists and practicing health professionals is essential. The potential for a dramatic impact of genetic discoveries on clinical practice requires that this issue be taken seriously. Several factors will influence the overall demand for genetics services. First, the demand for services will be dependent on the nature and timing of the scientific discoveries and the public's interest and demand for services. The willingness of third parties, principally health insurers and managed care plans, to pay for these services will influence their utilization. Finally, the extent to which physicians, nurses, and possibly other health care practitioners will be able to take on new skills and responsibility for genetic counseling and the ways that they choose to refer patients to genetic specialists, such as geneticists, genetic counselors, medical sub-specialists who manage conditions with genetic risks, such as oncologists and neurologists, will affect the demand for genetic specialty services. In each of these areas there should be ways to study the critical questions and to monitor outcomes.

Introduction

In their 1994 report, *Assessing Genetic Risks: Implications for Health and Social Policy*, the Institute of Medicine (IOM) noted the importance of adequately trained health professionals to meet the challenges of integrating genetic testing and new knowledge into clinical practice.[1] The IOM committee identified the dual needs for 1) an adequate supply of genetics specialists and 2) enhanced training for primary care practitioners on the role of clinical genetics in their practice.

A follow-up study commissioned by Working Group Ethical, Legal, and Social Implications of Human Genome Research examined issues of genetic testing. This group took as a starting position that "The rate of increase of health care professionals trained and board certified in medical genetics and genetic counseling has not kept pace with the rate of increase of genetic discovery and the potential for genetic tests (p. 64)."[2] This report went on to discuss the role of the non-genetic health care professionals (physicians, nurses, social workers, and community based and public health providers) in genetic testing and counseling, noting barriers and the need for multifaceted training programs.

Francis Collins, Director of the National Human Genome Research Institute (NHGRI) noted key concerns in his address to the Healthy People 2010 conference in January, 2000: "Can health care providers and the public become genetically literate in time? "Will we successfully shepherd new genetic tests from research into clinical practice?"[3]

The rapid progress on the Human Genome Project and the awareness of a significant lead time for training new specialists and training existing practitioners with new knowledge and skills has stimulated interest in both major workforce training issues. While many professions provide clinical counseling services for genetic conditions, this report examines only a specific component within the genetic specialist workforce, namely genetic counselors. This study was conducted with funding provided by the Bureau of Maternal and Child Health (BMCH) and the Bureau of Health Professions of the Health Resources and Services Administration. The Bureaus asked the HRSA-funded Illinois Center for Health Workforce Studies to conduct this study. The other three HRSA-funded state workforce studies centers (in California, New York and Washington state) were invited to review and add comments to the draft report. One of the centers

(New York) has developed a proposal to conduct a comprehensive national study of the medical genetics workforce.

This report examines genetic counselors defined as those professionals who have trained in master's level programs recognized by the American Board of Genetic Counseling. The report is organized to present an overview of the profession; a description of training programs; professional certification and licensure; findings from association surveys that present the demographic characteristics of the workforce, employment settings, and professional practice; genetic counseling conducted by other health professionals; and current issues facing the genetic counselor profession. The final section has conclusions and recommendations.

Overview of the Profession

Genetic counselors are health professionals who provide a variety of services to individuals or families at risk for genetic conditions. The first master's level training program for genetic counselors was established in 1969 and the first class graduated in 1971. In 1994, there were 17 programs with 105 graduates per year, by 1999 this had increased to 24 programs with about 130 graduates. The national association for the profession, the National Society of Genetic Counselors (NSGC), has 1,819 members that include master's trained genetic counselors, counselors with other professional degrees, and student.[4] Taking into account the non-members, the NSGC estimates the current supply of master's trained genetic counselors at about 1,800.

Most genetic counselors work in academic medical centers or hospitals, with smaller numbers in other settings such as HMOs, private medical practices, diagnostic laboratories, and government agencies. Accreditation of training programs and certification of practitioners is offered by the American Board of Genetic Counseling (ABGC). Certification was previously offered by the American Board of Medical Genetics (ABMG). Genetic counselors are not currently licensed by any state, although California has pending legislation for licensure (see below). The profession has considered licensure a critical policy issue for greater recognition and a potentially positive impact on third party reimbursement.

The practice scope is best described by the statement adopted by the National Society for Genetic Counselors in 1983:

> Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. Most enter the field from a variety of disciplines, including biology, genetics, nursing, psychology, public health and social work.
>
> Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They identify families at risk, investigate the problem present in the family, interpret information about the disorder, analyze inheritance patterns and risks of recurrence and review available options with the family.
>
> Genetic counselors also provide supportive counseling to families, serve as patient advocates and refer individuals and families to community or state support services. They serve as educators and resource people for other health care professionals and for the general public. Some counselors also work in administrative capacities. Many engage in research activities related to the field of medical genetics and genetic counseling.
>
> *Adopted by the National Society of Genetic Counselors, Inc. 1983*

Training Programs

Master's level training programs are offered by 24 institutions (See Appendix 1 for a list of programs and directors). Programs are sponsored by a college or university, usually within the genetics program of the academic medical center; although three programs are offered at colleges and universities without medical centers. The largest program, with 23 graduates in 2000, and the first to be founded, is at Sarah Lawrence College located in the greater New York City area. The next largest program, located at the University of Pittsburgh, was the second program founded, and will have 10 graduates in 2000. Many programs are small with three to six graduates per year.

Accreditation for training programs was fully developed in 1997 by the American Board of Genetic Counselors (ABGC). Previously the American Board of Medical Genetics (ABMG) had approved clinical training sites. The ABGC reviewed all existing

programs in 1997 and granted Interim Accreditation. Beginning in 1997, the ABGC began a planned full review and accreditation process that will review five training programs a year, based on the seniority of the programs, until all programs are reviewed.

The curriculum of training programs follows the guidelines of the ABGC and generally spans 18 to 24 months with didactic courses, clinical training, conferences and other small group learning and independent study activities, culminating in a masters thesis in about half of the programs. (The joint program at Johns Hopkins University/ National Human Genome Research Project, has a strong focus on research and counseling and requires 24 to 30 months). Students must have managed 50 patients with a variety of genetic conditions and present a case logbook of these cases when they apply for the certifying exam. Several programs note that their students often have more than 100 cases by the time they complete the program.

Clinical training sites provide students with diverse patient populations and practice settings that include prenatal clinics, pediatrics clinics, cancer centers, specialty clinics (e.g. neurology, connective tissue diseases, metabolic diseases), and disease specific clinics for patients with conditions such as cystic fibrosis, spina bifida, or muscular dystrophy. The ABGC requires a board certified genetic counselor at training sites to supervise and mentor students on at least fifty percent of the required cases that students will submit for their logbook. Other sites may be used with clinical geneticists, pediatricians, obstetricians or other physician specialists as supervisors. Many programs send students to hospitals or community-based sites away from their home academic institution.

Interviews were conducted with seven program directors to provide the following overview of training issues.[5] About 50 to 70% of program applicants apply directly from college with the majority having undergraduate degrees in the biological sciences or psychology or other social sciences. Many of these students have had volunteer experiences in counseling services. The remaining applicants have generally had a few years of work experience, often in a science field. The applicants are over 90% women with high GPAs and GREs. Schools report applicant to acceptant ratios that range from about four to one to more than twenty-five applicants to one position.

Many training programs have small budgets (some report no specific budget until recent years). Some programs are entirely dependent upon tuition and others receive lim-

ited direct institutional support. Most faculty are drawn from other parts of the institution and clinical genetic counselor faculty, except for the program directors, are usually volunteer and funded by their clinical work. Clinical sites from institutions outside of the sponsoring institution are almost always voluntary with unpaid clinical faculty. Most directors felt that their budgets were either very vulnerable to enrollment (e.g one program had one of four students drop out and lost that portion of their budget for about 12 months) or very limited in amount and flexibility. Any expansion of programs is limited by the availability of clinical sites to train students. One program reported a need to reduce their class size by 15% when they lost a major clinical site. Other programs note the heavy faculty time involved with one-on-one preceptor relationship with students during their clinical training or with students working on their master's research theses.

There have been discussions within the profession and the training programs about the amount of time and training in counseling services that trainees receive. Some programs stress the counseling preparation more than others (in terms of basic and advanced counseling courses offered). Other programs seem to place greater emphasis on the role of the genetic counselor as an educator and one who can present information in clinical settings or through programs that educate the public or other health professionals. Genetic counselors take a nondirective approach in their counseling of patients, some studies have noted that this approach is a distinguishing feature for genetic counselors.[6,7]

When program directors were asked if they would recommend that public policy support expansion of training programs or support of existing programs, several consistent responses were heard. First program directors tended agree that public support for existing programs would be very useful. They noted the generally small program size with limited budgets left many programs with financial vulnerability to changes in institutional support, tuition/enrollment fluctuations, and demands for clinical faculty practice to generate some departmental revenues. They also noted that public funds support training of many other health professionals. However, program directors almost all responded that it would be difficult for them to increase their own program size due to the major limitation of clinical sites to train students and the limited number of faculty to mentor students. Several also cited concern about the market for genetic counselors and not wanting to train students who would not be able to find jobs. Thus many directors noted that any significant increase in the number of genetic counselors trained should

that any significant increase in the number of genetic counselors trained should proceed only hand-in-hand with steps to address the reimbursement for services issue.

Professional Certification and Licensure

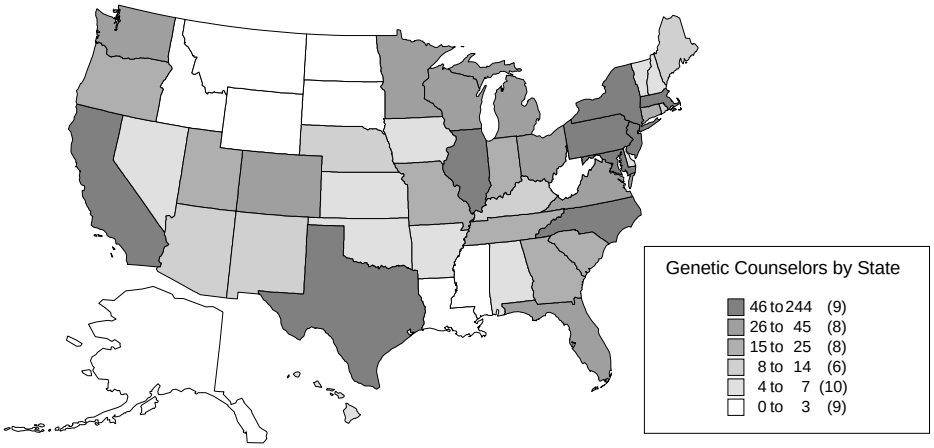
Authority for certification of genetic counselors was transferred from the ABMG to the ABGC in 1993. Genetic counselors must sit for two exams to be certified, the first covers the core knowledge of medical genetics and this part of the exam is offered jointly by both Boards (ABMG and ABGC). The second exam covers material specific to genetic counselors and is offered by the ABGC. Due to the small number of applicants and the costs of offering the certifying exams, these are offered only every three years.

As of early 2000, no state had a program for licensure for genetic counselors. However, California may be moving toward licensure. In 1998, California passed legislation requesting the State's Department of Health Services (DHS) develop regulations and standards for licensing genetic counselors.[8] The DHS, through the chief of the Genetic Disease Branch, had supported this legislation to help assure the quality of personnel offering genetic counseling services. Most oversight of professional licensure in California is provided by another state agency, the Department of Consumer Affairs, but this agency did not object to this arrangement, noting that the profession was small and could be most appropriately overseen by individuals familiar with the profession. The California DHS has submitted their plans for licensure to the legislature (January 2000) and a bill authorizing them to proceed is expected this year. The DHS notes that there has been no opposition to the bill, particularly since the State has clarified that this bill will not jeopardize performance of genetic counseling services by any other licensed professions whose scope of practice includes counseling services (e.g. physicians, nurses, social workers). The DHS expects that if this bill is approved by the legislature and is successful, it may be adopted as a standard for other employers and the health insurance and managed care plans in the state.

Workforce and Professional Practice

The genetic counselor workforce is estimated to be about 1,800. The most readily available data on the distribution comes from the NSGC which reported 1,819 members with 1,436 being full members (MS or MA degree in genetic counseling) and 1,119 members board certified in genetic counseling.[4] The remaining members are students and professionals with other training and degrees. The geographic distribution of full members of the NSGC is seen in Figure 1 and Table 1.

Figure 1. Genetic Counselors (members of the NSGC) by State, February 2000



The states with the largest numbers of counselors are California (244), New York (140), Pennsylvania (72), Illinois (60), New Jersey and Massachusetts (54 each), Texas and North Carolina (48 each), Maryland (46), and Michigan (44). Currently, all states but two (North Dakota and South Dakota) have at least one counselor. The following states have three or fewer counselors (Arkansas, Idaho, Louisiana, Mississippi, Montana, West Virginia, Wyoming).

Table 1. Genetic Counselors (NSGC members) by State, 2000

State	Number	State	Number	State	Number
AK	2	LA	3	OH	43
AL	4	MA	54	OK	4
AR	6	MD	46	OR	21
AZ	13	ME	8	PA	72
CA	244	MI	44	RI	10
CO	33	MN	25	SC	21
CT	15	MO	19	SD	0
DE	4	MS	2	TN	14
FL	38	MT	3	TX	48
GA	23	NC	48	UT	15
HI	5	ND	0	VA	43
IA	5	NE	7	VT	5
ID	1	NH	6	WA	39
IL	60	NJ	54	WI	38
IN	19	NM	11	WV	1
KS	4	NV	5	WY	1
KY	8	NY	140	Wash DC	15

Source of data National Society of Genetic Counselors, February 2000.

The most complete information on the demographic composition, training, work setting, and professional activities of genetic counselors is provided by the biennial survey of members of the National Society of Genetic Counselors. The most recent survey was conducted in May 1998 and includes responses from 816 of the 1,208 full members of the society (68% response rate) (Appendix 2 provides the complete survey findings). The survey asked 64 questions with many questions that are similar to those asked in prior years allowing comparisons over time. Response rates for various years of the survey are noted on Table 2, and they are between 66 and 70%.

In the1998 survey, the demographic composition of the respondents was 96% women; 93% of respondents were Caucasian, 4% Asian, and 1 % each Hispanic, African American and other. One third of respondents were 21 to 30 years of age, 40% were between 31 and 40 years and the remainder were 41 years or older. Most respondents (91%) had a master's degree in human genetics or genetic counseling, with the reminder having degrees in nursing, social work, public health and law.

Most respondents were employed in a university medical center (47%) or a hospital (24%), followed by an HMO (7%), diagnostic lab (6%), physicians' practice (5%), government office (3%), or other setting (7%). Table 2 reports on work setting from 1986 through 1998. Since 1986 there has been a decline in the percent of respondents

working in university medical centers (from 53% to 47%) and government offices (from 10% to 3%); an increase was reported for hospitals (from 16% to 24%).

Table 2. Work Settings and Specialty Areas, Professional Status Surveys

	1986	1992	1994	1996	1998
Primary Work Settings					
University Medical Center	53%	51%	47%	45%	47%
Hospital/Medical Facility	16%	28%	25%	27%	24%
HMO	5%	6%	7%	5%	7%
Diagnostic Laboratory		5%	5%	5%	6%
Fed/State/Co Office	10%	4%	4%	4%	3%
Physician Offices			3%	3%	5%
Outreach/satellite/filed clinic		1%	2%	2%	1%
Self-employed/private practice		4%	2%	2%	1%
Other	16%	3%	6%	6%	6%
Total	100%	102%	101%	99%	100%
Specialty Area of Counselors					
Prenatal		47%	77%	52%	70%
Pediatric		13%	51%	18%	45%
Prenatal and Pediatric		25%			
Prenatal screening (triple screen)		2%	44%	1%	26%
Teratogen			40%	1%	
Public Health/Newborn Screening		2%		2%	6%
Adult		1%	30%	1%	31%
Specialty Disease Counseling			26%		20%
Cancer genetics			10%	8%	34%
Molecular/Cyto/Biochemical Testing		2%	23%	2%	12%
Neurogenetics			6%	1%	8%
Other		5%	50%	12%	16%
Total		97%	357%	98%	268%
Respondents - response rate	141 - NA	537 - 70%	605- 67%	684 - 66%	816- 68%

Source: National Society of Genetic Counselors, Professional Status Survey: 1986, 1992, 1994, 1996, 1998

Table 2 also reports on the specialty area, however due to changes in the responses allowed by surveys, from a single responses (1992 and 1996) to all applicable responses (1994 and 1998), it is difficult to compare time trends across all years. Comparisons from 1992 to 1996 (years allowing a single response) can be compared. Historically, the largest specialty areas have been prenatal followed by pediatrics; the recent

survey shows more diversity, with a large increases in cancer genetics. In the1998 survey, 73% of respondents reported more than one specialty, thus the specialty responses are difficult to compare. However, 70% of respondents reported their specialty area as prenatal, followed by pediatrics (45%), cancer genetics (34%), adult (31%), maternal screening (26%), teratogens (25%), specialty disease counseling (20%), molecular/cyto/biochemical testing (12%).

In 1998, most respondents (92%) report that their responsibilities include clinical patient counseling, with a mean of 351 patients counseled in a year. Salaries for respondents varied by years of experience, work setting, job category, and region of the country. The overall mean salary was $43,700, with a mean for new graduates (less than five years experience) at $38,100, and a mean for those with 10 to 15 years experience at $50,400. Only five percent of respondents reported a salary of great than $60,000.

Satisfaction with their professional activities was rated as very high by greater than 90% of respondents for the patient contact, scientific content, learning opportunities, and personal growth. However, only about one third of respondents reported being satisfied with their opportunity for professional advancement and their earnings potential. In each of the survey years, about 12% of respondents reported considering leaving the profession.

The survey directors and program directors have noted the lack of racial, ethnic, and gender diversity among genetic counselors.[9] The IOM report noted the value of recruiting more individuals from minority and ethnically diverse populations to enhance the provision of culturally sensitive counseling and information (p. 228-230).[1] Ways to address this issue including enhanced recruitment efforts and stipends for students in training programs have been discussed.

Job Market and Factors Influencing Demand

Based on discussions with program directors and information on the 1998 survey of NSCG it would appear that graduates generally find jobs shortly before or within two or three months of graduation. Thus the market appears to be absorbing the increasing numbers of recent graduates each year. Many program directors described the experience

of their graduates in the 1980s of "creating their own jobs", that is working with a clinical team and starting a new service. As knowledge about the profession expanded and practitioners filled positions in a growing number of practice sites, the geographic distribution of practitioners has grown and the number of groups seeking to hire counselors has increased. The NSCG has tracked information on new job openings through the advertisements for positions listed in their Job Connections Service. The yearly total of new jobs listed showed some decline in the early 1990s (74 in 1991 and 1992, 67 in 1993 and 1994, 50 in 1995), followed by a steady increase each year (66 in 1996, 107 in 1997, 121 in 1998, and 137 in 1999). [8]

Scientific advances, notably the Human Genome Project and other research on specific disorders and common diseases and conditions (e.g. Huntington disease, Alzheimer's disease, breast cancer) are expected increase the demand for public and professional information on medical genetics, and expanded use of testing and counseling services. One area that has seen recent growth is cancer genetics. Training program directors reported that there were very few clinical placements for cancer clinics prior to the mid 1990s. Now cancer centers make up a significant portion of training sites and the 1998 survey found that 34% of practicing counselors report cancer genetics as one of their specialty areas. While genetic counselors have historically been employed in prenatal and children's (pediatrics) care areas, emerging growth areas as noted by program directors appear to be cancer centers, clinics or settings offering genetic services for adult onset conditions, and commercial laboratories, with modest growth in clinical research programs.

The rapid growth of new knowledge within the field of genetics requires that current counselors be actively engaged in continuing education. The IOM report recognized the importance of continuing education (p. 229).[1] The IOM also noted that counselors could play a lead role in programs to educate the public and other health professionals about the emerging areas of human genetics. Annual surveys of counselors confirm this with counselors reporting a variety of activities to disseminate information including professional presentations, developing conferences, and preparing curricula. In the 1998 survey, 80% of respondents reported speaking to lay groups, 40% had been interviewed by the media, and 31% had served on a state or local committee or advisory board.

A critical issue for the employment opportunities is the limited ability to bill for genetic counseling services. The costs of genetic testing and counseling services can extend beyond the ability of many individuals and families to pay out-of-pocket for these services. Thus payment or coverage of the services by insurers or managed care plans is an important issue that was discussed in depth by the IOM report and remains a significant problem.

Most counselors work in teams, often under the supervision of physicians, although they are considered capable of providing services independently. There are no CPT codes (a nomenclature and coding system used to identify the medical service for billing purposes) specific to the services provided by genetic counselor. If services are billed to a third party, such as an insurance company, a common practice is to bill under the name of the physician supervising the clinical site and staff. However, the policy of billing under a physicians name has been scrutinized by Medicare under other situations (attending physicians billing for services provided by medical and surgical resident physicians) and several medical schools and academic medical centers have been fined heavily by Medicare for fraud and abuse of the billing/supervisory rules. This is causing reassessment of the appropriateness and risk of this billing practice.

The profession has worked to identify CPT codes and to seek approval for these. The ACMG has supported development of CPT codes specific for genetic counseling services and made known their position to the CPT Advisory Committee of the American Medical Association, the group that publishes the CPT codes.[10] Having a code that identifies services would provide a step toward reimbursement, however insurance plans may only recognize certain clinicians for payment. Historically, it has been difficult for non-physicians to qualify.

Reimbursement has been affected by the shift of genetic testing from academic medical centers to commercial labs. In the past, some academic genetics services could include the costs of personnel, such as counselors, in the test lab fees to help obtain third party payment for services. However, the loss of the laboratory services has reduced this opportunity.

Many program directors noted the difficult financial times for academic medical centers and teaching hospitals have increased pressure on their clinicians to generate

clinical revenue. Yet, a commonly reported problem related to generating revenue was the time spent by practicing counselors trying to obtain approval from insurers or managed care plans for the genetic services needed by patients. These parties had limited knowledge or awareness of genetic services. Often counselors could succeed in obtaining coverage commitments, but only after substantial expenditures of their time. Several program directors report their frustration as clinicians in feeling that they have to "justify their existence" and the value of their services to insurers and managed care plans, and at times to their home institution.

The most enlightened approach of a managed care plan has been reported by the Kaiser-Permanent plan of northern California.[11] This plan hires more genetic counselors than any other employer in California (35 genetic counselors) and they offer a full range of medical genetic services. Counselors have not described this approach as they have held discussions about coverage with managed care plans in other parts of the country.

Throughout the interviews and in reading of reports and peer reviewed articles, one notes the lack of any consistent call to increase the number of genetic counselors – despite statements about a shortage of genetic specialists. Many articles start with a comment such as "due to the scarcity of genetic counselors" or "the number of counselors is insufficient to meet demand and the shortage is likely to continue". Often these studies or reports begin with a stance that it is impossible to train enough genetic specialists to meet the expected growing needs for services and take an "either-or" approach, saying that the focus should be on training primary care practitioners to provide services, rather than calling for any expanding training of genetic specialists.

Yet, most interviewed program directors take a position that appears at first to be paradoxical in not calling for substantial expansion in training. This cautionary stance may reflect concerns about training professionals who may not enjoy full employment unless the reimbursement system changes. It may reflect uncertainty about the pace and nature of basic genetic research and its translation to clinical practice. Concerns about health care cost containment and managed care efforts to raise expectations that primary care physicians and existing medical specialists should be able to offer these new services. It was beyond the scope of this study to further assess this position or to conduct a systematic assessment of key stakeholders for their view on the future demand or re-

quirements for genetic counselors. The need for this important assessment is discussed below.

Other Professions Offering Genetic Counseling

Master's trained genetic counselors represent the sole profession specifically trained and dedicated to provide genetic counseling services. However, several other professions have a significant stake in providing counseling for genetic related conditions and issues – physicians (obstetricians, pediatricians, internists, family practitioners, neurologists, oncologists, and geneticists), nurses (genetic specialists, other clinical nurse specialists, nurse practitioners), and medical social workers. There are also non-physician geneticists and other counselors such as psychologists who provide services in some settings. Genetic counselors often work with each of these professions through clinical teams offering genetic services and through referrals to counselors (medical social workers or psychologists) for patients or families members in need of more continued counseling.

The relative size of the genetic specialist workforce can be obtained the estimates from 1996 when the workforce included only about 2,500 individuals:

> Fewer than 1,000 physicians in the United States today are trained to provide genetic information to their patients. Only 200 nurses identify themselves as providers of genetic information, and there are currently fewer than 1,000 genetic counselors.[12]

Many studies have assessed the knowledge and skills of primary care physicians to provide counseling; these studies usually find a need for improved genetics education and training. In addition to the significant educational challenge of outreach to primary care providers, obstacles to greater use of physicians' serving as the key provider of genetic counseling services have been identified.[2] These may include the ongoing need for current knowledge in a rapidly evolving field, a tendency toward directive counseling, lack of awareness of referrals for further counseling services, and the difficulty busy practitioners may have in fitting the time needed for counseling into their practices.

The importance of integrating new genetic advances into primary care practice has been the subject of conferences and has fostered new curriculum development for educators, students, trainees, and practicing clinicians and professional education programs in medical schools, nursing schools, and graduate medical education programs.[12]

The nursing profession has advocated for expanded genetics training in core nursing curricula. The International Society of Nurses in Genetics (ISONG) is one of the nursing specialty associations with a focus on clinical genetics. This group was established in 1989 to promote professional and scientific advances of nurses in human genetics and has a strong commitment to increase practice-based nurse education in genetics. The society sponsors programs that offer advanced training in human genetics for nurses.[13]

Issues Facing the Profession

The question that prompted this study was whether there should be expansion of training programs to increase the supply of genetic counselors. It is not clear that this question can be answered at this time. As described above, training program directors express an interest in support of existing programs. However expansion of the number of graduates, either by expansion of existing programs or starting new programs met with mixed views from program directors and other key informants. Many program directors felt that expansion should follow only after steps to assure that new graduates could be employed. This may require developing mechanisms for health insurers to pay for the services of genetic counselors or other arrangements from the major current employers (medical centers and hospitals) or greater employment opportunities by others, such as testing laboratories, clinical research programs, staff model managed care plans, and government agencies, these re groups that do not have to deal with private insurance issues.

Another interviewee's perspective was that incremental growth in training programs should continue. Start-up funding would be necessary to allow academic medical centers without programs to develop new training programs and this would expand access to genetic counselors. There may be a greater need now, than twenty years ago, to inform the public, healthcare providers, and payers, of the services that are offered by ge-

netic counselors. Ideally, training program growth should be a step ahead of the market for genetic testing expansion.

Several interviewees recommended more attention from the profession to ongoing assessment of students training needs and the evolving roles for counselors. The content and nature of counseling changes dramatically when one moves from the prenatal and pediatrics areas, where the majority of counselors have been trained and employed, to counseling for adult onset conditions and complex genetic conditions.

Counselors recognize the need to train all primary care providers about medical genetics. Yet the profession strongly believes there is a role for a specialized provider of information and counseling, in part due to the nature of their field with the large number and diversity of conditions, the complexity of genetic and other risk mechanisms, special counseling considerations, and the rapidly evolving knowledge in human genetics.

Several of the program directors and respondents to the professional survey noted the lack of professional upward mobility and salary growth for clinincans. One interviewer felt more information should be obtained on those who leave practice and those who have considered leaving practice. Several directors commented that new graduates have had to take jobs where they open – often away from the urban areas where counselors trained.

Conclusion/Recommendations

The following conclusions are drawn from this study.

1. *Current genetic counselor training programs should be maintained. The job market and rate of new clinical applications of genetic testing should be monitored.*

   The strong applicant pool, the quality of current training programs, the growing job market, and the expressed sense of a shortage of genetic counselors, all suggest that the existing training programs and numbers of trainees should be maintained. In general, significant expansions in genetic testing would be expected to increase the demand for services by genetic counselors. It would be very useful to monitor the demand for genetic testing, counselor positions, and output from training programs. If training program expansion were considered, external funding may be necessary to assist existing programs with expansion and to start new programs.

2. *Efforts should be increased to inform health insurers, managed care plans, and health care systems about the pace of advances in human genetics and the translation of this new knowledge into clinical applications.*

   The potential impact of genetics discoveries on clinical practice and the consequent demand for general and disease specific information, genetic testing, and risk assessment and reduction, may be underestimated by the groups involved with organizing and paying for health care services. Counselors report limited awareness by many insurers that they contact on behalf of patients. Educational programs aimed at this audience should be supported. Companies or plans with clinical experience, such as Kaiser-Permanent, could be asked to share their experience.

3. *Training programs for primary care providers on human genetics and counseling and testing should continue to be supported.*

   Training primary care providers is essential and research in this area has been helpful in identifying training and practice-related issues. Those involved with funding and organizing these programs should recognize that training efforts for

practicing primary care providers would require substantial long term commitment. The efforts involved with training primary care providers on counseling, testing and management of HIV/AIDS throughout the 1990s may be a useful model. This training required long-term efforts (greater than ten years) of public health departments and agencies, hospitals, academic medical centers, professional associations, federally funded education and training centers (e.g. HRSA funded Education and Training Centers, ECTs), advocacy groups, educational institutions, and service providers. The initial lack of interest by primary care providers to genetics training should not discourage efforts to support broad education and training program development.

4. *A comprehensive study is required to 1) assess the current status of the genetic specialist workforce and the role of primary care providers in genetic services; and 2) estimate the impact of current research on the demand for genetic testing and other services.*

   It is very difficult to draw any conclusions on the need for expansion of the genetic counselor workforce when this relatively small professional group is studied in isolation. The general expectation is that the Human Genome Project and other active research will have a major impact on clinical practice in many arenas, and that it will come on a short time horizon, thus having an impact on genetic specialists and current medical and health practitioners (as well as students and trainees). Thus it is critical that a comprehensive study be undertaken and that its findings be reviewed and discussed. Ideally one would take into account key stakeholders that may influence the demand for services including genetic specialists, relevant physician specialties, nurses, advocacy and genetic support groups, health care systems and managed care plans, health insurers, and public health agencies. While it may be difficult to estimate the future impact of research, some parameters and estimates under various scenarios should be obtainable.

5. *Evaluation studies, using a health services research approach, should be encouraged to better understand and plan for the utilization, costs, and outcomes of genetic services.*

Since the use of genetic services is expected to grow, it is an ideal time to plan and implement studies using various approaches to assess the organization, costs and outcomes of services. This information should be useful to practitioners and to those asked to pay for services. With their training in research methods, genetic counselors would be ideal research team members.

6. *Expanded opportunities for genetic counselors to participate in clinical and outcomes research studies should be supported.*

Genetic counselors should be considered a resource for genetics related clinical research programs. Their research training and clinical experience makes this profession a valued resource for a wide range of genetics related outcome research; efforts to involve counselors in research should be expanded.

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University of California, Berkeley, CA	Jon Weil, PhD
Northwestern University, Chicago, IL	Kelly Ormand, MS
University of Maryland, Baltimore , MD	Lisa Steinberg, MS
Sarah Lawrence College, Bronxville, NY	Caroline Leiber, MS
University of Pittsburgh, Pittsburgh, PA	Robin Grubs, MS
Johns Hopkins Univ/Nat Human Genome Research Inst, Bethesda MD	Barbara Biesecker, MS*
University of California, Irvine CA	Ann Walker, MS*

* Former president of the NSGC.

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Appendices

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