Chapter 2
Providers, Clientele, and Genetic Services

The purpose of the OTA survey was to evaluate the extent to which genetic counselors and nurses in genetics are routinely offering carrier screening for cystic fibrosis CF to their clientele, to assess their attitudes and beliefs about the appropriateness of such screening, and to obtain a sense of the environment in which they work. While members of the National Society of Genetic Counselors (NSGC) and the International Society of Nurses in Genetics (ISONG) are by no means the only health professionals providing genetic counseling, they comprise a professional segment devoted explicitly to that end. Physicians, social workers, public health workers, and research scientists also provide genetic services. Those groups were not included in this survey.

To better understand the setting in which routine carrier screening for CF might take place, OTA gathered data regarding not only counselors' attitudes and practices regarding CF carrier screening (ch. 3), but also the settings in which they work, the numbers and types of clients they serve, clinical practices, work routines, fees charged, and third-party payment options available to their clientele. Understanding the environment in which CF carrier screening takes place was a critical part of the analysis reported in *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening (10).*

THE SURVEY POPULATION

Of the **703** members of the NSGC who received questionnaires, 351-or 50 percent—responded. Of the 110 members of ISONG who received the questionnaire, 80-or 73 percent—responded. Thus, 80 percent of the respondent group are members of NSGC and 20 percent are members of ISONG.[1]

As preliminary analysis revealed no significant difference in question response between the two populations, all data were combined for the final analysis. The combined response rate is 53 percent.

Genetic Counselors

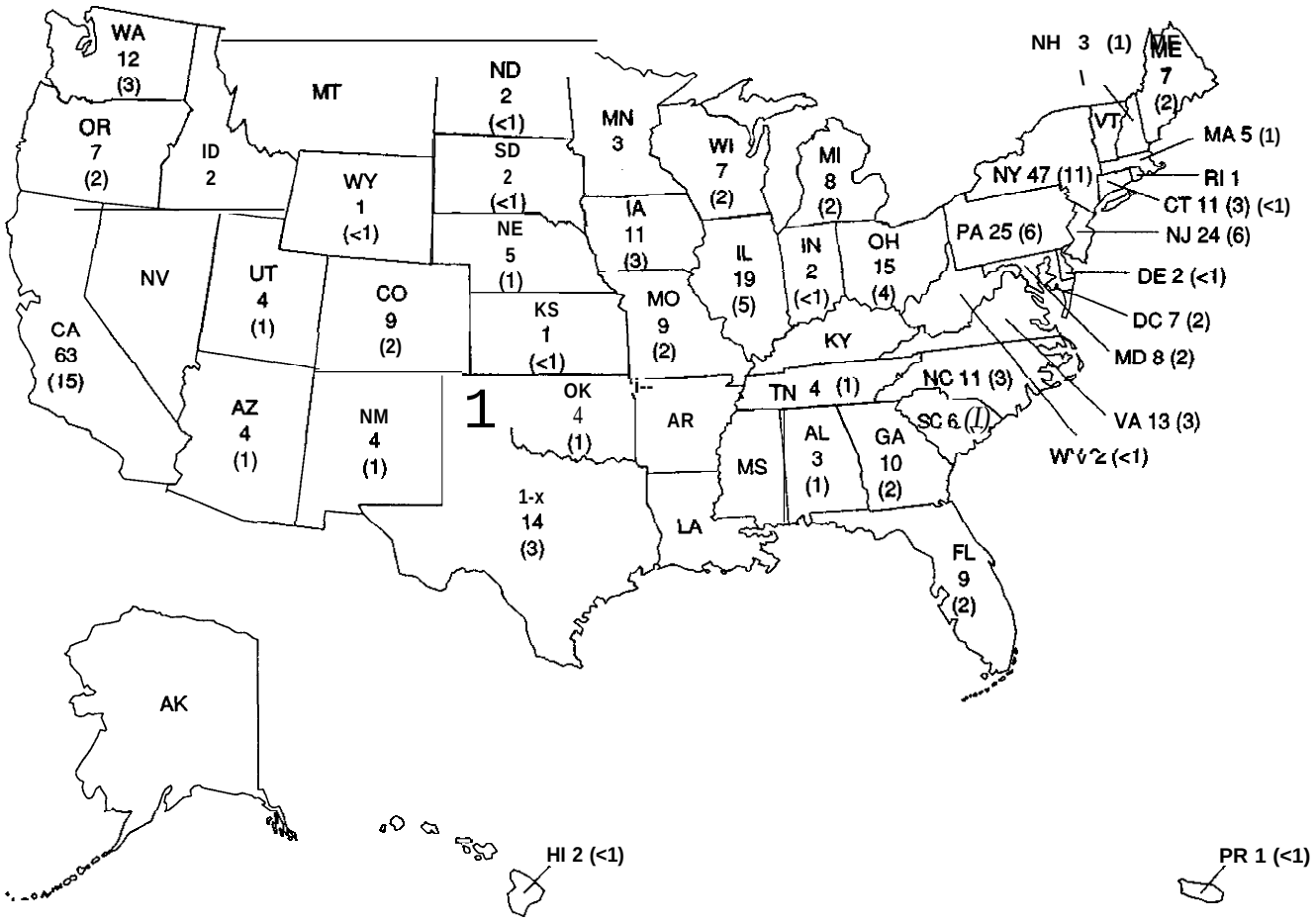
The master' s-level genetic counselor is a relatively new addition to the health care system. In 1971, 10 graduates of the first such program entered the workforce; in 1979, the NSGC was incorporated as a professional organization. Today, there are approximately 1,000 master' s-level genetic counselors practicing in the United States.

Master' s-level genetic counselors receive specialized multidisciplinary training and experience to prepare them for counseling related to a wide variety of genetic disorders and birth defects. They are typically graduates from a 2-year master's degree program, during which time they receive didactic course work in the principles and application of human genetics, clinical and medical genetics, genetic laboratory methods, and interviewing and counseling. Genetic counselors are also trained in social, ethical, legal, and cultural issues relating to genetic diseases, principles of public health and health care delivery systems, and education for the lay and professional community (12). Over the past 20 years, master' s-level graduate programs in genetic counseling have increased to 15, and combined, they produce approximately 75 graduates each year (7). At the time of the OTA survey, there were 703 genetic counselors who were full members of NSGC (associate, student, and foreign members were not surveyed). Of all respondents to the survey, 70 percent had a master's degree in genetic counseling. An additional 10 percent held a master's degree in another area, and 8 percent had a Ph.D.

Genetic counselors receive a minimum of 400 hours of supervised clinical trainingin at least three clinical settings, including a general genetics clinic, a prenatal diagnosis clinic, and a speciality disease clinic. Until 1992, graduates were eligible to sit for the certification examination in genetic counseling by the American Board of Medical Genetics (ABMG), but continuing certification of these individuals by this body is uncertain. In the past, counselors were required to submit their credentials and a logbook of 50 cases obtained in a clinically accredited training

[1] These response rates are typical of other mail surveys reported in the literature (1,6). One review found response rates for a two wave survey (initial mailing and one followup) ranged from 37 to 58.4 percent (6). OTA's aggregate response rate clearly falls within this range, as does the response rate of the genetic counselors; the response rate of the nurses in genetics exceeds it.

Figure 2-I-Geographic Distribution of Survey Respondents[a]



[a]Actual number of respondents from a State is listed, with the percentage the number represents in parentheses.
SOURCE: Office of Technology Assessment, 1992.

site before taking the exam (7). Most survey respondents survey were board certified (65 percent) or board eligible (19 percent).

Nurses in Genetics

There are nearly 2 million registered professional nurses in the United States, many involved in maternal and child health nursing. These professionals provide a unique potential to contribute to the effective delivery of genetic services. Efforts are under way to encourage the incorporation of clinical genetics into the curricula of schools of nursing at both the graduate and undergraduate level (4). The need for better genetics education in nursing stems from the recognition that genetics generally has been within the realm of tertiary care; thus, genetics specialists are not always in the position to screen every individual needing genetics referral (4). That is, individuals in need of genetic services must first be identified by the primary health care professiona1, and in some settings-such as community, occupational, or school health-nurses are the only link with the health care system (3). Thus, nurses can assist in the identification, education and counseling, and followup of patients (2,4). Though nurses can be a valuable part of genetics services, to date they are a largely untapped resource (3).

Opportunities for clinical genetics experience in nursing programs vary. Genetics is generally a part of the nursing school curriculum, but variability exists among programs (3). Four of the 200 universities in the United States that offer graduate degrees

in nursing have established programs providing a master 's-level genetics major (3). A small number of nurses, particularly those in maternal and child health nursing, have focused on genetics in order to sit for the genetic counseling examination given by the American Board of Medical Genetics (ABMG) (3,5). There are over 100 nurses employed in genetics who also belong to ISONG and therefore received OTA's questionnaire. It is likely that many more nurses deliver genetic services but are unidentifiable through current databases. Of the total survey respondents, 12 percent reported having either an R.N. or B.S.N. degree. Nurses might also have a master's degree or Ph.D. and could be included in the 80 percent of respondents who reported having a master's degree or the 8 percent who reported having a Ph.D.

Demographic Profile of Survey Respondents

The typical individual working as a genetic counselor or nurse in genetics is likely to be female (92 percent), in her mid-30s (mean age of 37), Caucasian (96 percent; 2 percent are Hispanic, 1 percent African American, 1 percent Asian American), and married (70 percent). On average, she is likely to have been in practice for 6 to 7 years, having received her degree in 1985. Eight-seven percent of these individuals speak only English; 5 percent also speak Spanish, and 8 percent speak English and a language other than Spanish.

Respondents represented every State except Arkansas, Louisiana, Kentucky, Mississippi, Montana, and Nevada (figure 2-1). There is a heavy concentration of counselors in five States, with 43 percent of respondents located in California, Illinois, New Jersey, New York, and Pennsylvania, and 23 percent located in three northeastern States, New Jersey, New York, and Pennsylvania (table 2-l). California had the highest representation at 15 percent. These data are consistent with those collected and biannually reported by the NSGC (8). Hence, OTA's survey respondent pool is representative of the NSGC membership and no sample weighting was necessary.

WORK ENVIRONMENTS

The majority of respondents (83 percent) are currently engaged in providing genetic counseling. Seventeen percent work in an environment where they are not encountering direct patient contact, perhaps serving as administrators, educators, or researchers. The primary work settings for all respondents are presented in table 2-2. Most counselors and nurses are employed in a university medical center (36 percent) or a private hospital or medical facility (36 percent). The remainder work in a variety of settings, such as public health departments, health maintenance organizations, colleges or universities, private group practices, free standing clinics, or commercial laboratories. Again, these data are consistent with the data collected by NSGC on a biennial basis for its professional status survey (8).

Table 2-l-Geographic Concentration of Survey Respondents

State	Number (percent)
California	63(1 5)
New York	47(1 1)
Pennsylvania	25(6)
New Jersey	24(6)
Illinois	19(5)
Total	178 (43)

SOURCE: Office of Technology Assessment, 1992.

Table 2-2—Primary Work Setting

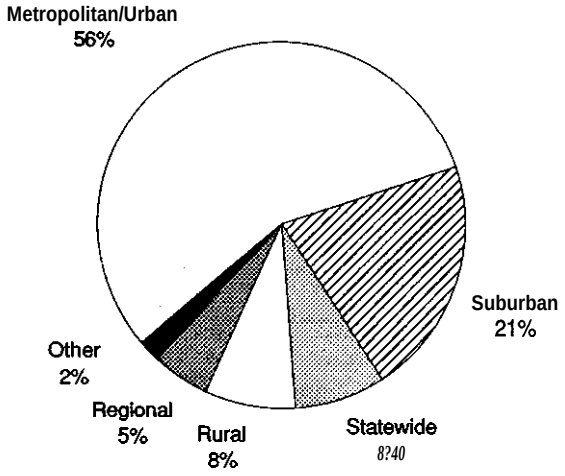
	Number (percent)
University medical center	151 (36)
Private hospital or medical facility	150(36)
Public health department	22(5)
Health maintenance organization	15(4)
College or university	14(3)
Private group practice	11 (3)
Free-standing clinic	10(2)
Commercial laboratory	9 (2)
Other	31 (7)

SOURCE: Office of Technology Assessment, 1992.

Centers of expertise in clinical genetics tend to be located at large urban medical centers, often with a teaching mission. The work location and setting of the survey population reflect that tendency. Respondents are most likely to work in a metropolitan or urban setting (58 percent) (figure 2-2). Counselors and nurses in genetics are less likely to be found working in rural settings. Counselors tend to work with M.D. geneticists, Ph.D. geneticists, other genetic counselors, and a variety of support staff. Most rural centers are unable to support this level of professional personnel and often rely on regional service areas. Five percent of respondents reported working in a regional genetics area.

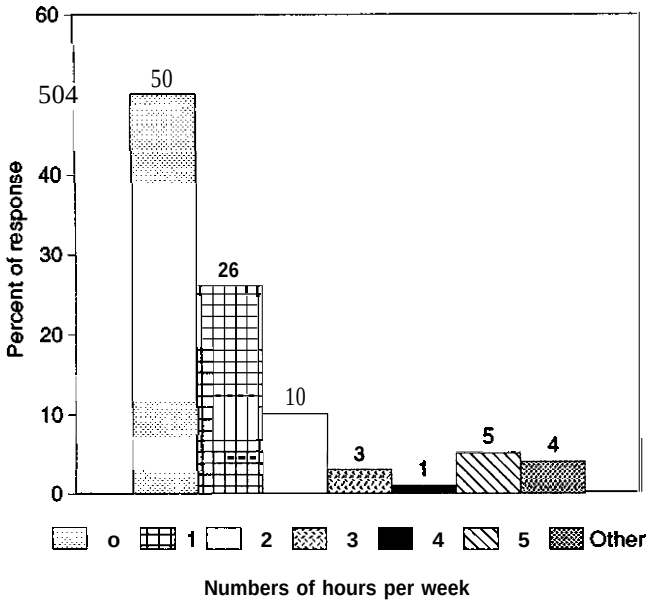
Respondents spend nearly two-thirds (65 percent) of their work week—about 26 hours per week-on patient activities, whether direct patient contact

Figure 2-2—Primary Service Areas of Respondents



SOURCE: Office of Technology Assessment, 1992.

Figure 2-3—Average Hours Spent Per Week on Public Education



SOURCE: Office of Technology Assessment, 1992.

(e.g., intake or counseling) or indirect (e.g., written communication, scheduling, and management of referrals) (table 2-3). An additional day is spent on administrative procedures. This leaves little time for other activities such as educating other health professionals or the general public. On average, counselors and nurses in genetics spend little time on public education. Fifty percent report spending no time on this activity, while 26 percent report spending, on average, an hour a week on public education (figure 2-3). Individual counseling sessions are time and labor intensive and are the primary format for delivering genetic information (table 2-4). Respondents report that they seldom if ever rely on group counseling (67 percent) or videotape with counseling (76 percent).

On average, each genetic counselor and nurse in genetics saw 482 patients in 1990. Averages do not, however, speak to the great variability among practices. Responses ranged from 10 to 2,300 clients. Counselors and nurses providing prenatal diagnosis and followup for elevated maternal serum alpha-fetoprotein (MSAFP) screening tend to have more clients.

In routine genetic counseling, the genetics specialist elicits the reasons for testing or screening and discusses the implications of possible outcomes. The counselor prepares the individual for both positive and negative test results. A genetic counseling session is also the time to discuss risk reduction strategies, irrelevant, and the nature and severity of the disorder for which the test is being done. One task of the genetics professional is to communicate risks to the client-a job not easily performed. The more complex the information, or the more emotionally laden, the more time might be required. Survey respondents estimate that the time needed to conduct routine prenatal counseling is 1 hour. Counseling for

Table 2-3-Average Weekly Schedule of Genetic Counselor or Nurse in Genetics

Activity	Hours per week
Direct patient contact	15
indirect patient activities.	11
Administration/management	7
Educating health professionals	3
Research	2
Educating the general public.	1
Marketing/business	1

SOURCE: Office of Technology Assessment, 1992.

Table 2-4-Formats for Genetic Counseling

	Predominant response (%)
individual counseling sessions	Almost always (84)
Group counseling	Seldom if ever (67)
Videotape alone	Seldom if ever (98)
Videotape with counseling	Seldom if ever (76)
Written educational materials.	Very often (24)
Slide-tape	Seldom if ever (88)
Interactive computer.	Seldom if ever (97)

SOURCE: Office of Technology Assessment, 1992.

newly diagnosed genetic disorders in newborns, children, or adults takes more time and more visits. Carrier testing for families with a positive family history for CF was estimated to take, on average, two visits involving more than 1 hour each. Counseling for CF carrier screening, with no family history, however, was estimated to take one visit of less than an hour. The need for sufficient and appropriate pretest education and post-test counseling is discussed in depth in the full OTA report (10).

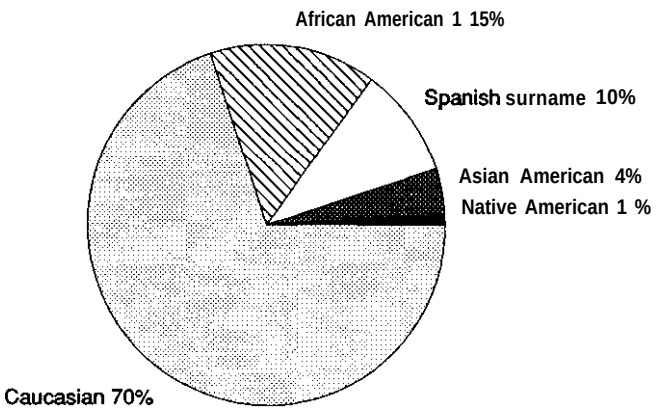
GENETICS CLIENTELE

Genetic counselors and nurses in genetics work in a variety of settings and often the setting in which they work dictates the types of clients they encounter. For example, working in a department of obstetrics and gynecology is likely to mean that the majority of one's clients are pregnant or undergoing family planning prior to pregnancy. Employment in a department of pediatrics or a children's hospital means that most clients are likely to be children and their families. Some counselors work in specialty clinics, such as cranio-facial clinics or sickle cell screening centers. Thus, their clientele are more likely to be adult or African American, respectively. The OTA survey results are reported in the aggregate and fail to illustrate that some practitioners work in specialized settings, often with one type of clientele.

The majority of individuals seen by genetic counselors and nurses in genetics are Caucasian (70 percent) (figure 2-4). Respondents report an ethnic and racial breakdown that is reflective of national population averages. For example, approximately 15 percent of genetics clientele are reported as African American; this minority group represents 12 percent of the U.S. population. These data do not provide information, however, about equitable allocation of genetic services locally or regionally. African Americans or Asian Americans might find genetic services accessible in one city or one region but not in another. Genetics services in cities with large minority populations might be more likely to hire health care providers with language or cultural skills suitable to certain populations.

Ninety-two percent of genetics clientele are English speaking. As mentioned earlier, 13 percent of genetic counselors and nurses reported fluency in a language other than English, but no effort was made by OTA to correlate provider fluency with clientele needs.

Figure 2-4—Racial/Ethnic Background of Clinical Genetics Clientele

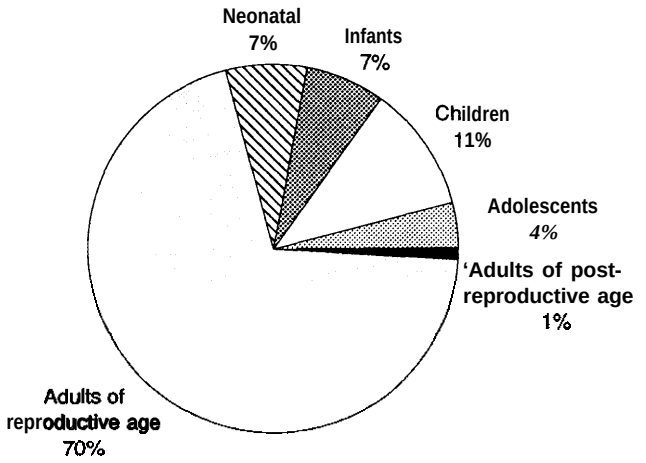


SOURCE: Office of Technology Assessment, 1992,

A variety of age groups are seen, but adults of reproductive age comprise 70 percent of the average clinic clientele. The second largest group of individuals seen are children (11 percent). Infants and neonates collectively comprise 14 percent of genetics clientele (figure 2-5).

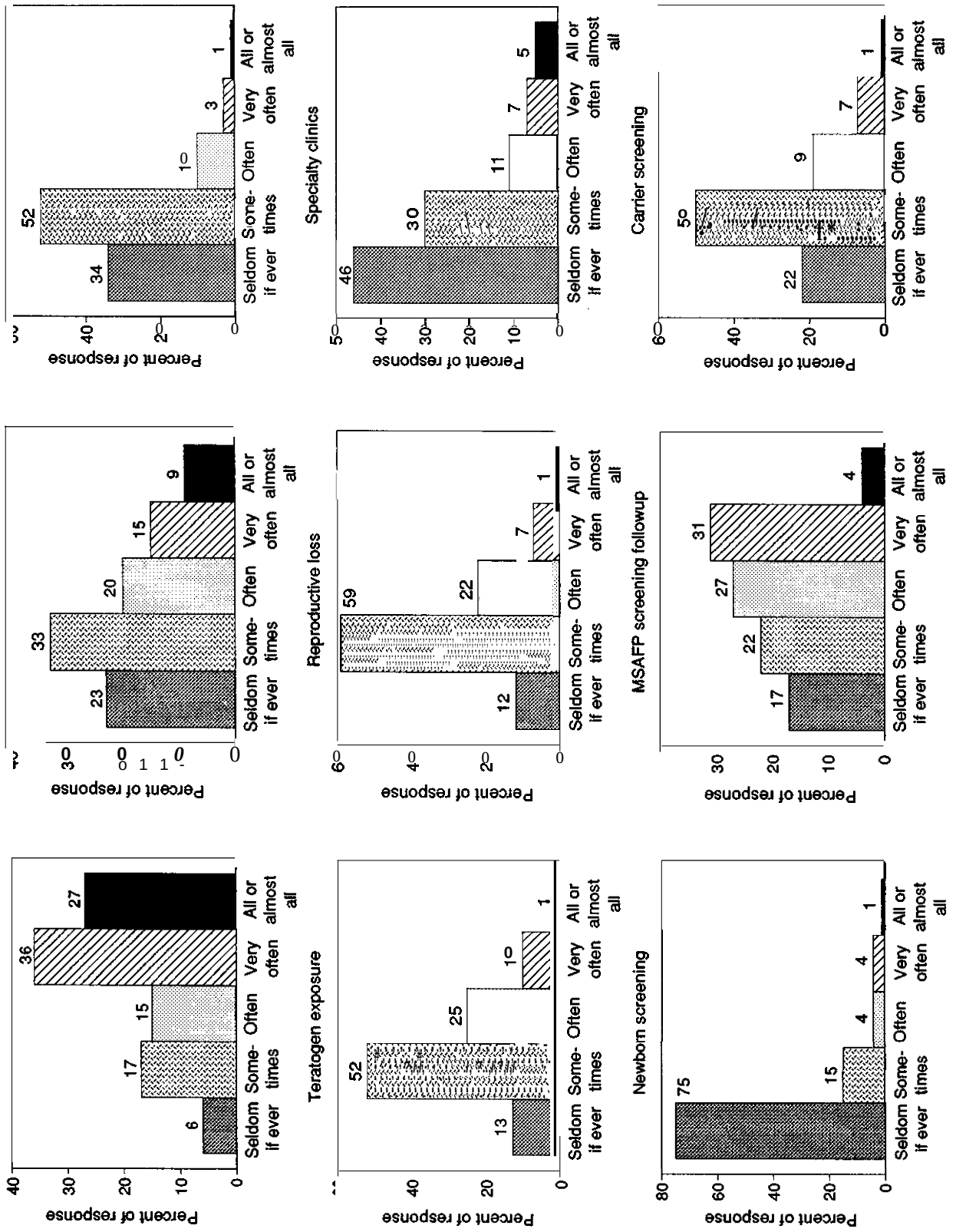
Most of the adults of reproductive age are seen for prenatal diagnosis (figure 2-6), most likely for advanced maternal age. Prenatal genetics patients were reported as being seen very often or almost always by nearly two-thirds of respondents (figure 2-6). Clearly, prenatal diagnosis is a primary reason for individuals to have contact with the clinical genetics setting. Respondents also reported that

Figure 2-5—Age Distribution of Genetics Clientele



SOURCE: Office of Technology Assessment, 1992.

Figure 2-6—Frequency of Patients Seen by Major Areas of Clinical Practice



SOURCE: Office of Technology Assessment, 1992.

pregnant women receiving followup counseling for abnormal MSAFP results often (27 percent) or very often (31 percent) are apart of their clientele (figure 2-6). Individuals seeking carrier screening for a variety of genetic disorders, such as those described in table 2-5, seldom (22 percent) or sometimes (50 percent) comprise the clientele in genetics clinics (figure 2-6). Cystic fibrosis was reported most frequently as the disease for which carrier screening or testing is offered (table 2-5), and a majority of respondents (62 percent) report they have seen more than 100 clients for CF-related reasons in 1990 (figure 2-7).

FEES AND THIRD-PARTY COVERAGE

How expensive are genetic services and will insurers pay for them? How do third-party payers decide what is medically indicated and, therefore, should be covered? Many of these issues are addressed in the full OTA report (10) as well as the Background Paper, *Genetic Tests and Health Insurance-Results of a Survey* (11). In this survey of genetic counselors and nurses, OTA obtained information about the fees charged by providers for a variety of genetic services, including those related to CF and their experiences with third-party coverage. Costs of services and the availability of third-party coverage will be crucial to the rate and magnitude at which services will be used. This is particularly relevant to the debate about CF carrier screening as the procedure is relatively new, is counter to most insurers' policies against paying for screening, and could involve potentially large numbers of people.

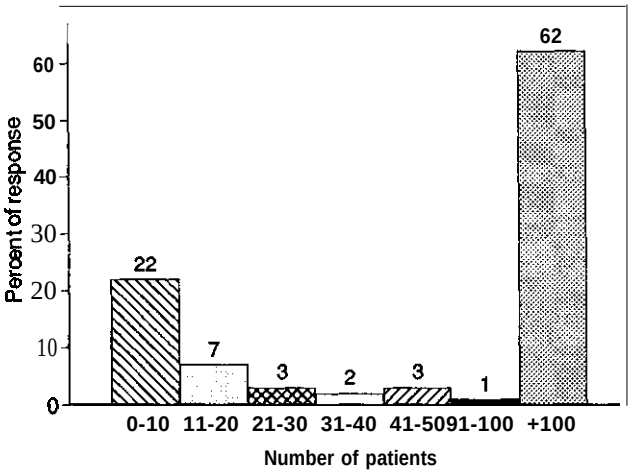
For many years, genetic counselors have faced the problem that few third-party insurers will reimburse for counseling services unless performed by a physician. The costs of counseling are reimbursed as general medical consultation fees or absorbed as part of costs on research grants (9).

Table 2-5-Most Common Diseases for Which Carrier Screening/Testing Is Offered

(Ranked by frequency of response)
1. Cystic fibrosis
2. Tay Sachs disease
3. Sickle cell anemia
4. Duchenne muscular dystrophy
5. Thalassemia
6. Hemophilia
7. Hemoglobinopathies
8. Fragile X syndrome

SOURCE: Office of Technology Assessment, 1992.

Figure 2-7—Number of Cystic Fibrosis Patients or Families Seen in Genetics Units in 1990



SOURCE: Office of Technology Assessment, 1992.

Fees for Genetic Services

Genetic counseling can be provided alone or in conjunction with diagnostic procedures. Most survey respondents work in large university or private medical centers where billing departments are often quite separate and distinct from the various clinical departments. Fees are coded and processed independently. This might explain why a majority of respondents did not know whether certain genetic services were reimbursable and, in some cases, did not even know the fee schedule for basic genetic services (table 2-6). For those who knew the fee schedule for genetic services, general genetic counseling averaged $80 per session. The range was $0

Table 2-6-Average Fees and Knowledge of Fees for Genetic Services

Service	Fee	Percent respondents uncertain of fee
General genetic counseling	$80	45
Genetic counseling for CF with a positive family history	$112	54
Genetic counseling for CF with a negative family history	$105	68
Routine metabolic screen	$157	70
Routine cytogenetic analysis	$425	50
DNA analysis for CF	$235	66

SOURCE: Office of Technology Assessment, 1992.

Table 2-7—Fees for General Counseling

Fee	Percent response
$0 to 50	
$51 to loo	31
$101 to 150	25
$151 to 200	2
$201 to 250	7
$251 to 300	
$301 to 350	38

SOURCE:Office of TechnologyAssessmentj 1992.

to $350 (table 2-7). The fee for genetic counseling for individuals with a family history of CF was not significantly different from the fee that would be charged to individuals requesting the same services with a negative history for CF($112 versus $105). In the summer of 1991, the average fee for DNA analysis for CF was $235 although spring 1992 data collected separately by OTA found an average cost of $170 per sample.

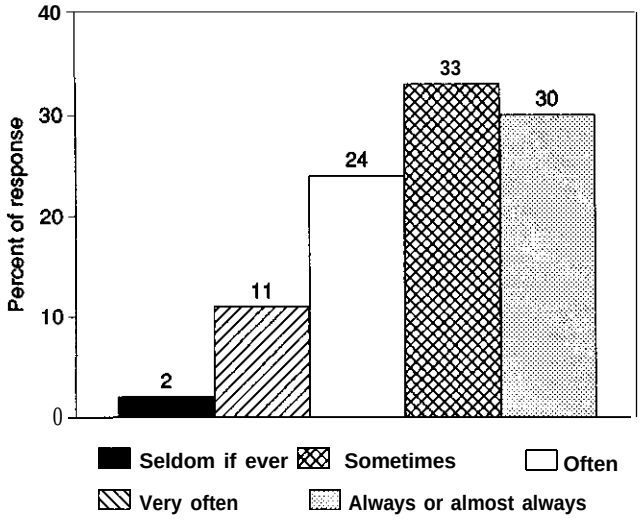
Third-Party Coverage

Respondents reported that most of their clients are covered by some type of health insurance. Two percent said that their patients seldom if ever have health care coverage, whereas 63 percent reported that their clients very often or always have coverage (figure 2-8). Commercial insurance, health maintenance organizations, or managed care programs comprise over half of the coverage (figure 2-9). Medicaid (21 percent) and Blue Cross/Blue Shield plans (17 percent) also cover genetics clients. Four percent of clients have no insurance and 3 percent are indigent.

With regard to coverage of genetic counseling services accompanying DNA-based tests to determine CF carrier status, respondents reported a higher likelihood of coverage if there is a family history of CF than if there is no family history (figure 2-10). This result was confirmed by OTA's survey of health insurers, which found health insurers rarely reimburse individuals for CF carrier tests in the absence of a family history (11).

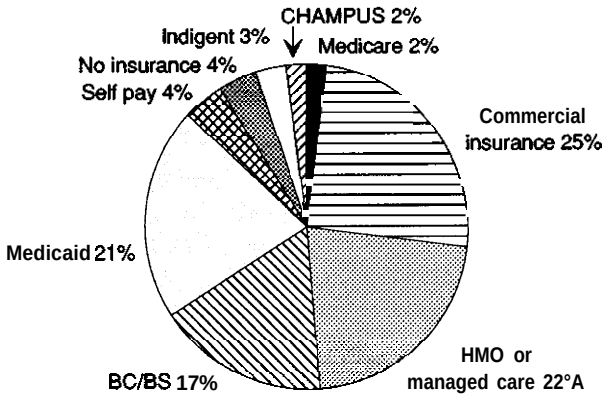
OTA attempted to ascertain whether individuals who avail themselves of genetic tests subsequently have difficulty obtaining or retaining health insurance. The survey asked for reported occurrences for genetic tests, generally, not just carrier tests for CF or other disorders.[2] OTA asked:

Figure 2-8-Health Care Coverage for Genetics Clientele



SOURCE: Office of Technology Assessment, 1992.

Figure 2-9-General Types of Health Care Coverage for Genetics Clientele



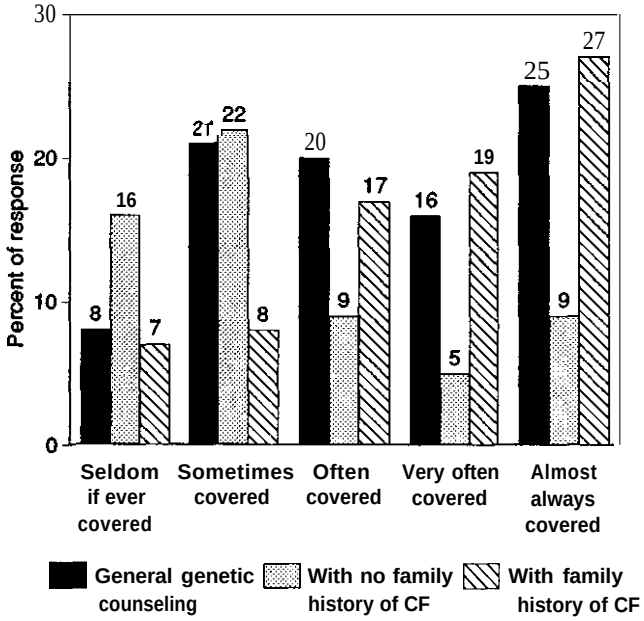
SOURCE: Office of Technology Assessment, 1992.

Have any of your patients experienced difficulties in obtaining or retaining health insurance coverage as a result of genetic testing? If yes, please provide details.

Approximately four-fifths (347) of the 431 respondents to OTA's inquiry currently perform genetic counseling. Fifty respondents (14 percent) reported they had clients who had experienced difficulties obtaining or retaining health care cover-

2 In a separate survey of health insurers, OTA asked respondents to speculate about accepting applicants with certain genetic conditions (11).

Figure 2-10-Third-Part y Reimbursement for General Genetic Counseling and Counseling Specifically for Cystic Fibrosis



SOURCE: Office of Technology Assessment, 1992.

age as a result of genetic testing (table 2-8). Because some respondents described more than one case, the number of affirmative answers understates the actual number of cases. Examination of the qualitative responses, some of which are presented in table 2-9, reveals affirmative responses represent, at minimum, 68 individual cases. (Where the term ''patients" was used with specifics not described, a single event was recorded.)

It is important to emphasize that most of the cases revealed through the OTA survey do not involve recessive disorders and carrier screening for conditions like CF And while one assumption might have been that health care coverage for CF carriers would not be an issue because the individuals have no symptoms of the disorder, OTA's survey of health insurers reveals that a few respondents would require a waiting period or deny coverage for CF carriers (10,1 1).

Test results for some conditions where positive results led to reported difficulties-such as for Huntington disease, adult polycystic kidney disease, and Marfan syndrome-were cited by more than one respondent. In addition to affirmative answers, several respondents reported that although they had no direct experience with a patient's difficulty in

Table 2-8-Difficulties in Obtaining or Retaining Health Insurance After Genetic Tests

Question: Have any of your patients experienced difficulties in obtaining or retaining health insurance coverage as a result of genetic testing?

	Number	(percent)
No	281	81
Yes	50	14
No answer	16	5

SOURCE: Office of Technology Assessment, 1992.

obtaining or retaining health care coverage, they had clients who feared their coverage would be dropped if they requested payment for tests from insurers. One respondent commented that greater than 80 percent of her clients who test for Huntington disease self-pay. Similarly, others with no direct experience said they often advise patients not to request reimbursement for a test so that an insurer would not learn that testing had occurred. One counselor offered the information that a patient had refused testing for adult polycystic kidney disease because of concern over health insurance. Another respondent reported that a patient with a CF-affected child had been dropped by one insurance company and would not consider prenatal testing in the future for fear her current insurer would not cover the child should she decide to continue the pregnancy.

The data collected through this question permit neither extrapolation about the total number of cases that have occurred in the United States nor speculation about any trends. OTA also did not attempt to ascertain whether patients had challenged-or were challenging-insurers' rulings. Thus, OTA cannot determine whether some of the disputes reported in table 2-9 were resolved fully in favor of the consumer because the initial judgment was deemed improper or illegal. Some cases, for example, reported a fetus or newborn had tested positive and the policy cancelled. In all 50 States and the District of Columbia, insurers must cover (or offer the option to include) a newborn child if a valid insurance contract for the parent exists. However, whether the insurance company can deny specific benefits for the newborn by evoking the preexisting condition clause generally contained in all insurance contracts is unclear.

In presenting table 2-9, OTA does not judge the validity-positively or negatively-of the claim. Some cases might have been settled in favor of the individual. Others might have been cases where an

Table 2-9-Case Descriptions of Genetic Testing and Health Insurance Problems[a]

Positive test for adult polycystic kidney disease resulted in canceled policy or increased rate for company of newly diagnosed individual.
Positive test for Huntington disease resulted in canceled policy or being denied coverage through a health maintenance organization.
Positive test for neurofibromatosis resulted in canceled policy.
Positive test for Marfan syndrome resulted in canceled policy.
Positive test for Down syndrome resulted in canceled policy or increased rate.
Positive test for alpha-1 -antitrypsin defined as preexisting condition; therapy related to rendition not covered.
Positive test for Fabry disease resulted in canceled policy.
Woman with balanced translocation excluded from future maternity coverage.
Positive Fragile X carrier status and subsequent job change resulted in no coverage.
After prenatal diagnosis of hemophilia-affected fetus, coverage denied due to preexisting condition clause.
Denied coverage or encountered difficulty retaining coverage after birth of infant with phenylketonuria.
Woman diagnosed with Turner's syndrome denied coverage for cardiac status based on karyotype. Normal electrocardiogram failed to satisfy company.
Family with previous Meckel-Gruber fetus denied coverage in subsequent applications despite using prenatal diagnosis and therapeutic abortion.
Mother tested positive as carrier for severe hemophilia. Prenatal diagnosis revealed affected boy; not revered as preexisting rendition when pregnancy carried to term.
After a test revealed that a woman was a balanced translocation carrier, she was initially denied coverage under spouse's insurance because of risk of unbalanced conception. Subsequently overturned.
Woman without prior knowledge that she was an obligate carrier for X-linked adrenoleukodystrophy found out she was a carrier. She had two sons, both of whom were healthy, but each at 50 percent risk. Testing was done so they could be put on an experimental diet to prevent problems that can arise from mid- to late childhood or early adulthood. One boy tested positive. The family's private pay policy (Blue Cross/Blue Shield) is attempting to disqualify the family for failing to report the family history under preexisting conditions.
After birth of child with CF unable to insure unaffected siblings or themselves.

[a]1991 OTA survey of genetic counselors and nurses in genetics. Not all cases, or multiple cases involving same disorder, listed.

SOURCE: Office of Technology Assessment, 1992.

applicant attempted to select against an insurer by misrepresenting his or her health history, which would have been resolved against the individual.

In 1991, at least 50 genetic counselors or nurses in clinical practice knew of at least 68 actual incidents where their own patients reported difficulties with health insurance due to genetic tests. OTA estimates, based on the average number of patients directly counseled, that genetic counselors and nurses responding to the survey collectively saw about 110,600 individuals in 1990. However, OTA did not advise respondents to limit descriptions of clients' insurance difficulty to 1990. Thus, it is unlikely that all reported cases occurred in 1990; assuming all cases occurred in 1990 means the 68 cases represent 0.06 percent of patients seen by respondents.

Critics question whether the data-especially the qualitative descriptions—merely represent more anecdotal stories that unfairly present one side of the story and for which no response can be developed. Skeptics point out that some of the cases might fall into the gray area of whether exclusion or increased rates resulted because an adverse medical condition was revealed through a diagnostic test that just happened to be genetic. The border between what conditions are genetic or not is blurred, however, and will become increasingly diffuse. Because genetic-based predictive testing promises to have a profound impact on clinical medicine-and because access to medical care is inextricably linked to private health insurance in this country-these cases underscore certain policy dilemmas arising from the increased availability of genetic assays.

SUMMARY

Although genetic counselors and nurses in genetics work in a variety of settings, they are concentrated in metropolitan medical centers on the West coast or Northeast region. States with a large proportion of rural residents are less likely to be served. The clientele served, in the aggregate, tend to be representative of the national averages for majority and minority groups, although no effort was made by OTA to match racial and ethnic data with regions, cities, or localities.

Most genetic counselors have a master's degree and are either certified or eligible for professional

certification. They spend most of their work week seeing or talking with clients. Less time is spent on administration and research, and even less on professional and public education. Seventy percent of the genetics clientele is comprised of adults of reproductive age suggesting the strong influence of prenatal diagnosis as a primary genetics service. Respondents report that their counseling services are frequently not covered by third parties, even when "medically indicated.'

OTA's survey reports consumers can experience difficulties in obtaining or retaining health care coverage after genetic tests. Because genetic-based predictive testing promises to have a profound impact on clinical medicine-and because access to medical care is inextricably linked to private health insurance in this country-these cases underscore certain policy dilemmas arising from the increased availability of genetic assays.

CHAPTER 2 REFERENCES

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