



July 2020

GENETIC SERVICES

Information on Genetic Counselor and Medical Geneticist Workforces

Why GAO Did This Study

Advances in genetic technology and research have increased the amount of information available to individuals and providers, and may have increased the demand for genetic services. The medical genetics workforce—which includes genetic counselors and medical geneticists—plays an essential role in providing access to genetic services. Some studies have identified concerns with the size of the medical genetics workforce and its ability to meet the current and future demand for genetic services.

A House Committee on Appropriations report included a provision for GAO to conduct an analysis of the medical genetics workforce. This report describes, among other objectives, what is known about changes in the size of the genetic counselor and medical geneticist workforces; and what is known about the geographic distribution of these workforces.

GAO reviewed relevant studies of the genetic counselor and medical geneticist workforces; interviewed agency officials and professional organizations representing each workforce; and analyzed the most recent available data on the size and distribution of each workforce in the United States, as well as population data from the Census Bureau.

GAO provided a draft of this report to the Department of Health and Human Services and the Department of Labor. The Department of Health and Human Services provided technical comments, which GAO incorporated as appropriate.

View [GAO-20-593](#). For more information, contact James Cosgrove at (202) 512-7114 or CosgroveJ@gao.gov.

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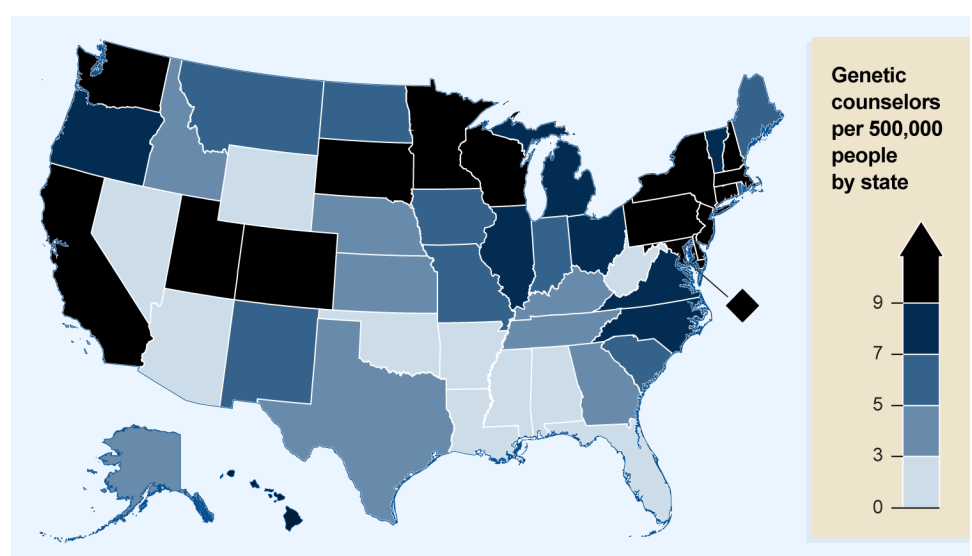
What GAO Found

Genetic counselors and medical geneticists are two groups who typically work together to provide genetic services, such as genetic testing and counseling. Genetic counselors have at least a master's degree in genetic counseling and assess individuals or families with or at risk for genetic conditions, and provide counseling and education on test results. Medical geneticists are typically physicians who specialize in medical genetics and genomics, and provide comprehensive genetic services, ranging from diagnosis and interpretation of test results to the management and treatment of genetic conditions.

GAO's analysis of data from the professional organizations representing this workforce shows the number of genetic counselors certified to provide genetic counseling services has nearly doubled since 2009, and is projected to continue growing. The data show there were approximately 4,700 certified genetics counselors in the United States in 2019. The data also show the number of new medical geneticists has increased modestly since 2009, and the total number certified in the United States was approximately 1,240 as of April 2020. There is no widely accepted measure for how many genetic counselors and medical geneticists should be available; however, representatives from professional organizations GAO interviewed stated that demand for genetic services is rising.

Data from the professional organizations representing the genetic counselor and medical geneticist workforces, as well as data from the Census Bureau, also show the number of genetic counselors and medical geneticists varied across states. States averaged seven genetic counselors per 500,000 people in 2019 and two medical geneticists per 500,000 people in 2020. Genetic counselors and medical geneticists primarily practice in hospital settings.

Distribution of Genetic Counselors by State, 2019



Source: GAO analysis of data from the American Board of Genetic Counseling and Census Bureau; Map Resources. | GAO-20-593

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Abbreviations

ABGC	American Board of Genetic Counseling
ABMGG	American Board of Medical Genetics and Genomics
ACGC	Accreditation Council for Genetic Counseling
ACMG	American College of Medical Genetics and Genomics
AGCPD	Association of Genetic Counseling Program Directors
BLS	Bureau of Labor Statistics
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
NIH	National Institutes of Health
NSGC	National Society of Genetic Counselors
RGN	Regional Genetics Networks

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July 31, 2020

The Honorable Roy Blunt
Chairman
The Honorable Patty Murray
Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and
Related Agencies
Committee on Appropriations
United States Senate

The Honorable Rosa DeLauro
Chairwoman
The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and
Related Agencies
Committee on Appropriations
House of Representatives

Advances in genetic technology and research have increased the amount of information available to individuals and providers, and have increased the demand for genetic services, which include genetic testing, diagnosis and interpretation of test results, and genetic counseling. Genetic test results can help diagnose, confirm, or indicate increased risk for developing a particular condition, while genetic counseling can help explain the results and available treatment and care options. There is broad consensus that the field of medical genetics and genomics will continue to grow.¹

The medical genetics workforce—which includes genetic counselors and medical geneticists—plays an essential role in providing these services to individuals and family members with or at risk for a genetic condition. Genetic counselors have at least a master’s degree in genetic counseling, assess individuals or families with or at risk for genetic conditions, and provide counseling and education on test results. Medical geneticists are

¹According to the National Human Genome Research Institute at the National Institutes of Health, genetics refers to the study of individual genes one at a time. In contrast, genomics refers to the study of the entire genome, or all the genes that can be found in an organism. The field of medical genetics and genomics is the application of genetics and genomics to medical care.

typically physicians who specialize in medical genetics and genomics and provide comprehensive genetic services, ranging from the diagnosis and interpretation of test results to the management and treatment of genetic conditions. Genetic counselors and medical geneticists typically work in conjunction with one another in providing genetic services. For example, a medical geneticist will order genetic testing and interpret the results, and a genetic counselor will provide further education on the results and how they may affect an individual or their family.

Some studies have raised questions about the size of the medical genetics workforce and its ability to meet the current and future demand for genetic services. For example, one study concluded that demand for medical geneticists has increased, but the number of medical geneticists has not.² Similarly, we have reported on different aspects of the health care workforce and noted concerns with the supply and distribution of this workforce.³ A report accompanying the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Bill, 2019, included a provision for us to examine the medical genetics workforce.⁴ In this report, we describe

1. what is known about changes in the size of the genetic counselor and medical geneticist workforces;
2. what is known about factors that may affect the size of the genetic counselor and medical geneticist workforces; and
3. what is known about the geographic distribution of genetic counselors and medical geneticists.

To examine what is known about changes in the size of the genetic counselor and medical geneticist workforces, we analyzed the most recent available data from the professional organizations that track these

²For examples, see Deborah R. Maiese et al., “Current Conditions in Medical Genetics Practice,” *Genetics in Medicine*, vol. 21, no. 8 (2019): p. 1874; and David B. Flannery, “Challenges and Opportunities for Effective Delivery of Clinical Genetic Services in the U.S. Healthcare System,” *Current Opinion in Pediatrics*, vol. 30, no 6 (2018): p. 740-745.

³See GAO, *Veterans Health Administration: Better Data and Evaluation Could Help Improve Physician Staffing, Recruitment, and Retention Strategies*, [GAO-18-124](#) (Washington, D.C.: Oct. 19, 2017); and *Physician Workforce: Locations and Types of Graduate Training Were Largely Unchanged, and Federal Efforts May Not Be Sufficient to Meet Needs*, [GAO-17-411](#) (Washington, D.C.: May 25, 2017).

⁴H.R. Rep. No. 115-862, at 26 (2018).

workforces. Specifically, we reviewed data from the American Board of Genetic Counseling (ABGC)—the certifying body for genetic counselors—on the total number of certified genetic counselors and number of newly certified genetic counselors in the United States and Canada from 2009 through 2019. We did further analysis of the 2019 data to identify the total number of genetic counselors certified in the United States. For the medical geneticist workforce, we reviewed data from the American Board of Medical Genetics and Genomics (ABMGG)—the certifying body for medical geneticists—on the number of newly certified medical geneticists from 2009 through 2019 and on the total number of certified medical geneticists in the United States as of April 2020.⁵

We described all data as they were reported by these professional organizations, and we identified some limitations, which we note when we present the data. For example, ABGC's data on the number of certified genetic counselors include data for some genetic counselors who identify as being located in countries beyond the United States and Canada.⁶ While we were able to identify the number of certified genetic counselors in the United States alone as of December 2019, we were not able to do this for earlier years. Also, we use approximations in reporting the total number of certified genetic counselors over time, because, according to ABGC officials, its data may not account for all instances of deaths, retirements, or genetic counselors who are no longer actively practicing. Therefore, the data may somewhat overstate the actual number of certified genetic counselors, but would not affect the overall trend over time. Similarly, for the total number of certified medical geneticists in 2020, ABMGG officials told us their data may not account for all instances of deaths, retirements, or certified medical geneticists who are no longer practicing, and we report this limitation when we present the data. Further, ABMGG officials could not provide data on the total number of certified medical geneticists for prior years, because they do not track changes in workforce numbers over time that exclude those who have retired or died. Based on our interviews with officials from these organizations, our review of the data, and noting data limitations when we present them, we determined the data on genetic counselors and certified

⁵Our scope is limited to medical geneticists who specialized in clinical care and genomics.

⁶According to 2019 ABGC data, approximately 93 percent of the certified genetic counselors are in the United States. One ABGC official told us that genetic counselors self-report their address information, which may reflect their work or home address, including country information.

medical geneticists to be sufficiently reliable for the purposes of our reporting objectives.

To further describe the size of the genetic counselor workforce, we reviewed Bureau of Labor Statistics (BLS) employment projections for genetic counselors from 2018 through 2028, the most recent data available.⁷ To assess the reliability of BLS data, we reviewed relevant documentation and information from BLS staff for the most recent data available and determined that the data were sufficiently reliable for our purposes.

To describe what is known about factors that may affect the size of the genetic counselor and medical geneticist workforces, we assessed and summarized available training program data for genetic counselors and medical geneticists. Specifically, we reviewed the number of accredited genetic counselor training programs from 2008 through 2019 in the United States as provided by the Accreditation Council for Genetic Counseling (ACGC)—the accreditation body for genetic counselor training programs. We also reviewed data from the Association of Genetic Counseling Program Directors (AGCPD)—an organization representing genetic counseling training programs—on genetic counselor training program enrollment, as well as the number of program applicants and positions filled from 2013 through 2019. Data for 2015 program applicants and positions filled were missing and we note this limitation. For the medical geneticist workforce, we reviewed ABMGG’s data on the number of accredited training programs for medical geneticists, and the number of medical geneticist residents by school year and training program type from 2014 through 2020. We assessed the reliability of training program data for both workforces by comparing data over time, analyzing the changes in how the organizations tracked the information, and interviewing officials from ACGC, AGCPD, ABMGG, and the American College of Medical Genetics and Genomics (ACMG)—the medical specialty society for medical geneticists. Based on these steps, we determined the data were sufficiently reliable for the purposes of describing what is known about factors that may affect the size of the genetic counselor and medical geneticist workforces.

⁷BLS—an entity of the U.S. Department of Labor—measures labor market activity, working conditions, price changes, and productivity in the U.S. economy to support public and private decision making. According to BLS officials we interviewed, BLS does not collect and report data specific to medical geneticists.

To describe what is known about the geographic distribution of genetic counselors and medical geneticists, we analyzed the number of genetic counselors as of December 2019 and medical geneticists as of April 2020 by state and the District of Columbia. For each state and the District of Columbia, we obtained the number of currently certified genetic counselors from ABGC, and the number of currently certified medical geneticists—those who specialized in clinical care and genomics—from ABMGG. In order to account for differences in the size of state populations, for each state and the District of Columbia we report the approximate number of genetic counselors and medical geneticists per 500,000 people based on 2019 Census Bureau estimates, the most recent data available at the time of our review. We performed data checks to remove any data irregularities and determined that the data we present are sufficiently reliable for the purposes of our reporting objectives.

To further identify characteristics of the genetic counselor and medical geneticist workforces for all of our objectives, we reviewed available genetic counselor data from Professional Status Surveys administered by the National Society of Genetic Counselors (NSGC)—the advocacy organization for genetic counselors—from 2012 through 2019. For medical geneticists, we reviewed available data from a 2019 workforce practice survey administered by ACMG. For medical geneticists, we analyzed the workforce survey results to describe age and retirement rates, and for both genetic counselors and medical geneticists, we analyzed survey results to describe where these professionals practice. To assess the reliability of these survey data, we reviewed survey response rates to individual questions, examined survey instrument questions, and sought clarification from NSGC and ACMG officials regarding their methodologies to summarize the survey responses. Based on these activities, we found the data to be sufficiently reliable for the purposes of our reporting objectives.

For all three objectives, we interviewed officials from three federal agencies—the Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and BLS—because these agencies either collect data on parts of the medical genetics workforce or have a genetic component to their work. We also interviewed representatives of two of seven Regional Genetics Networks (RGN), which are programs funded by the Department of Health and Human Services (HHS) to increase access to genetic services for populations and regions throughout the United States and its territories, and representatives from seven professional organizations representing

different aspects of the medical genetics workforce.⁸ We conducted these interviews to obtain perspectives on the size of the genetic counselor and medical geneticist workforces, factors affecting the size of these workforces, and the geographic distribution of these workforces. We identified these stakeholders through referrals from other stakeholders we interviewed.

For all three objectives, we identified and obtained relevant studies and reports about the genetic counselor and medical geneticist workforces from federal agency officials and officials from the professional organizations we interviewed. We reviewed these studies to identify information on the size of the medical genetics workforce, factors affecting size, and the geographic distribution of the workforce. We reviewed related documentation from the RGNs about their training programs and initiatives to identify their strategies for providing genetic services to the people in their regions.

We conducted this performance audit from August 2019 to July 2020 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

To help identify information about the health of an individual, a genetic service provider may order genetic testing. Genetic testing is a type of medical test that identifies changes in an individual's chromosomes, genes, and proteins. Genetic testing results can confirm or rule out a suspected genetic condition, help determine a person's chance of developing or passing on a genetic condition, or provide information on the management and treatment of a genetic condition.

⁸Appendix I lists the professional organizations we interviewed and their areas of focus.

There are many different types of genetic tests, including newborn screening, diagnostic testing, and predictive testing.⁹ Newborn screening is used to screen babies just after birth to identify certain genetic conditions that can be treated early in life, such as phenylketonuria, which if left untreated, could hinder normal development and cause life-threatening illnesses.¹⁰ According to HRSA officials, an abnormal newborn screen must be followed by a diagnostic test. Diagnostic testing is used to confirm or rule out a suspected genetic condition, and predictive testing can identify gene mutations that increase a person's risk of developing conditions with a genetic basis, such as cardiovascular disease or certain types of cancer, and can be helpful to people with a family history of a genetic condition.

The decision to undergo genetic testing is often done in consultation with a genetic service provider or team of providers, who may first conduct a physical examination of an individual to identify any physical symptoms, or collect an individual's family health history to determine how likely it is that an individual has a genetic condition. Once testing is complete, these providers interpret and communicate the test results to the individual or their family and identify treatment options.

There is no comprehensive data on the demand for genetic services. Genetic testing can help individuals make informed decisions about their health and the medical care they receive. According to NIH's genetic testing registry website—a repository for genetic testing information that providers submit voluntarily—the number of genetic tests have increased rapidly since 2012.¹¹ NIH's genetic testing registry website has over 60,000 genetic tests registered, and the number continues to increase.

⁹Other types of genetic tests include carrier testing, prenatal testing, and reproductive testing. Direct-to-consumer genetic testing can be conducted without involving a health care provider. Individuals can purchase these tests from a company, send in their sample for laboratory analysis, and obtain their results directly rather than through a health care provider. Individuals may take the results to a health care provider for further interpretation.

¹⁰Phenylketonuria is a genetic condition that makes foods that contain phenylalanine—an essential amino acid—dangerous to the child. If phenylketonuria is not treated, phenylalanine can build up to harmful levels in the body, causing intellectual disability and other serious health problems.

¹¹National Institutes of Health, Genetic Testing Registry, accessed May 18, 2020, <https://www.ncbi.nlm.nih.gov/gtr/>.

Genetic Counselors

Genetic counselors assess individuals or families with or at risk for genetic conditions, and provide counseling and education on test results. Genetic counselors help individuals understand their health status and background, and how genetic conditions may affect them or their family. They can help families understand medical terminology, identify available resources, and help explain what information genetic testing may provide. While genetic counselors are trained to interpret genetic risk and discuss with patients applicable testing options, they are not trained in physical diagnoses and do not perform physical examinations.

Genetic counselors have at least a master's degree from an accredited two-year genetic counseling training program that includes supervised clinical experience.¹² Upon graduation, genetic counselors who want to become certified must pass a certification exam. ABGC—the certifying body for genetic counselors—develops and administers the certification exam and recertifies genetic counselors.¹³

Genetic counselors can work in all medical specialties, or practice in one specialty area, such as pediatrics, oncology, or cardiology. Genetic counselors typically work in conjunction with a medical geneticist or other specialist in providing patient care. For example, a genetic counselor may work alongside an oncologist, who orders a genetic test, and then the genetic counselor meets with the patient to discuss test implications for the patient or their family. Genetic counselors also work in a variety of non-patient care areas, such as diagnostic laboratories, research, and insurance companies.

Medical Geneticists

Medical geneticists specialize in the field of medical genetics and genomics and are trained to evaluate, diagnose, and manage care for individuals with genetic conditions.¹⁴ Medical geneticists who provide patient care—also known as clinical geneticists—are physicians who specialize in clinical genetics and genomics and are trained to provide

¹²Genetic counseling graduate training programs are accredited by the Accreditation Council for Genetic Counseling, which maintains standards for education and clinical training.

¹³Certification is valid for 5 years, after which time genetic counselors must recertify.

¹⁴Medical genetics and genomics—the application of genetics and genomics to medical care—is recognized by the American Board of Medical Specialties as a medical specialty.

comprehensive genetic services including diagnosis, management, and treatment of genetic conditions.¹⁵

To become a certified medical geneticist, individuals must complete all requirements of their accredited residency training program and pass a certification exam.¹⁶ ABMGG is the medical board responsible for certifying and recertifying medical geneticists.¹⁷ Accredited residency programs in medical genetics and genomics can be either 2 years or 4 years in length, depending on the type of residency, and include at least one year of direct patient care. Categorical residencies—residency programs that enable a resident to be certified in medical genetics and genomics—are 2 years in length, while combined residencies—residency programs that include training in two medical specialties and enable a resident to be certified in both specialties—are 4 years.¹⁸

Medical geneticists work in many different specialty areas, including cardiology, pediatrics, oncology, and neurology. They also work with a broad set of providers, including laboratory geneticists, genetic counselors, and dietitians, to diagnose and treat genetic conditions. Medical geneticists can work with patients of all ages, but often work with pediatric patients.

Genetic Services Offered by Other Health Professionals

Genetic services are also provided by other health professionals. Genetic nurses are registered nurses with advanced training in genetics. Depending on their level of training, they can assess and diagnose patients, provide counseling, and help manage their care. Genetic nurses

¹⁵The field of medical genetics and genomics has two other specialties—clinical biochemical genetics and laboratory genetics and genomics. Individuals in these specialties direct and supervise clinical laboratories that conduct genetic testing. They perform genetic testing, interpret and communicate results, and act as consultants to other medical genetic professionals in the laboratory diagnoses of a broad range of genetic disorders and conditions. For purposes of this report, medical geneticists refers to individuals who provide clinical care and who specialized in clinical genetics and genomics.

¹⁶Residency training programs are accredited by the American College of Graduate Medical Education.

¹⁷Once certified, medical geneticists follow a 3-year continuous certification cycle and must pass a recertification exam at least every 10 years. Medical geneticists certified prior to 1993 received non time-limited certification, meaning their certification never expires.

¹⁸Residents in combined programs train concurrently in medical genetics and genomics and one of four other specialties—pediatrics, maternal and fetal medicine, internal medicine, or reproductive endocrinology and infertility.

obtain their genetic nursing credential by completing coursework and continuing education hours and compiling a portfolio of case studies.¹⁹ Genetic services may also be provided by registered nurses who are not credentialed in genetics, but who work in specialties that include genetic components, such as oncology practices. According to the Nurse Portfolio Credentialing Committee, there are roughly 100 certified genetic nurses; however, it is difficult to know the actual numbers of nurses providing genetic services, because nurses may choose not to get credentialed in genetics.

Genetic services are also delivered by providers who are licensed in another medical specialty and may not have formal genetics training, such as pediatricians, obstetricians, or other specialists. For example, a pediatrician will receive the results of newborn screening and determine if further testing is needed. Similarly, a specialist may order genetic testing for a breast cancer patient to determine the best treatment or whether the patient is at risk for other types of cancer.

Federal Genetics Initiatives

A few federal entities have genetics and genomics initiatives. In 2015, the White House launched the Precision Medicine Initiative to understand how an individual's genetics, environment, and lifestyle can help determine the best approach to treat disease. As part of this initiative, the *All of Us* Research Program aims to collect health and genetic information from one million or more participants around the United States. Nationwide enrollment in the program began in 2018 and is expected to last at least 10 years. The information collected will help build a database for researchers to study how to better predict disease risk and find improved diagnosis, prevention, and treatment strategies. Program participants will have their genetic data analyzed, and will have the option to obtain their genetic research results and to receive genetic counseling to help them understand those results. Participants will be advised to consult their health care providers for confirmation of their results, and before making any changes to their care.

¹⁹In 2017, the American Nurse Credentialing Center—the committee responsible for certifying genetic nurses—was dissolved. As a result, the Advanced Genetics Nursing Certification was discontinued for new applicants and was only available for renewals. In December 2019, the Nurse Portfolio Credentialing Committee began accepting new applications for two new credentials in genetic nursing—Advanced Clinical Genomics Nurse and Clinical Genomics Nurse.

In 2004, HRSA—an HHS agency that aims to improve health care for medically vulnerable individuals—created the RGN program to develop and support a regional system to educate providers and improve patient access to genetic services, with a particular emphasis on the medically underserved populations across the country.²⁰ HRSA funds seven RGNs across the United States and its territories.²¹ RGNs have varying projects and initiatives to increase access to genetic services depending on the needs of each region.

The Number of Genetic Counselors and Newly Certified Medical Geneticists Has Increased in Recent Years

The Number of Genetic Counselors Has Grown from 2009 through 2019 and Is Projected to Grow in Future Years

The genetic counselor workforce has shown significant growth over the past decade. Data provided by ABGC—the certifying body for genetic counselors—shows that the total number of certified genetic counselors in the United States and Canada has nearly doubled since 2009, increasing from approximately 2,500 in 2009 to approximately 5,000 in 2019.²² According to our analysis of ABGC data, there are approximately 4,700 certified genetic counselors in the United States as of December 2019.²³ The annual number of new certifications has varied since 2009, but has

²⁰HRSA defines medically underserved populations as specific sub-groups of people living in a defined geographic area with a shortage of primary care health services.

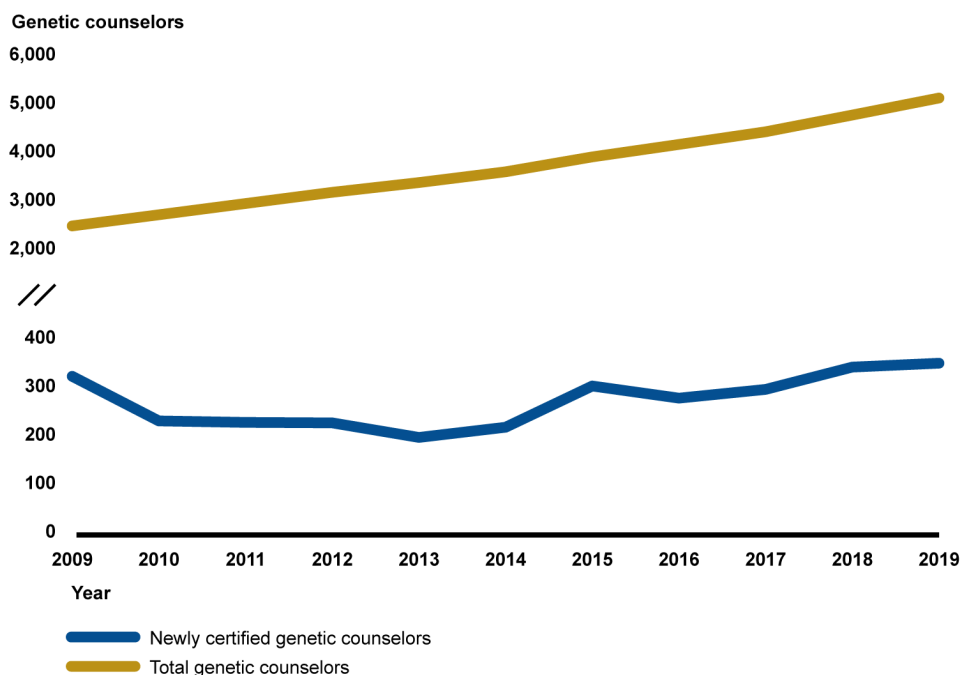
²¹The seven RGNs are the New England Regional Genetics Network, the Mid-Atlantic Regional Genetics Network, the Southeast Regional Genetics Network, the Midwest Regional Genetics Network, the Heartland Genetics Network, the Mountain States Regional Genetics Network and the Western States Regional Genetics Network. Each region covers roughly an equal amount of births.

²²Certification numbers include genetic counselors in direct patient care positions and non-patient care positions, such as industry and research.

²³Across all certified genetic counselors in the United States and Canada in 2019, approximately 93 percent were in the United States. We were only able to separate U.S. genetic counselors for the most recent year of data available. All other data on the total number of genetic counselors in this section includes both U.S and Canadian genetic counselors and some who identify as being located in other countries beyond the United States and Canada.

generally increased since 2016. (See fig. 1.) Officials from two of the professional genetic counseling organizations in our review agreed that the workforce has grown significantly.

Figure 1: Number of Certified Genetic Counselors in the United States and Canada, 2009-2019



Source: GAO analysis of data from the American Board of Genetic Counseling. | GAO-20-593

Note: Numbers include those certified in either the United States or Canada and some genetic counselors who identify as being located in other countries beyond the United States and Canada. According to 2019 data from the American Board of Genetic Counseling (ABGC), the most recent year of data available, approximately 93 percent of the certified genetic counselors are in the United States. According to an ABGC official, genetic counselors self-report their address information, which may reflect their work or home address, including country information. Also, according to an ABGC official, its data representing totals over time may not account for all instances of deaths, retirements, or genetic counselors who are no longer actively practicing.

The genetic counselor workforce is projected to continue growing. The magnitude of these projections varies. While some limitations exist in the genetic counselor workforce data collected by BLS, the bureau projects the workforce to grow by 27 percent from 2018 through 2028—more than twice as fast as other health care practitioners and technical

occupations.²⁴ NIH officials noted that as genetic advances continue, the demand for genetics services will continue to grow. Officials from four professional organizations in our review also projected growth in the workforce. Officials at NSGC—the advocacy organization for genetic counselors—predicted in 2019 a growth rate of 80 to 100 percent in the genetic counselor workforce over the next 10 years. (By comparison, the ABGC data we analyzed show a 100 percent growth rate for the period 2009 through 2019.) Officials from three of the four professional genetic counseling organizations in our review agreed that demand for genetic services is increasing or is expected to increase. Officials from one organization noted that advances in genetic technology and increases in the number of available genetic tests will drive demand for genetic counselors.

While the genetic counselor workforce is projected to continue growing, there is no widely accepted measure for how many genetic counselors should be available to serve a given population. A 2017 workforce analysis study commissioned by the Workforce Working Group indicated a shortage of genetic counselors in direct patient care that could persist for the next 10 years, depending on the demand for services.²⁵ However, the study also noted that, given the lack of guidelines for determining the appropriate number of genetic counselors per population, more research

²⁴See Bureau of Labor Statistics, *Occupational Outlook Handbook: Genetic Counselors*, accessed May 28, 2020, www.bls.gov/ooh/healthcare/genetic-counselors.htm. Genetic counselors are the only part of the medical genetics workforce for which BLS collects data. BLS collects and reports workforce data based on occupational categories listed in the Standard Occupational Classification system, which is used by federal agencies to classify workers into occupational categories for the purpose of collecting, calculating, or disseminating data. According to BLS officials, genetic counselors are the only occupational category specific to genetics in the Standard Occupational Classification system; thus, they are the only component of the medical genetics workforce for which separate data are available. BLS estimated there were about 2,600 genetic counselors in the United States in 2018. BLS officials noted that BLS is not able to publish data separately for every state, because the estimates do not meet quality or confidentiality standards in all states. Further, BLS's national estimates for genetic counselors contain all data reported for this occupation, including data in states for which estimates could not be published.

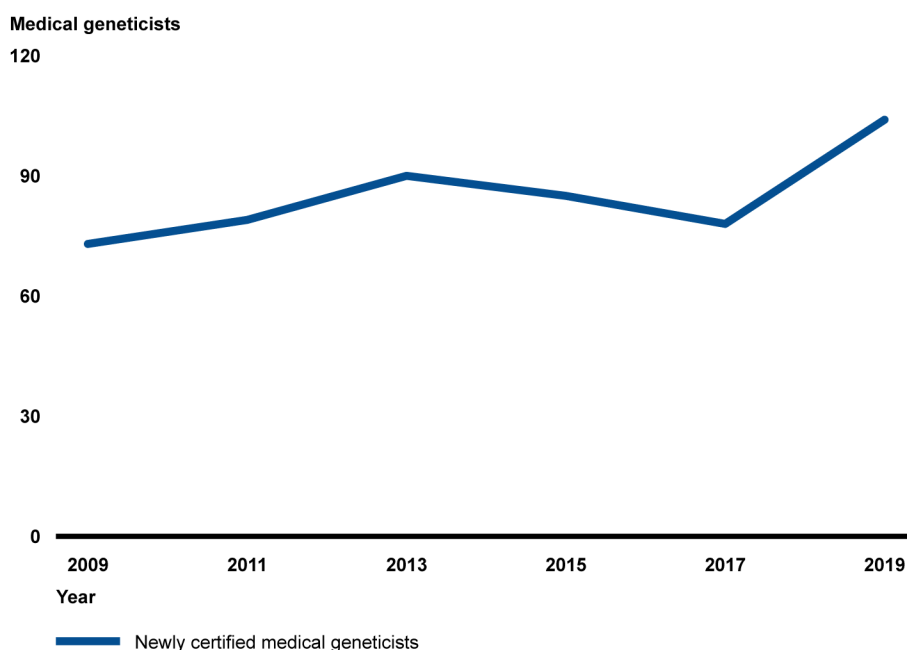
²⁵The Workforce Working Group was formulated in 2015 by professional genetic counseling organizations to address the state of the genetic counselor workforce. Members of the group included representatives from NSGC, ABGC, the Accreditation Council for Genetic Counseling, the Association of Genetic Counseling Program Directors, and the American Society of Human Genetics. See Jennifer M. Hoskovec et al., "Projecting the Supply and Demand for Certified Genetic Counselors: a Workforce Study," *Journal of Genetic Counseling*, vol. 27, no.1 (2018): p.16.

is needed to assess the appropriate number needed to meet demand.²⁶ Officials from two professional organizations in our review had similar views. ABGC officials said they did not have a standard for the number of genetic counselors to meet demand and NSGC officials stated that identifying a sufficient number of genetic counselors is challenging.

The Number of New Medical Geneticists Increased Modestly from 2009 through 2019

Our analysis of data from ABMGG—the certifying body for medical geneticists—shows that the number of newly certified medical geneticists grew from 73 in 2009 to 104 in 2019, with the largest increase from 2017 through 2019. (See fig. 2.)

Figure 2: Number of Newly Certified Medical Geneticists, 2009-2019



Source: GAO analysis of data from the American Board of Medical Genetics and Genomics. | GAO-20-593

Note: Certification exams are held every 2 years.

²⁶Due to the lack of guidelines for determining the appropriate number of genetic counselors and the uncertainty of demand, the study calculated the number of genetic counselors needed using two different demand scenarios. The study also noted that the supply of genetic counselors could meet demand sooner than predicted if training program numbers continue to grow. NSGC officials stated that the study was outdated by the time it was published due, in part, to an increase in the number of training programs and available slots in those programs.

In addition, according to data provided by ABMGG, the current number of medical geneticists certified in clinical genetics and genomics in the United States is approximately 1,240, as of April 2020.²⁷ The medical geneticist workforce makes up a small part of the overall physician workforce. BLS estimated that there were 756,800 physicians and surgeons in 2018 and projects the number of physicians and surgeons to grow by 7 percent, or 55,400, in the next 10 years.²⁸ Based on the current number of medical geneticists and BLS estimates of the physician workforce in 2018, medical geneticists may account for less than 1 percent of the physician workforce.

It is difficult to identify changes in the size of the medical geneticist workforce over time, because there are limited data. Due to the small size of the workforce, BLS and HRSA do not collect data on the size and growth of this workforce. While ABMGG tracks the number of newly certified and recertified medical geneticists, an official told us they do not track changes in workforce numbers over time that exclude those who have retired or died. An ABMGG official said it is difficult to know how many medical geneticists are actually practicing, because many geneticists or their families, particularly those with a lifetime certification, do not notify ABMGG if they are deceased, retired, or still practicing.

Officials we interviewed from the professional medical geneticist organizations in our review expressed concerns about the size and future growth of the medical geneticist workforce. While an ABMGG official considered the 104 newly certified medical geneticists to be a significant increase in new entrants, she stated that there may not be enough medical geneticists to meet the growing demand for services. Officials from ACMG—the medical specialty society for medical geneticists—also stated concerns about the long-term projections for the workforce. The ACMG officials noted that their 2019 medical geneticist workforce survey results indicate potential shortages given the number of respondents over

²⁷Medical geneticists can specialize in clinical or laboratory specialties and subspecialties. We are focusing on the numbers of medical geneticists in clinical genetics—those who specialize in clinical genetics and genomics—because they see patients and provide medical care. The approximate number of certified medical geneticists as of April 2020 may be somewhat overstated, because it does not account for all instances of deaths, retirements, or certified medical geneticists who are no longer practicing.

²⁸Bureau of Labor Statistics, *Occupational Outlook Handbook: Physicians and Surgeons*, accessed May 28, 2020.
<https://www.bls.gov/ooh/healthcare/physicians-and-surgeons.htm>.

the age of 60, and the number who may retire within 10 years.²⁹ Officials from both RGNs we interviewed expressed concerns with the size of the workforce in their region. An official from one RGN stated that medical geneticists are generally an older workforce than genetic counselors, adding that there are medical geneticists in the network who are considering retirement, and replacing them will be challenging. The official also noted there are not enough medical geneticists to handle all of the work in their region and estimated a 6 to 9 month wait for an appointment. Research articles we reviewed supported that workforce growth is a concern. An article summarizing key points from a 2015 workforce study conducted by ACMG concluded the medical geneticist workforce is not growing.³⁰

According to some organization officials we interviewed and research we reviewed, there is no widely accepted measure for how many medical geneticists should be available to serve a given population. As with the genetic counselor workforce, officials from one organization noted that there is no consensus on the ideal size of the medical genetics workforce. However, officials we interviewed from the professional medical geneticist organizations in our review agreed that demand for genetic services is rising. For example, according to ACMG officials, there is more demand for genetic services, such as newborn screenings, and the workforce is not keeping pace with the demand. ACMG officials stated that advancements in genetics and the availability of different types of genetic tests create more demand for medical geneticists.

²⁹According to 2019 ACMG survey results, about 29 percent (133 of 466) of respondents were over 60 years old. Further, 25 percent (120 of 490) of those who responded to the question on retirement said they were either retired or were planning to retire within 10 years. ACMG, in collaboration with ABMGG, administered the survey from September 10, 2019 through December 7, 2019, to 2,405 certified medical geneticists (across all clinical and laboratory genetic specialties) in the United States. They received 990 responses for an overall 41 percent response rate. Of the 990 survey responses, 560 respondents identified as being certified in clinical genetics and genomics. Some of these respondents were also certified in another medical genetics and genomics specialty. Of the 560 responses, 491 of those responded that they provide direct patient care. We are reporting survey responses based on those 491 medical geneticists.

³⁰Maiese et al, "Current Conditions," p.1874.

Continued Interest in Genetic Counseling Training Programs and Varying Interest in Medical Genetics Programs Likely to Affect Size of Each Workforce

Continued Applicant Interest and Increasing Program Numbers Likely Contributing to Future Workforce Growth for Genetic Counselors

Our analysis identified two factors that are likely to contribute to future growth in the genetic counselor workforce: increases in the number of applicants to genetic counseling training programs, and increases in the total number of programs. Since at least 2013, the number of applicants to genetic counseling training programs—2-year master’s degree programs—has surpassed the number of open positions within these graduate training programs, according to data from AGCPD—the organization that represents genetic counselor training programs. AGCPD training program data shows that from 2013 through 2019, the number of program applicants has consistently been at least three times more than positions filled. For example, in 2013, there were 3.2 applicants per position, and in 2019, there were 3.5 applicants per position. (See table 1.) The ratio of program applicants to program positions filled has increased even though the number of program positions has increased by over 70 percent during the same time period.

Table 1: Number of Genetic Counselor Graduate Training Program Applicants and Positions Filled

Year	Program applicants ^a	Positions filled	Applicants per position
2019	1,569	448 ^b	3.5
2018	1,328	385 ^b	3.4
2017	1,299	378	3.4
2016	1,079	318	3.4
2015 ^c	Not available	Not available	Not available
2014	869	264	3.3
2013	826	260	3.2

Sources: Association of Genetic Counseling Program Directors and GAO analysis. | GAO-20-593

Note: According to officials from the Association of Genetic Counseling Program Directors (AGCPD), in 2018, they began using the Genetic Counseling Admission Match program, a centralized

mechanism for processing offers of program admission. Using the Match program mechanism, AGCPD officials obtained the genetic counseling program match data for 2018 and 2019. AGCPD officials told us their data sets prior to 2018 may be less reliable, because they did not use the Match program mechanism to obtain their data.

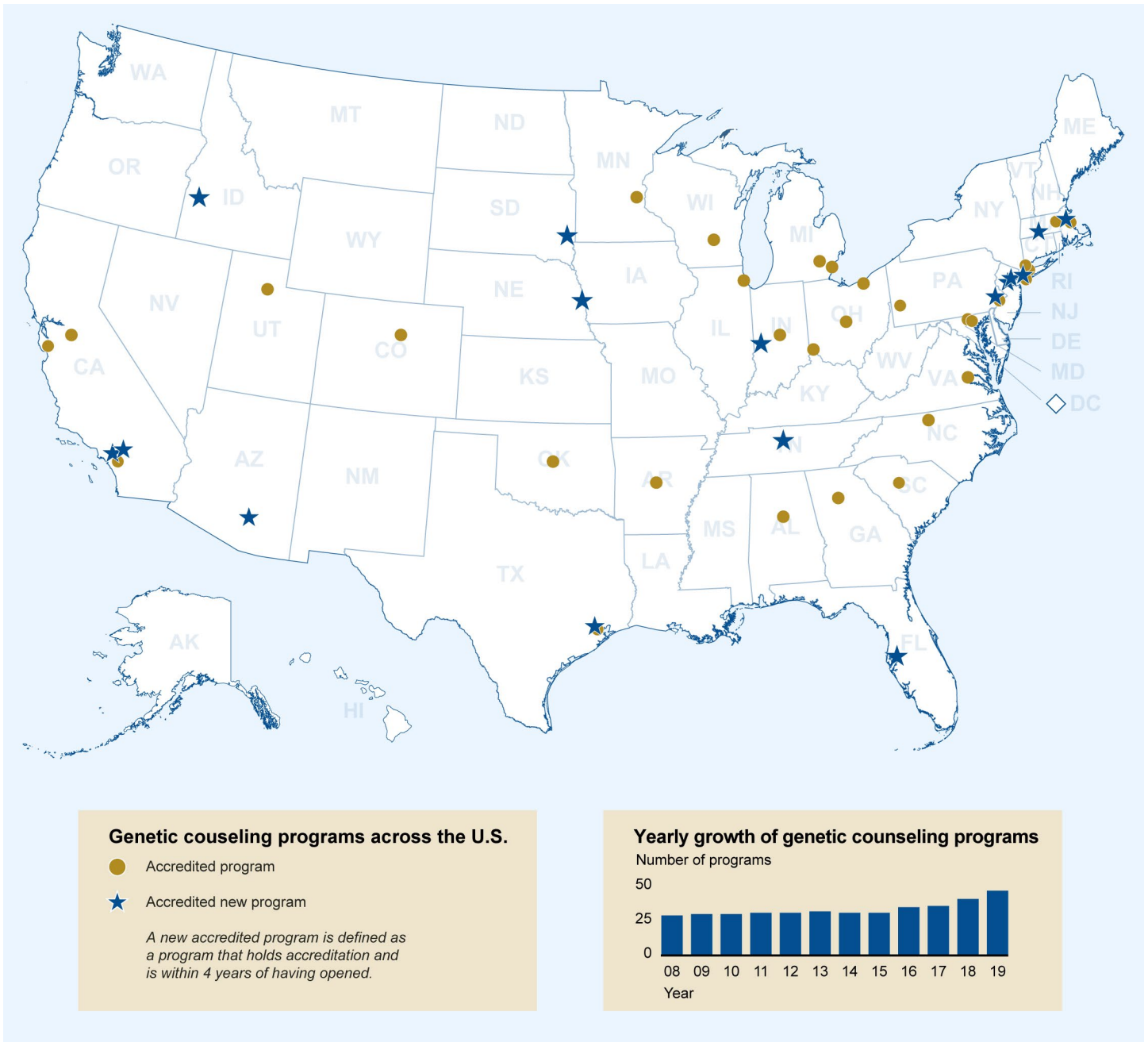
^aAGCPD officials reported that the majority of program applicants for 2018 and 2019—those who registered in the Match program—were from the United States, but they also told us that applicants may be from any country.

^bFor 2018 and 2019, AGCPD officials reported the number of positions in the United States only, and the remaining years—2013, 2014, 2016, and 2017—represent the number of total positions for both the United States and Canada. Separately, they reported the number of positions in Canadian programs for 2018 and 2019 were 21 and 20, respectively.

^cAGCPD officials reported that 2015 data was not available.

The number of genetic counselor training programs has increased significantly since 2009. According to ACGC—the accrediting body for genetic counseling training programs—the number of genetic counseling training programs in the United States has grown from 29 programs in 2008 to 47 programs in 2019, with most of that growth occurring since 2015. (See fig. 3.) ACGC officials told us they attribute the increase in recent years to the growth of genetic testing and more public awareness of genetic risk and disease prevention, among other factors. ACGC officials also noted that more universities are opening up master's degree programs, because they recognize the need to train genetic counselors to address projected growth in the field. Of the 47 currently operating genetic counseling graduate programs, about 34 percent are defined by ACGC as new programs, meaning these programs started enrolling students within the past 4 years. According to ACGC, four more training programs are being developed in California, Missouri, North Carolina, and Washington, but have not yet been accredited. Figure 3 shows the location of all 47 accredited programs, including the 16 new programs.

Figure 3: Accredited Genetic Counseling Graduate Training Programs in the United States, 2019



Source: GAO analysis of information from the Accreditation Council for Genetic Counseling; Map Resources (map). | GAO-20-593

Although the number of genetic counselor programs has increased, enrollment in individual genetic counseling programs remains relatively small. Officials from AGCPD told us programs admit four to 30 students per year. According to a 2016 study of the genetic counselor workforce, the average genetic counselor program enrolled approximately seven students per year.³¹ AGCPD officials stated that the availability of genetic counselor supervisors and training sites to provide clinical training as part of the 2-year master's degree program is one limiting factor for program size. AGCPD officials said that students are required to do extensive clinical training, and if there are not enough supervisors to oversee this training, programs cannot increase in size. These officials added that maintaining a sufficient number of clinical supervisors is an ongoing challenge, because, as experienced genetic counselors, supervisors have various work opportunities and may decide not to remain in clinical supervisory roles. AGCPD officials also said that clinical site administrators may resist handling more training, because training standards are rigorous and require time that is generally volunteer-based. See the text box below for further information on the movement of genetic counselors to non-patient care roles once they enter the workforce.

Movement of Genetic Counselors to Non-Patient Care Roles

Due to their diverse training, genetic counselors are able to move from patient care roles to non-patient care positions, according to two professional organizations we interviewed. For example, genetic counselors hold positions in commercial diagnostic laboratories, health care organizations, and research development companies. According to annual surveys conducted by the National Society of Genetic Counselors (NSGC), nearly 25 percent of respondents in both the 2018 and 2019 surveys reported that they do not provide direct patient care.* However, NSGC officials told us distinguishing the percent of genetic counselors who have a direct patient care position is challenging, because some respondents report having a mixed role of both patient and non-patient care. One Regional Genetics Network (RGN) official noted that one institution in the RGN lost approximately 30 percent of its genetic counselors in the past few years, in part, because they moved to better-paying industry jobs. Another RGN official stated that genetic counselors have many employment options, and some enter industry jobs without ever seeing patients.

*In the 2018 NSGC Professional Status Survey, 610 of 2,477 (25 percent) respondents identified as being in a non-patient care work setting, and in the 2019 survey, 591 of 2,372 (25 percent) respondents identified as being in a non-patient care work setting.

Source: GAO analysis of information provided by professional organizations and RGNs. | GAO-20-593

³¹Vivian Pan et al., "Expanding the Genetic Counseling Workforce: Program Directors' Views on Increasing the Size of Genetic Counseling Graduate Programs," *Genetics in Medicine*, vol. 18, no. 8 (2016).

Declining Numbers in 2-Year Medical Genetics Programs, but Increasing Numbers in Combined 4-Year Programs May Affect Future Workforce Growth

According to two professional organizations we interviewed and data we reviewed, relatively few new students are entering the 2-year medical genetics residency programs, but more are entering residency programs that combine genetics training with other specialty training. According to data provided by ABMGG, 2-year residency training program slots for medical geneticists are not being filled. Additionally, the number of 2-year residency programs decreased from 51 programs in school year 2010-2011 to 46 programs in school year 2016-2017 and has remained at 46 programs for the last four school years. ABMGG officials told us some programs voluntarily close due to never having a resident apply, or due to a lack of funding for the program, among other reasons. The number of residents in the 2-year programs also decreased, from 80 residents in school year 2014-2015 to 61 residents in school year 2019-2020, as shown in table 2.

Table 2: Number of Medical Genetics Residents by Year and Training Program Type, School Years 2014-2015 to 2019-2020

School year	Two-year programs		Four-year combined programs			Total combined 4-year programs	Total residents in 2- and 4-year programs
	Medical Genetics and Genomics (MGG)	MGG/Pediatrics	MGG/Maternal Fetal Medicine	MGG/Reproductive Endocrinology and Infertility	MGG/Internal Medicine		
2019-2020	61	63	8	3	6	80	141
2018-2019	59	65	10	1	6	82	141
2017-2018	75	58	5	1	7	71	146
2016-2017	72	55	9	2	6	72	144
2015-2016	72	43	11	2	5	61	133
2014-2015	80	35	12	1	1	49	129

Source: American Board of Medical Genetics and Genomics. | GAO-20-593

Note: According to guidelines from the American Board of Medical Genetics and Genomics (ABMGG), in order for a university to offer a combined residency program, both 2-year programs (e.g., MGG and Pediatrics) must be accredited and located in the same sponsoring institution, or the sponsoring institution must be a participant in an integrated multi-institutional program, among other requirements.

However, according to ABMGG data, the combined 4-year residency programs have shown modest growth in the number of residents over the last 5 years and has led to growth in the total number of medical genetics residents. For example, as shown in table 2, the number of residents in the combined Medical Genetics and Genomics and Pediatrics program increased from 35 residents in school year 2014-2015 to 63 residents in

school year 2019-2020. One ABMGG official stated that when they began reducing a combined residency program from a 5-year to a 4-year program, more students became interested in completing the combined program.³² According to ABMGG data, there are now 34 combined residency programs for school year 2019-2020, and the number of residents in these combined programs increased from 49 to 80 (63 percent) from school year 2014-2015 to school year 2019-2020. This increase in residents in combined residency programs also led to a total increase in the number of medical geneticist residents from 129 in school year 2014-2015 to 141 in school year 2019-2020, as shown in table 2. One ABMGG official stated that more students are looking at combined residency programs, because the students are recognizing the importance of incorporating genetics within a number of other specialties, such as pediatrics or internal medicine, among others.

A decrease in the number of 2-year programs could impact the number of 4-year combined programs. According to ABMGG guidelines, in order for a sponsoring university to offer a combined 4-year program, it must also sponsor both 2-year residency programs (e.g., Medical Genetics and Genomics, and Pediatrics), among other requirements. Officials from ACMG and ABMGG provided several reasons why students are not entering 2-year residency programs. ACMG officials stated that salary is a factor in deterring medical students from pursuing a career in the field of medical genetics and genomics; in particular, medical geneticist salaries are not enough to pay off debt incurred from high education costs. In addition, both ACMG and ABMGG officials told us that medical geneticists' training programs may not be attractive, because they have intensive education requirements. For example, ACMG officials stated that medical geneticist residents may examine approximately 7,000 rare genetic diseases that span across all medical areas as part of the broad knowledge base they would study. Further, one ABMGG official said medical students are not familiar with the field of genetics—medical schools do not have a required genetics rotation and lack role models to encourage students to enter the field.

³²For example, in 2013 ABMGG revised their guidelines for the combined Medical Genetics and Genomics and Pediatrics program and reduced the program to 4 years instead of 5 years, according to one ABMGG official.

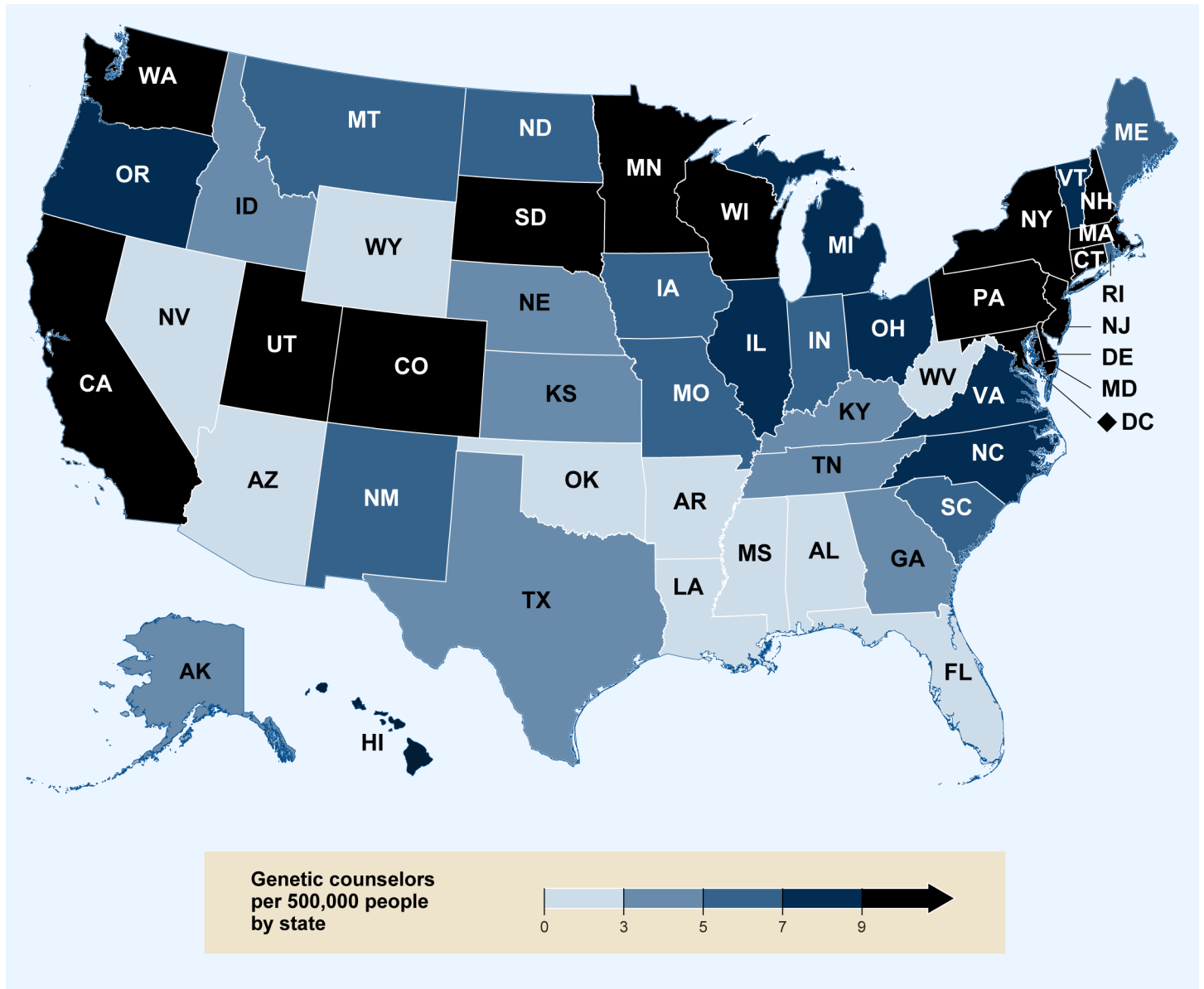
Number of Genetic Counselors and Medical Geneticists Vary by Region and State across the United States

Number of Genetic Counselors and Medical Geneticists Vary by Region and State, and Primarily Work in Hospital Settings

According to our analysis of data from ABGC, ABMGG, and the Census Bureau, the number of genetic counselors and medical geneticists varies by geographic region and state. Specifically, there are more genetic counselors and medical geneticists per 500,000 people in most northeastern states and some midwestern and western states, while most of the southern states and other midwestern and western states have lower proportions. (See fig. 4 and fig. 5.) According to our analysis, the District of Columbia had the greatest numbers of both genetic counselors and medical geneticists per 500,000 people. Three states—West Virginia, Mississippi, and Wyoming—had less than one genetic counselor per 500,000 people. Similarly, 12 states had less than one medical geneticist per 500,000 people. Of the 12 states, one state—Wyoming—did not have any medical geneticists listed in the data provided by ABMGG.³³ Overall, states averaged seven genetic counselors per 500,000 people, and two medical geneticists per 500,000 people, according to our analysis.

³³The 12 states are Alaska, Arizona, Idaho, Kansas, Kentucky, Mississippi, Montana, Nevada, North Dakota, Oklahoma, Rhode Island, and Wyoming.

Figure 4: Distribution of Genetic Counselors per 500,000 People by State, 2019

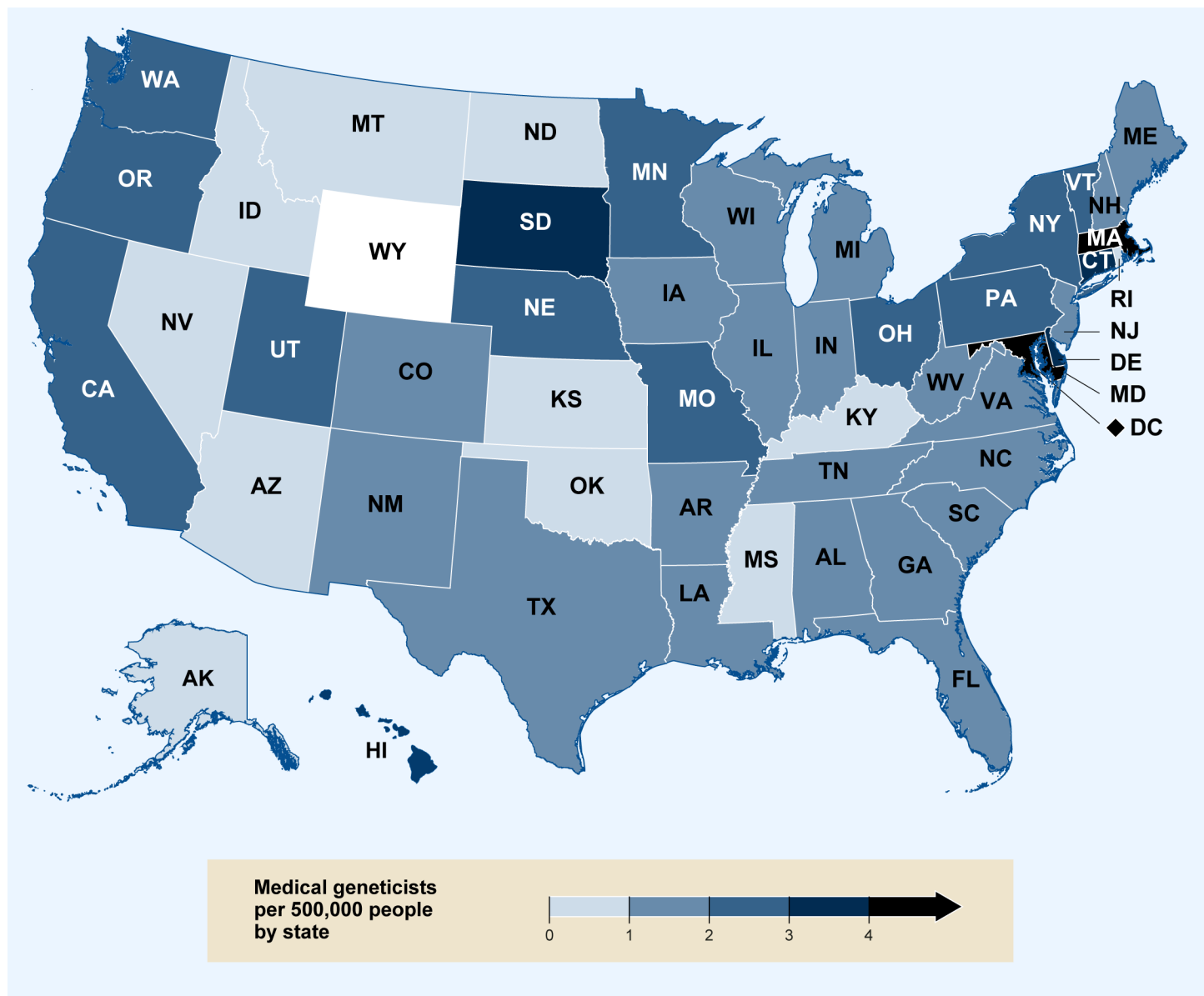


Source: GAO analysis of data from the American Board of Genetic Counseling and Census Bureau; Map Resources (map). | GAO-20-593

Note: The distribution of genetic counselors by state population is based on data from the American Board of Genetic Counseling (ABGC) showing approximately 4,700 certified genetic counselors in the United States as of December 2019. When we analyzed the data, we removed individuals residing in any country other than the United States and adjusted for missing values and duplicate records. The data may slightly overestimate the number of genetic counselors in a state, because, according to ABGC officials, the data may not account for all instances of deaths, retirements, or genetic counselors who are no longer actively practicing. In addition, the number of certified genetic counselors may include those in direct patient care roles and non-patient care roles, such as industry

and research. Data provided to us on the location of genetic counselors could be a residence or work location.

Figure 5: Distribution of Medical Geneticists per 500,000 People by State, 2020



Source: GAO analysis of data from the American Board of Medical Genetics and Genomics and Census Bureau data; Map Resources (map). | GAO-20-593

Note: The distribution of medical geneticists by state is based on data from the American Board of Medical Genetics and Genomics (ABMGG), which showed about 1,240 certified medical geneticists

by state as of April 2020. According to ABMGG officials, the number of medical geneticists may be slightly overstated, because of limitations in identifying and removing medical geneticists who are no longer practicing; for instance, due to retirement. The data on medical geneticists was based on practice location. Our calculation of the proportion of medical geneticists per 500,000 people was based on 2019 Census Bureau estimates.

Identifying the number of available genetic counselors across states is complicated by the fact that some of these providers have the capacity to practice in more than one state.³⁴ ABGC officials stated that genetic counselors who provide telegenetics services—the delivery of genetic services via telephone or videoconference—may reside in one state, but provide services in other states. Therefore, the geographic spread of certified genetic counselors may not be representative of where patients are receiving care. According to ABGC officials, there are a number of genetic counselors working in telegenetics, but it is not clear how many.

Both genetic counselors and medical geneticists primarily work in academic medical centers and other hospital settings. According to a 2019 genetic counselor workforce survey conducted by NSGC, approximately 60 percent (1,462 of 2,367) of respondents report working in an academic medical center or other hospital setting.³⁵ (See table 3.) Medical geneticists are similarly located. According to the ACMG 2019 survey, 73 percent of respondents (357 of 490) reported their primary practice facility to be an academic medical center; the remaining respondents reported their primary practice facility to be the following: 11 percent (54 of 490) private practice; 8.6 percent (42 of 490) community hospital; 6.5 percent (32 of 490) other location; and 1 percent (5 of 490) commercial laboratory.

³⁴According to an ABGC official, data provided to us on the location of genetic counselors could be a residence or work location.

³⁵NSGC reported they electronically administered their Professional Status Survey from January 7, 2019, through February 28, 2019 to genetic counselors in the United States and Canada who are either full or new members of NSGC, or newly certified by ABGC. NSGC received 2,438 completed surveys of 4,996 distributed, resulting in a 49 percent response rate. NSGC's 2019 survey included the following categories under "Employer Work Settings": University Medical Center, Public Hospital/Medical Facility, Private Hospital/Medical Facility, Diagnostic Laboratory - Commercial, Non-Academic, Diagnostic Laboratory - Commercial, Academic, among others. For the purposes of our analysis, we combined the number of respondents who indicated University Medical Center or Public Hospital or Private Hospital work settings into a single Hospital work setting.

Table 3: Genetic Counselor Primary Practice Work Setting, 2012-2019

Year ^a	Academic medical center (percentage)	Hospital (percentage) ^b	Diagnostic lab (commercial, non-academic) (percentage)	All other (percentage)
2019	30.9	30.9	16.2	22.0
2018	30.0	30.6	18.2	21.2
2016	30.3	31.6	17.2	20.9
2014	33.6	37.4	13.9	15.2
2012	36.0	33.4	8.8	21.8

Source: National Society of Genetic Counselor Professional Status Surveys, 2012-2019. | GAO-20-593

Notes: The response rate for the National Society of Genetic Counselors' (NSGC) 2019 Professional Status Survey was 49 percent (2,438 responses out of 4,996 administered surveys). NSGC's 2020 Professional Status Survey had similar results. Approximately 62 percent (1,635 of 2,614) of respondents reported working in an academic medical center or other hospital setting. The survey response rate was 50 percent (2,691 responses out of 5,427 administered surveys).

^aFrom 1980 through 2018, NSGC administered their Professional Status Survey on a biennial basis. In 2019, NSGC began administering parts of the survey annually.

^bThe hospital work setting category represents genetic counselors who responded to the National Society of Genetic Counselors Professional Status Survey as working in either public or private hospitals. Examples of "other" work settings include health maintenance organizations, not-for-profit organizations, and telegenetics companies, among others.

Regional Genetics Networks Have Strategies to Increase Access to Genetic Services

Officials from both the Western and Mountain States RGNs—programs funded by HHS to increase access to genetic services for populations and regions throughout the United States and its territories—told us that telegenetics provided by genetic counselors and medical geneticists is one way to increase access to genetic services for rural populations in their regions. An official at one RGN told us that during the Coronavirus Disease 2019 pandemic, there has been an increased use of telegenetics to provide genetic services. An official at the Mountain States RGN stated that because certain areas of their region—such as rural areas of Colorado—do not have access to a local medical geneticist, telegenetics is a helpful strategy for medical geneticists to see patients in those areas. In addition, the official told us, the RGN partners with other RGNs on telehealth training and they developed a regional map of providers—including telehealth clinics—so that families can find the closest clinic offering these services. According to an official at the Western States RGN, one of their goals for telegenetic services is to facilitate access for families who would otherwise have to drive several hours for diagnostic appointments and follow-up visits. The official explained that the Western States RGN developed and operates, along with other RGNs, a telegenetics training program for genetic providers. According to ABGC officials we interviewed, telegenetics has helped provide access to services for people in areas that do not have access to a local genetic

counselor and more companies are emerging to provide telegenetic services.

The Mountain States RGN stated that implementing telegenetics can present challenges. For example, some rural states rely on telegenetics to link patients to care, but these states do not have the capacity to expand their telegenetics services beyond the state's border, because there is so much demand for in-person care within their own state. ACMG officials also noted that a medical geneticist who sees patients in one state, but provides telegenetics services in another, must be licensed in both states, which can be time consuming to obtain. Therefore, unless a medical geneticist is licensed in multiple states, the capacity to provide telegenetics services to patients may be limited to the state in which the medical geneticist is licensed. However, telegenetics may not present the same challenges for genetic counselors, who, as we previously mentioned, can live in one state, but provide services in another state.

Officials at both RGNs we interviewed told us about other efforts to increase access to genetic services, including conducting outreach to other types of providers about genetic testing and genetic diseases, and increasing the number of genetic providers from minority backgrounds. For example, because patients in the region are often on wait lists to see a medical geneticist, the Mountain States RGN provides resources and simple instructional materials to primary care providers so they can begin preliminary evaluations and determine what referrals to make. The Western States RGN developed a national mentoring network program to support current minority genetic providers and encourage minority students to become genetic providers. According to one Western States RGN official, the program assigns mentors to minority genetic professionals to help guide them through their training and workplace experiences.

Agency Comments and Third Party Views

We provided a draft of this report to the Department of Health and Human Services and the Department of Labor for review and comment. The Department of Health and Human Services provided technical comments, which we incorporated as appropriate. The Department of Labor told us they had no comments on the draft report.

We also provided relevant portions of the draft report to the seven professional organizations and two RGNs that we interviewed. Officials from ABGC, ACGC, ACMG, AGCPD, NSGC, and both RGNs provided technical comments, which we incorporated as appropriate.

We are sending copies of this report to the appropriate congressional committee, the Secretary of Health and Human Services, the Secretary of Labor, and other interested parties. In addition, the report is available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or cosgrovej@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix II.

A handwritten signature in black ink, appearing to read 'James Cosgrove', with a stylized, cursive script.

James Cosgrove
Director, Health Care

Appendix I: Professional Organizations in our Review

Table 4: Professional Organizations in our Review

Professional organizations	Area of focus
American Board of Genetic Counseling (ABGC)	ABGC is the certification body for genetic counselors, which develops the certification exam, and manages recertification for genetic counselors.
American Board of Medical Genetics and Genomics (ABMGG)	ABMGG is the certification body for medical geneticists, which develops certification exams and manages recertification.
Accreditation Council for Genetic Counseling (ACGC)	ACGC is the accreditation body for genetic counseling training programs in the United States and Canada.
American College of Medical Genetics and Genomics (ACMG)	ACMG is an interdisciplinary professional membership organization comprised of clinical geneticists, genetic counselors, and other medical genetics professionals.
Association of Genetic Counseling Program Directors (AGCPD)	AGCPD is comprised of genetic counseling program directors and aims to facilitate recruitment, admissions, and give guidance to genetic counseling students.
American Society of Human Genetics (ASHG)	ASHG comprises over 8,000 members in the United States and other countries. The society seeks to advance human genetics and genomics in science, health, and society through excellence in research, education, and advocacy.
National Society of Genetic Counselors (NSGC)	NSGC promotes the professional interests of genetic counselors and provides access to continuing education opportunities, professional resources, advocacy, and discussion of issues relevant to human genetics and the genetic counseling profession.

Source: GAO | GAO-20-593

Appendix II: GAO Contact and Staff Acknowledgments

GAO Contact

James Cosgrove, (202) 512-7114 or CosgroveJ@gao.gov

Staff Acknowledgments

In addition to the contact named above, Lori Achman (Assistant Director), Maggie Holihan (Analyst-in-Charge), Ashley Nurhussein, and Marie Suding made key contributions to this report. Also contributing were Krister Friday, Sarah Harvey, Cynthia Khan, Yesook Merrill, Laurie Pachter, Eric Peterson, Ethiene Salgado-Rodriguez, and Jennifer Whitworth.

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