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Regional models of genetic services in the United States

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Purpose: To outline structures for regional genetic services support centers that improve access to clinical genetic services.

Methods: A workgroup (WG) and advisory committee (AC) (1) conducted a comprehensive review of existing models for delivering health care through a regional infrastructure, especially for genetic conditions; (2) analyzed data from a needs assessment conducted by the National Coordinating Center (NCC) to determine important components of a regional genetic services support center; and (3) prioritized components of a regional genetic services support system.

Results: Analysis of identified priorities and existing regional systems led to development of eight models for regional genetic services support centers. A hybrid model was recommended that included an active role for patients and families, national data development and collection, promotion of efficient and quality genetic clinical practices, healthcare professional support for nongeneticists, and technical assistance to healthcare professionals.

Conclusion: Given the challenges in improving access to genetic services, especially for underserved populations, regional models for genetic services support centers offer an opportunity to improve access to genetic services to local populations. Although a regional model can facilitate access, some systemic issues exist—e.g., distribution of a workforce trained in genetics—that regional genetic services support centers cannot resolve.

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INTRODUCTION

Increasing genetics and genomics knowledge of health-care professionals and the general population promises disease prevention, improved diagnosis, and innovative treatments of genetic conditions. However, limited access to genetic services for many individuals remains a problem (Alexander et al., 2015). In 2004, the Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB/HRSA), Genetic Services Branch (GSB) awarded grants to establish seven Genetics and Newborn Screening Regional Collaborative Groups (RCs) and a National Coordinating Center (NCC) as part of efforts to improve the health of children and their families. Their goal is to promote the translation of genetic medicine into public health and healthcare services.

In 2015, the NCC began a process of assessing what models of regional genetic services support centers might help close gaps in access to genetic services. In addition, the process considered how future genetic services might be designed/defined given the increased role of non-genetic service providers, the shifting healthcare environment within the United States, and future technological developments within the science of genetics and genomics. Primary care professionals and other specialists, rather than genetic services providers, will be expected to not only oversee the long-term management of a clinical condition, but also to understand the genetic risk factors underlying the condition and how genetics will affect treatment options for the individual patient. Movement toward implementing precision medicine paradigms will further introduce pressures to increase genetic considerations into practice models.

Identifying the structures required for the delivery of genetic services and the indicators of quality, effectiveness, and success of genetic services requires definition of the overall aims and elements of clinical genetic services. For the NCC assessment process, genetic services were divided into

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family-focused clinical services and population-based services. Objectives of genetic services encompass genetic testing, diagnosis, counseling, follow-up, support services to extended families, education, and coordination of health surveillance.

This report summarizes the data gathering and analysis of the Regional Support Services Model Workgroup (WG) and Advisory Committee (AC), established by NCC to outline structures for regional genetic services support centers that improve access to clinical genetic services. The WG and AC recognized that the use of recent technologies, especially in healthcare informatics and telehealth, might increase access and quality of service delivery and thereby address unmet needs for genetic services. Recommendations to address some systemic barriers, including the variability and number of health insurance plans and the variability of their essential genetic services, lack of mandatory coverage for certain important services, and low payment for cognitive as opposed to procedural work, were beyond the scope of this project. Rather, the WG was asked to consider ways in which various service model structures might improve access in the face of these barriers. Other barriers, such as licensure across state lines and an inadequate focus on the mental health domain, were considered to be within the broad scope of this review. Redefinition of the roles of primary care providers, subspecialists without genetics training, and genetic counselors were also considered as a method to improve quality and access to genetic services.

MATERIALS AND METHODS

The WG conducted a literature review seeking published data and information on genetic service delivery models[1–12] using the following key words: genetic service delivery, regional models, public health genetics, regional health systems, healthcare services delivery. The WG then focused on two sets of information: need for genetic services and the infrastructure needed to deliver those services. First, NCC and the National Genetics Education and Consumer Network (NGECN) conducted an assessment of the need for genetic services. This assessment began with stakeholder listening sessions from January through July 2015 for stakeholders not engaged in the current regional genetics collaborative system. Stakeholders were identified through open solicitation of American College of Medical Genetics and Genomics (ACMG) members, Family Voices members, American Academy of Pediatrics (AAP) Genetics workgroup, regional genetics collaboratives, public health genetics professionals, and consumer organizations. The in-person and telephone-based sessions asked at least the following four broad questions, but were otherwise unstructured and open-ended: (1) How do you define genetic services?, (2) What are existing gaps in genetic services?, (3) What are existing regional models that should be considered?, and (4) What key elements should a regional genetic support service center model contain? The sessions offered insight into how genetics professionals, consumers, public health, and primary care providers perceived the current gaps in services. These sessions, with more than 250 participants, formed the basis for the NCC and NGECN-led national needs assessment surveys conducted in late 2015 with consumers, genetics professionals, public health, and primary care professionals (NCC provider survey, fall 2015, 924 respondents; NGECN consumer survey, fall 2015, 1355 respondents). Data from the surveys were provided to the WG and AC[13] and were analyzed to identify priorities for future regional genetic services support centers. Based on the priorities identified from the needs assessment surveys, the WG developed an initial set of 25 components to be included in future regional genetics services support centers. By combining similar components, this list was refined to 15 priority needs that were grouped into 6 categories (Table 1).

Next, the WG reviewed existing national and regional centers supporting individuals and their families with genetic and other conditions. Thirty-five service centers providing regional care were identified via the listening sessions, along with AC and WG member recommendations. Ultimately 14 centers were prioritized for review based on a survey sent to the WG and AC; they were then reviewed using a center review template. The service centers chosen represented diverse programs serving individuals and their families with genetic and other conditions and providing services at the state, regional, and/or national levels. See Table 2 for reviewed centers, and Table 3 for the center review template.

The WG and AC included center characteristics as components of model systems based on information received from the centers; for example, no center provided onsite mental health services, so this characteristic was not included as a characteristic as models were proposed. However, characteristics considered as high priority in the needs assessment, such as inclusion of families in decision-making roles, were included in final recommendations even if not identified in reviews of the 14 centers. As a result of this process, the WG and AC identified eight models. These models sought to identify possible organizational structures and overall purposes of these structures. Each model's advantages and disadvantages were identified by the WG and AC. The AC provided the WG oversight and reviewed the products of the WG. Together, the AC and WG proposed a series of recommendations, based on considerations of local, regional, and national needs, to build a system to improve access to genetic services.

RESULTS

Review of the 14 centers showed great variability in mission, resulting in highly individualized organizational structure, budget, source of funding, populations served, services provided, staffing, and ability to measure impact. Key themes across all reviewed centers included the following: a regional collaborative structure with a central coordinating office can facilitate sharing of resources; technical assistance (e.g., telehealth) can expand the availability of health care to underserved populations; and workforce issues are real, which limits the expected role of the specialist. The eight models

Table 1 Identified priorities based on national needs assessments and potential strategies to address them (not ranked; listed alphabetically)[1]

Data collection
• Facilitate the acquisition of new knowledge
• Utilize appropriate existing data sources
Education and training on genetics for non-genetic providers
• Provide access to appropriate genetic resources
• Facilitate ongoing relationships between nongenetics and genetics providers
• Provide genetic consults for non-genetic providers (more like ECHO and less like a direct service)
• Increase public education
• Target education at points of care, e.g., federally qualified health centers (FQHCs) and other large providers that don't focus on genetics
Efficient practice
• Enhance effectiveness of workforce through telegenetics and other service delivery models
• Promote and facilitate entry into the field (workforce)
Formal relationships with state public health, healthcare institutions, and university centers
• Develop contract and/or partnerships agreements for specific services, e.g., provide telemedicine support in your institution, report specified data, provide referrals to specialists
• Formalize relationships between institutions, health departments
• Facilitate partnerships to bring resources to the table
• Provide technical assistance to states with no genetics beyond newborn screening (NBS) to internalize the importance of genetics in public health at a state level, e.g., cancer
• Work actively with Medicaid
• Demonstrate a minimum set of core partnerships (e.g., Medicaid, Department of Health, university centers, Title V)
Practice support
• Support authorization and reimbursement (including billing and insurance)
• Support contractual services
• Support medical home model
• Connect with or provide access to national level expertise
Promotion of family engagement
• Facilitate finding and providing ongoing care to underserved families and groups (broadly defined; underserved may include initial services)
• Detect health disparities
• Consider health equity
• Identify relevant resources and supports including where to find providers with knowledge of the condition
• Enhance availability of social and emotional support
• Improve care coordination
• Provide information to consumers on tests and treatments for their conditions
• Assure information is delivered at the right time, as part of a standard of care and is provided where people are receiving care

Table 2 Reviewed regional centers

California Genetic Disease Screening Program (GDSP) Regional Newborn Screening Model
Cystic Fibrosis Centers/Cystic Fibrosis Foundation
East Anglia Regional Genetics Services (a unit of United Kingdom Clinical Genetic Services)
Geisinger Health System
Hawaii Department of Health Genomics Section/Hawaii Community Genetics
Hemophilia (Thrombosis) Treatment Centers: National Hemophilia Program
Muscular Dystrophy Association (MDA) Clinics
National Coordinating Center (NCC) and the seven Regional Genetic Service Collaboratives (RC)
National Down Syndrome Society
State of Alaska Genetics and Birth Defects Program
State of Alaska Metabolic Clinic
Seattle Children's Hospital
Veteran's Administration Genomic Medicine Service (Telegenomics Program)
Washington State Department of Health: Regional Genetics Clinics

Table 3 Template elements

Item	Description
Mission	Includes specific services that the agency engages in to address the mission
Organizational structure	How is the organization organized internally (e.g., hub and spoke model)? Nonprofit, for profit, government agency? Number and locations of regional centers
Patients/populations served	Indicate population the center is attempting to reach (e.g., all individuals with Down Syndrome in a state) and the actual number served (within the context of a time frame)
Services provided	Direct care, enabling, infrastructure building, population-based, etc.
Funding	What is the source of funding and the amount of funding over a specified period of time? Include mechanism for how funds are distributed (e.g., accreditation, reimbursement, satellite offices) and percentage from all funding sources; if there is a central coordinating body, how is it funded? (excluding physician fees unless the central coordinating body is the recipient or payer of such fees); include budget when available (if not available, include % of budget used for services being described)
How do they reach underserved populations (if they do)?	
Cross-state line challenges (licensure, etc.)	
Impact	How do you measure the impact and/or success of your services? Please share any data you have on impact or outcomes
Mental health services provided	
Resources	Is there a set of resources that the central coordinating body makes available to satellite centers? If so, what are these resources?
How does an entity (clinic, provider, etc) become a part of the system?	Application, evaluation process, etc.
Staffing	Are there staffing issues, who is a part of the team?
Telephone consultation	Telemedicine technology (current or planned usage)
Please list any gaps/barriers that you (as the reviewer) have identified through the review process	

identified by the WG and AC are shown in Table 4; each model emphasized one of the following priorities: regionalization with state teams, local clinical support, education and technical assistance, patient engagement, public health, quality improvement, regional clinical support, and data collection. Focus on these individual priorities allowed the WG and AC to assess the feasibility of recommending a center structure that utilized all available resources for a well-defined but single purpose. The advantages and disadvantages of the different models were compiled by the WG and AC and are shown in Table 5.

DISCUSSION

Following review, the AC and WG proposed adoption of a hybrid model combining components of models 1, 2, and 3. Each of these three models utilized a regional infrastructure. Model 1 built upon the regional infrastructure, including public health and health-care professionals and families, to develop a team of stakeholders and implement projects to improve access to genetic services. Model 2 promoted efficient practice within genetic centers: technical assistance (TA) for telegenetics, TA for authorization of genetic testing and other genetic services, TA for genetic counselor licensure and billing, and other activities as identified through interaction with genetics providers. Model 3 emphasized aggressive and targeted support of nongenetics providers through promotion of their relationships with genetic centers, provision of point-of-care decision support tools, and development of other tools to enhance the level of care that can be delivered in conjunction with but outside of the genetics center itself. The hybrid model included all of these elements, although the WG and AC recognized that some issues might remain unaddressed.

The WG also identified two overarching principles that should guide the development of future genetic services support centers: (1) family engagement, including inclusion of family advocates in leadership roles, is fundamental to future genetic services support centers; and (2) the goals and activities of regional genetic services support centers should be similar enough to allow identification of meaningful national outcome measures and quality of genetic services. However, these national activities and goals should not preclude regional-level innovation. In addition to the overarching principles noted above, the WG and AC recommended that four key components be included in future regional genetics support service centers. These components were identified based on center reviews as well as the experience of WG and AC members in delivery of genetic services and in public health genetics:

1. A regionalized structure. This structure is envisioned as collaborative, with interventions at the delivery system level. This structure permits attention to geographic and demographic factors that vary across the United States (e.g., northeastern United States versus western United States, including Hawaii and Alaska). Such attention can increase access to genetic services by permitting the design of interventions that make sense in some regions but not in others. This recommendation was based on reviews of other regional infrastructures (e.g., cystic fibrosis centers); it leverages the success of the current regional infrastructure as a framework for bringing together genetics stakeholders and establishing relationships among diverse partners.
2. Coordination through a central coordinating body. Central coordination, through a collaborative process, ensures that the support centers adopt national goals and implement them to permit national data collection demonstrating national outcomes.
3. Integration within the health-care delivery system. This is a requirement for meaningful impact on access to genetic services. Providers and consumers agreed that substantial

Table 4 Eight regional models

Model 1: Regional genetic service resource network. A regional infrastructure with a central coordinating body. Regions would work with states, providers, and consumers to develop a team of stakeholders and implement projects that improve access to genetic service. Goals and priorities for these projects would be congruent with guidance provided by the Genetic Services Branch (GSB) and Health Resources and Services Administration (HRSA). Specific project deliverables would be consistent with regional needs. This model could utilize elements of the below models as project deliverables.
Model 2: Regional clinical support centers. Using a regional infrastructure, the focus would be on clinical providers, public health genetics, or both with activities limited to supporting clinical services through technical assistance (e.g., telemedicine), clinical support (education), care coordination, evaluation, and workforce capacity.
Model 3: Regional genetics education and technical assistance centers. A regional infrastructure would focus on both clinical and public health providers. Primary focus is on development of materials and/or education similar to the ECHO model, and public health and non-genetics provider education timed to the right time and place.
Model 4: Regional patient engagement centers. Regionalized centers would pursue activities focused on consumers. Primary partners may be Genetic Alliance, public health departments, or both. Activities would be limited to administration, patient engagement including care coordination, and education.
Model 5: Public health model. This model could be administered by a central coordinating body, only regional centers, or both. This would address public health concerns (e.g., policy development), and funding would support a state genetics coordinator in each state. The coordinator would work with individuals in genetic and chronic disease offices through Title V. The main role would be to build a tight integration with the public health workforce that would demonstrate and eventually address need.
Model 6: Quality improvement model. A regional infrastructure with a centralized coordinating body would engage in activities focused on a plan to develop, implement, and evaluate *formal* quality improvement processes to improve access. This could be a single project across the country. A modification could be a national quality improvement (QI) focused project, with a proportion of funds at the Regional Collaborative Group (RC) level supporting RC-specific projects.
Model 7: Regional clinical support network. Regions provide clinical services via local or state clinics receiving funds from regional centers to meet specific and unique needs as identified by the local/state centers. A national coordinating body would coordinate the regions, and specific goals and objectives would be established for each local/state clinic at the start of each funding period.
Model 8: Genetic service data centers. This model could utilize a regional infrastructure, where the central coordinating body would work with HRSA to determine the data of interest and possible national data sources. Regional centers would work with clinical entities, consumers, and states to collect data related to access to genetic services, focusing on where patients are, their demographic and clinical characteristics, when and where they receive services, and gaps in service.
Recommended hybrid model:
Genetic services support model: This model would have a primary focus on promotion of efficient practice within genetic centers (technical assistance [TA] for telegenetics, TA for authorization of genetic testing and other genetic services, TA for genetic counselor licensure and billing; other activities as identified through interaction with genetics providers), and aggressive and targeted support of nongenetics providers through promotion of other tools to enhance the level of care that can be delivered in conjunction with, but outside of, the genetics center itself.

day-to-day systemic challenges at all levels (provider, consumer, insurer, and clinic) prevent identification of patients needing services, referral, authorization, and timely provision of services. Active engagement with clinicians in their daily patient care activities (e.g., technical assistance in the development of telegenetics, design and monitoring of quality improvement projects, assistance in strengthening relationships between genetics providers and primary care providers) is critical if resource centers are to impact access.

4. Coordination/collaboration with state public health departments. States have a key role in identification, assessment, policy development, and assurance for individuals and populations in need of genetic services. Therefore, they must function with the health-care delivery system and consumers as all grapple with day-to-day systemic challenges of providing care. As examples of effective state engagement in genetic services, Hawaii and Washington public health departments have had a central role in reaching underserved populations through support of genetics outreach services and genetics professional recruitment.

The relationship of future regional genetics support service centers to state public health departments should be region-specific, taking into account the current commitment of individual states to genetic services, since there is wide variability in state fiscal and infrastructure commitment to genetics. Engaging all state public health departments within future regional service support centers will provide twofold benefit: where a state's commitment is limited, future support centers' activities should emphasize information exchange, partnerships and mentoring opportunities, and policy development for genetic conditions of public health impact. States that have invested significant resources in genetics have an integral role in regional centers. Such states demonstrate what

Table 5 Model Advantages and Disadvantages

Model	Advantages	Disadvantages
Regional genetic service resource network	• Team approach • Familiar structure for current HRSA regional collaboratives and other centers; would permit HRSA to build on what has been learned, using existing or similar infrastructure • Looks at a wide range of issues/priorities • Region could focus on what is lacking most for the region within the context of the goals of HRSA • Training could be administered readily; fellowships could be supported as well; genetic counselor training could also be supported • Center could be used to facilitate relationships between states, genetics providers, nongenetics providers, consumers, other existing programs • Demonstrating national impact is achievable if common goals/objectives	• Current RCs still not widely known; use of this structure would require aggressive promotion of the system to improve access • Core outcomes could be defined, but if each region uses own methodology, based on regional needs, identifying common elements to measure outcomes could be difficult; some consistency with other HRSA programs also desirable • Lack of consistency in outcomes could affect funding in the long run • Demonstrating national impact difficult if regional activities highly variable • Work needs to be done within the health-care delivery system to impact access
Regional clinical support centers	• May address workforce capacity • Promote efficiency • Most ability to get data for individual sites—clinical site data • For some payers, a national system may be OK • Other product development possible	• May not be needed in all regions • Limits services provided to other specialists and primary care providers • Education component for nongeneticists is not covered • Patient engagement component is left out • Health plans and structures vary so may not be able to provide national data on some access issues
Regional genetics education and technical assistance centers	• Easier to do than some other suggested models • Much of the work could be done using online methodology • Would maximize impact of limited dollars • Potential for broad reach • Broad expertise exists in the field • Simpler system: billing/reimbursement is difficult but straight education is easier • Providers need just-in-time materials; webinars could be used	• Focusing on providers and public education means we could miss consumers; need to include consumers in education • Difficult to measure behavior change following an educational program; difficult to show clinical impact (improved access) • Disease-specific educational materials are more beneficial but can be difficult to develop • Need capacity to develop and distribute just-in-time materials at sites where needed • Would have to be driven by other national organizations (AAP) to get into training programs
Regional patient engagement centers	• Addresses some high-need areas based on feedback from the survey: people aren't getting information they want/need (low literacy, other languages) • Potential outcome measures are close to HRSA goals (getting patients to services)	• Difficult to address in stand-alone centers • Outcome measures may be difficult • Information-seeking individuals will be helped but may not reach entire population • If workforce capacity issue isn't addressed, an influx of people could be entered into the system without appropriate workforce • Not addressing clinical/delivery systems; therefore doesn't address underlying issues
Public health model	• Enhanced data collection by state genetics coordinators • Increased access to individuals not getting services through coordination with Title V, Medicaid, and chronic disease programs • Many issues preventing access are at the state level • In a mixed model (combining elements of different models), some regions could support programs to provide information to state public health as needed by individual states • Easy access to other large public health programs (Medicaid, Title V) • Helps build relationships within state health departments and may provide access to other state budgets for specific programs (if genetics program budget isn't available); once matured there should be a return on investment • Regional centers would have no control over states but NCC/RC system has built state NBS capacity, suggesting this is a feasible model • Structure within states can be a sustainable model	• Some states may be unwilling or unable to accept small amounts of money available through these grants • Some states may not wish to accommodate this position within their state structures • There needs to be a state champion for genetics beyond the coordinator • Success is dependent on genetics coordinator being high enough in the state structure to be effective • May have an issue filling 50 slots for coordinator with a trained genetic counselor (workforce issue); salary may not be as competitive as industry; may need to recruit professionals with other backgrounds • Coordinator requires time to develop relationships, work with other units in the department to create/fund programs to address clinical, educational needs
Quality improvement model	• Validated method, evaluation built in, outcomes reportable • Could put almost any activity around access into a PDSA; in the absence of national baseline data, QI effort would address a specific problem, as opposed to all problems); development of metrics in genetics would be useful • Single national unified project would permit national data collection and outcomes assessment • Could permit coordination with MOC activities for providers • Many access problems could be addressed using QI methodology	• Higher cost • Would require a planning phase, lag likely in getting to data collection (identify methodology first, then start data collection) • Genetics professionals unfamiliar with QI and implementation science would require additional education. • Measurable outcomes from QI might not immediately promote access. • A single national QI focus may not be applicable to all regions. However, selection of regional QI projects would limit national data collection and outcomes assessment • Systemic issues related to genetic access seem too big for some QI approaches • Could end up with a number of pilot projects that might differ; local data easy to get, but national data difficult to collect
Regional clinical support network	• Trackable outcomes as long as effectively communicated between center and clinics • Could enhance funding already in place if state does have contract funding • States could coordinate their support of genetic services with resource centers, so that	• Regional centers would focus on contracting and evaluating; less than 12 months to contract, complete the work, evaluate is a problem • A lot of contracts with very little money depending on the state; could enhance the

Table 5 continued

Model	Advantages	Disadvantages
	funds could be equitably distributed • Takes advantage of mechanisms already in place in some states to contract out services	maldistribution of dollars • Because clinical centers must apply for funds to meet their specific needs, funds may not be distributed to the communities efficiently or equitably
Genetic service data centers	• Gets national, uniform baseline data • Allows measurement of impact of future programs • Data for policy development • National data set would be useful in informing the greater medical community • Could address health equity issues: drill down to different conditions, populations to identify regional and local needs • Reinforce formal relationships with state programs, can create data together so may not need to give money to state • Works well with meaningful use standards • Delays action steps until baseline data collected	• Does not improve access initially: no "action" steps until data are collected and analyzed to identify needed actions • Long-term results will be years from initiation of grant cycle; therefore more difficult to get buy-in from partners who would need to provide data • Would need to build in time to choose core data set (what to collect and from whom); also need time to define and create formal relationships with clinical programs and states • Would have to pay for data entry into a regional/national repository • This would be an all-consuming endeavor, and would obviate all other activities • States often don't have data on non-NBS conditions; would require data from clinical sites and other sources
Recommended hybrid model: regional genetic service support model	• Regions would focus on what is lacking most for the region within the context of the goals of HRSA as identified in this model (improved practice efficiency through technical assistance; nongenetics provider education using just-in-time point-of-care tools) • Center would be used to facilitate relationships between states, genetics providers, nongenetics providers, consumers, other existing programs; improved relationship would provide information on tailoring specific programs to the region • Demonstrating national impact is achievable since common goals/objectives are required • Should improve access to genetics services	• Core outcomes could be defined, but if each region uses own methodology, based on regional preferences, collection of comparable data may not be possible; some consistency with other HRSA programs also desirable • Lack of consistency in outcomes could affect funding in the long run • Demonstrating national impact difficult if regional activities highly variable • Work needs to be done within the health-care delivery system to impact access, requiring development of robust relationships with providers

AAP American Academy of Pediatrics, *HRSA* Health Resources and Services Administration, *MOC* maintenance of certification, *NBS* newborn screening, *NCC* National Coordinating Center, *PDSA* plan-do-study-act, *QI* quality improvement, *RC* Regional Collaborative Groups.

an expanded state engagement in genetics produces, and they can mentor other states as they enhance their genetics programs. HRSA, through MCHB and GSB, could model support for genetic services via prioritizing genetics objectives throughout MCHB programs and enhancing the role of genetic services in broader access to service programs, such as Title V.

The WG and AC recognized multiple remaining critical gaps in providing access to genetic services that extend in time, scope, and financial reach beyond what likely future regional genetic service support centers could address. These gaps fall within two general areas: workforce and data. Workforce gaps include provision of nongenetics provider education; support for increasing the number of physician geneticists, genetic counselors, and other highly specialized providers for treatment of genetic conditions (e.g., dietitians for metabolic conditions); and provision of mental health services for those impacted by genetic conditions. Genetics data gaps are systemic, in that there currently is no collection of robust national and regional data on access to genetic services. The WG and AC recommended that GSB and HRSA begin to address these gaps through internal resources and collaborations with national professional organizations.

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DISCLOSURE

The authors declare no conflicts of interest.

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