Improving Access to Genetic Services:
A Regional Genetics Reference Guide
to Needs Assessments and
Community Partnerships

HEARTLAND
GENETICS SERVICES
NETWORK

National Genetics Education
and Family Support Center

Acknowledgements

A special thank you to Perry Summers and Elise Sobotka who led the development of this resource. We are also grateful to all of the individuals who supported this project and the development of this resource, including: participating representatives from the Regional Genetics Networks and the National Genetics Education and Family Support Center.

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INTRODUCTION & BACKGROUND

This is a reference guide to provide Regional Genetics Networks (RGNs) with tools, resources and real-world case studies for the purposes of conducting needs assessments and partnering with a wide range of patient communities. Multiple external resources are linked throughout this document. RGNs can use this guide to help:

- Identify underserved populations and their specific barriers to genetic care.
- Develop culturally and linguistically appropriate practices that are respectful of diverse communities.
- Understand how to develop relationships with community partners and work together to conduct a needs assessment, as well as identify resources available to support these activities.
- Build on existing strengths within the network to expand upon strategies for working with diverse communities.

ADDRESSING THE NEEDS OF MEDICALLY UNDERSERVED POPULATIONS

While general healthcare services are distributed throughout rural and metropolitan areas, specialty healthcare services are frequently concentrated in high population density areas.[1] Genetic services and genetic testing are examples of this pattern, making it difficult for many patients who need genetic services to access them. Individuals who live in metropolitan areas and/or have sufficient health insurance and financial reserves to pay for genetic testing can access needed genetic services. But more effort needs to be made to ensure that *all* populations who need genetic testing and services have access to medically necessary care, independent of region or insurance access.

There are likely to be population groups in all regions, states, and communities who are not able to fully access and utilize genetic services. This may result in limited disease monitoring and prevention efforts, delayed or foregone diagnosis and treatment for chronic diseases, resulting in poor-quality health outcomes.[2]

While members of any social, cultural, or ethnic group may be underserved as a result of socioeconomic or geographic factors, some populations face additional barriers to healthcare access that members of majority populations do not face.[3] Members of these underserved communities may contend with additional financial burden (travel, accommodations/meals and time away from work) and also leave their family and social supports to obtain the medical services they need. Genetic testing providers must take cultural differences, as well as geographic and socio-economic issues into account when designing policies, practices, procedures, and services that can increase patient access to these services.

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To maximize success, providers should conduct a needs assessment and establish community partnerships to better understand the barriers to genetic services that exist within a region as well as the desired change a community wants. Using the information gathered in a needs assessment will ensure that improvement efforts are linked to

community needs and goals. Building community partnerships will help build trust and leverage available resources to easily connect families with other support to increase access to genetic services. The following guide aims to help Regional Genetics Network staff understand how to identify underserved populations within a region, connect with them to develop a better understanding of population health care needs, and connect individual families to needed genetic services.

CASE STUDY:
THE HEARTLAND COMMUNITY ACCESS PROGRAM

The following case study provides information on a research project conducted by the Heartland Regional Genetics Network to understand the barriers to accessing genetic services and what genetic service providers can do to provide culturally competent quality care for Hispanic patients. The information below can be used by groups wanting to partner with local populations and identify barriers to care.

DESIGN AND IMPLEMENTATION OF A NEW SERVICE MODEL

The Heartland region (Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota) is home to a rapidly growing Hispanic population, particularly in its rural areas. This growing community faces significant barriers in accessing adequate medical care.[4] The Heartland Genetic Services Network (Heartland) formed the Hispanic Access Project to identify specific barriers that Spanish-speaking families experience when attempting to locate and access genetic services for children with genetic conditions.[5] Over a period of nearly three years, the group built strong working relationships with the Hispanic community in Oklahoma, Nebraska and Kansas and conducted detailed interviews with community members in these states in order to better understand the barriers to accessing care for those patients as well as what genetic service providers can do to provide culturally competent quality care for Hispanic patients.[12a]

Analysis of the interview data revealed several key issues that community members strongly believe limit their ability to obtain treatment for their children. [12a] Specifically, interviewees believe that interpretation services are limited and often inadequate, both verbal and written communication problems are frequent during clinic visits, their healthcare expectations, based on their experiences in their native countries, are often not met, and their appreciation of the benefit of receiving genetic services is limited. The Hispanic Access team then reached out to community leaders, healthcare providers who served Hispanic communities in the Heartland region, and parents with affected children to form the Hispanic Access Advisory Committee. With the assistance and support of this expert group, a series of educational materials, including Spanish language educational materials and a video were developed to improve the Hispanic community's access to genetic services.[5]

Beginning in 2017, the Heartland began incorporating the results of the Hispanic Access project into its new program for meeting the needs of underserved communities across the region. They proposed to test the generalizability of new ideas both within the Hispanic community and in other underserved populations in the region. Specifically, they selected the Marshallese population in northwestern Arkansas, Iowa, and Oklahoma. Like the Hispanic population, this group contains a high percentage of persons with limited fluency in English, has been historically mistreated in the past by American healthcare providers (e.g. related to nuclear testing in the Marshall Islands), and faces barriers to accessing health insurance.[6,7] Rather than starting from the very beginning, Heartland has attempted to leverage the findings of its work with the Hispanic community and use it as a template for developing a plan to meet the unique needs of the Marshallese communities.

Heartland's ongoing work with these two populations has resulted in the formulation of a series of tasks to be done when attempting to work with underserved populations and resources to

help regions complete the following tasks.

- Interpreter services within your institution, primary care provider in the community (such as at a federally qualified health center/community primary care clinic), county health department, or the state's minority health commission can assist you in learning more about the community and identifying connectors.
- Connecting with a member of the community who could serve as a liaison is essential. This person could be an interpreter, community health worker, Family 2 Family or Family Voices staff member, health care provider, member of the clergy, or other community leader.
- Keep in mind the data that may be available from the state health department: birth statistics, birth defects, newborn screening, and children with special health care needs programs.
- Attend community events such as health fairs and festivals. If vendor booths are available, host a booth to provide education about genetics services. The rationale is for the community to see the genetics provider IN their community.
- Connect with churches. Many communities rely heavily on the church as a center for education, support, and advocacy. Often, there are ample opportunities to provide community education about genetic services through existing church programs.
- Given the low genetic literacy across the US, generally, it is not surprising that genetic literacy within minority communities is nearly nil. Therefore, asking what may be important to them is critical but may not produce viable results, immediately. Offer to share information that could be important to them, such as carrier testing or newborn screening.
- Follow through on any recommendations or plans that are made. Follow-through will contribute to building trust and relationships.
- Be patient. Building trust and relationships take time. The common ground is that providers and families want what's best for their children. Keep in mind that minority communities have many other pressures related to their basic needs. While they do want what's best for their health, specialty medical services are often postponed so that more pressing needs are met first.
- Learn. Once relationships and trust are established, take the position of a learner and learn from the community about navigating health care, genetic conditions/birth defects, barriers and facilitators to care, to name a few areas where providers often have much to learn.

Below are some examples of lessons learned by the Heartland team while completing this program.

Fear and Stigma
Heartland researchers determined that using connectors such as interpreters, translators, and recruiters, reduces the fear and stigma that many community members experience when dealing with individuals outside their community and increases community acceptance and participation in services such as making and attending medical appointments or receiving and completing follow-up care.[18] In addition, some members of diverse and medically underserved communities may be fearful or resistant of submitting to genetic testing.

Culturally Congruent Healthcare Expectations

Many of the patients interviewed by the Heartland investigators described disappointment with the medical services received in US healthcare facilities as compared to the medical services received in their home countries.[12a] For example, many patients who have been treated in Mexican and South American clinics expected to be seen the same day when they sought medical treatment in the US.[8,9] They felt that having to schedule an appointment sometimes weeks or months in advance and then coming to the clinic and having to wait for hours to be seen was disrespectful and created confusion about the purported importance of the appointment. In fact, they often thought this was deliberate because they were Hispanic. Also, when visiting non-American healthcare clinics, many Hispanic patients were seen by a doctor or nurse and were unfamiliar, and therefore less comfortable, with the many other health service providers that are common in the US system (physician assistants, nurse practitioners, genetic counselors, etc.). If someone went for an x-ray or laboratory test in Mexico, it was the same doctor who interpreted the results and then did the procedure.[9] Often times they were not asked to come back later, or to call the clinic to get test results in their originating countries.

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Moreover, participants expected to receive a prescription, shot, or some other treatment when seeing the specialist. When an intervention or treatment was not provided, it was often interpreted that they had received poor medical care. This, they suggested, often resulted in their not returning for follow-up visits or seeking other medical services. It is important for providers to know what patients expect to happen during a clinic visit when working with patient groups that are familiar with medical services in other countries and who may be unfamiliar with the U.S. health care system and services. Educating the patient about what to expect before coming to the appointment, test, and overall healthcare process during the initial consultation can help reduce future disappointment and noncompliance. Specifically, providers should discuss the expectations that these patients have for the type of provider they will be seen by and what kind of outcome this visit will have. Once these expectations are understood, providers can educate patients about the role of genetic service providers and provide additional context around the appointment.

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In-Person Communication

The Heartland's Hispanic Access team has found that having face-to-face conversations in community-based locations, such as community centers, churches or homes – as compared to a clinical setting – made participants more comfortable, especially when discussing sensitive health issues and concerns.[10] It was also found to be helpful when the program coordinator nodded to show understanding and took notes without jumping in to offer an immediate solution.[11] It is important to write exactly what the individuals are sharing when taking notes. This reduces the likelihood of misunderstandings between the community members and the program coordinators. In addition, maintaining eye contact, if culturally appropriate, and mirroring body positioning helps to prevent community members from feeling inferior or judged.[11]

Cultural Communication Norms

Some Hispanic patients expressed that providers spoke to the children directly, rather than to the parents. Some felt that providers should speak to the husband (male) if present and not to the wife (female)[12a]. Additionally, when the doctor motioned to have them come into the examination room, several stated that "hand gestures are how you call a dog, not a person."[11] Marshallese patients expressed frustration that physicians began with "Why are you here?". They felt that doctors should get to know them first, explain why they are asking certain medical questions, and why they are to change their diet, take certain medications (etc.).[12a] Regardless of race, ethnicity, or culture, all patients need to understand why they were being asked or told something in order to accurately comply.[12a] In these instances, patients were clear that it is not sufficient to be told "Oh, that is just how doctors do things here." It is important for providers to learn how these different cultures communicate and the expectations they have for communication – both verbal and non-verbal - from the providers they receive care from. Research from the Hispanic Access Project shows that patients expect that providers will conduct polite, professional communication and adjust their communication style accordingly.

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Considerations for Working With the Marshallese Community

Marshallese, because of their limited access to medical care in the US, may try traditional healing practices first, seeking western medical treatment as a last resort.[12b] Providers must be aware that a life-threatening diagnosis may trigger the patient to see a traditional healer and/or faith-based health practices before seeking treatment through western medicine or have traditional medicine sent in from the islands to it can be applied before or alongside the western medicine. Additionally, it is important for providers to greet a Marshallese patient with the traditional greeting of "iakwe" (pronounced, YOK-way) and to build rapport through small talk before moving into discussing the reason for referral. Whenever possible, it is best to match providers with the same gender as the patient. Provider attendance at Marshallese community events goes a long way to building trust and rapport with the community, which is then communicated throughout the community. A useful resource for providers can be found in a tip sheet developed by Blocker, K. et al (2020) [12a].

For more information on the Heartland Access Project or to ask any questions, please visit www.heartlandcollaborative.org or email HRCC@uams.edu.

NEEDS ASSESSMENTS

The following section contains information, examples and links to external resources to support the completion of needs assessments to identify gaps between current and desired conditions in providing genetic services.

OBTAIN ACCURATE POPULATION ESTIMATES

Many minority groups are underestimated in State and National Census counts.[13] Sometimes these estimates are drastically smaller than actual numbers.[11] According to the Heartland Regional Genetics Network, conversations with American Indian leaders in Oklahoma suggest that many Native people do not answer the Census, underestimate household numbers, and incorrectly indicate ethnicity, as they fear this information might lead to discrimination, racism, or stigma.[14]

Novel Methods – Estimating the Population in England

To obtain accurate population estimates of minority populations in England, Pete Large and Kanak Ghosh developed a methodology for estimating population size by ethnic group. Their cohort component methodology, along with factors of population change and existing population counts, allows for more reliable population estimates than sample surveys or Census data. Mortality, fertility, conversion between ethnic groups, migration, and existing Census data are among the factors considered within this methodology. A detailed explanation of how to utilize this methodology within your own region can be found in their [methodology for estimating the population by ethnic groups for areas within England](#) document.

The Marshallese are another under-represented Heartland population. They are one of the many indigenous groups identified by the U.S. Census as Pacific Islanders, which together make up the fastest growing population in the U.S., with the most rapid growth in rural, Southern and Midwestern states.[27] The Marshallese presence in Arkansas is significant, where Arkansas now has the largest population of people from the Marshall Islands outside of the Marshall Islands. Research done by McElfish in Arkansas, suggests that Census data significantly underestimate the size of this population. Specifically, in western Arkansas while the 2010 Census estimated the population of all Pacific Islanders as being 5,326, a review of state birth and death records and public-school enrollment data suggest the population of Marshall Islanders alone at more than 10,000.[28] Similarly, research done in by the Garfield County Micronesian Coalition and the County Health Department suggest a similar pattern of population under-reporting in the U.S. Census data. Specifically, the 2010 census data indicate the population of all Pacific Islanders in Oklahoma as 3,427 while the Micronesian Coalition of Garfield County, an agency of the Garfield County Health Department estimates 2,500 live in that county alone.[26] Again, this estimate includes data not captured by the U.S. Census. Similar underrepresentation is also likely in the other Heartland states. For this reason, any health-related difficulties faced by this population are likely to impact far more individuals than those indicated on frequently-cited Census population estimates.

When raising awareness about the need for medical services or attempting to gain grant funds for health service programs, accurate population numbers are necessary. Title V Maternal and Child Health Services Block Grant Programs conduct annual needs assessment to provide overviews of the state. Both are available in their annual reports.

Providers must earn the trust of community leaders as well as community members and make it clear that they are committed to providing long-term, culturally aligned medical care. Partnering with historically mistreated communities takes time.

In addition to presenting Census data, other kinds of "unofficial" data are useful, such as State Birth and Death records or community organization's attendance records. These records can be used to illustrate the need for additional resources, especially when population estimates based on these data are significantly larger than officially recognized estimates. For Native American Tribes, tribal membership counts can be useful. However, there are often far more persons who identify as members than those who have official tribal membership. Using multiple sources for population estimates can help support the claim that the population is larger than official Census numbers suggest and thus more services are needed.

BUILDING RELATIONSHIPS

Whether located in small rural communities or within urban centers, many medically underserved populations have a long history of abuse, mistreatment and neglect from the government and the majority white population. As a result, many are distrustful of outsiders and reluctant to welcome them into their communities. Before offering genetic services, providers must earn the trust of community leaders as well as community members and make it clear that they are committed to providing long-term, culturally aligned medical care.

Partnering with historically mistreated communities takes time. It could take a year or longer to build relationships and trust before providers are welcomed into communities.

Meet Them Where They Are

When reaching out to community leaders, a common practice is to call and do much of the initial and follow-up work by phone, email or webinar. However, at least for the initial meetings, it is essential to have in-person meetings with community leaders, usually within their community. This can be difficult to arrange, especially for smaller communities in distant

Tools to Use – Population Health Mapper Tool

Online databases with pre-existing population estimates exist for easier access to reliable population estimates. HealthLandscape offers a Population Health Mapper that displays factors pertaining to mortality, morbidity, access and quality of healthcare, health behaviors, demographics, social environment and physical environment across a county or state. HealthLandscape gathers information from portals that obtain their data from population studies, thus increasing accuracy of population estimates in relation to Census or survey data. These population estimates can be used to raise awareness about which populations in an area are underserved.

locations, but without this direct, personal contact, it is difficult, if not impossible, to create meaningful relationships and provide genetic services in marginalized communities.

In-person interviews are a valuable resource for gathering information about community opinion towards genetic services, previous genetic or healthcare experiences, and general difficulties that might compromise access to genetic services - such as lack of transportation. Additionally, in-person interviews should be open and bi-directional, providing an opportunity for patients to ask the provider questions and build trust with the interviewer. As a best practice, be sure that any surveys being distributed are written in plain language, do not contain acronyms, and are culturally and linguistically appropriate.

Various activities throughout the interview can help program coordinators better understand the concerns and priorities of underserved populations. For example, a card sort activity allows community members to prioritize words in order of importance. This can help program coordinators to understand the priorities of the community, as they might differ from expected cultural norms. Of note, many individuals choose not to participate in genetic testing due to financial conflict, thus understanding the financial status of individuals and where that ranks amongst other priorities will help programs better meet community needs.[15]

Assist– NYMAC's Missed Appointment Survey Experience

The New York Mid-Atlantic Consortium, NYMAC, sought to collect information about missed genetics appointments through an initial needs assessment survey. In order to provide quality genetics care, it is important that NYMAC understand what hinders an individual's ability to attend a genetics appointment. The survey helped NYMAC understand the individual's experience when seeking genetic care, such as scheduling appointments, financing their genetic care, and comprehending their genetic testing results. Asking for community feedback prior to proposing solutions helps build a trusting relationship with the community, while helping create solutions that address specific community concerns.[16]

For more details visit
wadsworth.org/programs/newborn/nymac
or email Beth Vogel at
beth.vogel@health.ny.gov

Find Ways to incorporate Community Leaders into Your Program

It is both informative and useful to begin by meeting with community leaders to discuss project goals and how these might help meet unmet needs within the community from the beginning. The next step is to create an Advisory Committee made up of members from this group, medical professionals serving the group and community members. Meeting and working closely with local Chambers of Commerce, County Health Departments, and community-based organizations can help identify opportunities for further collaboration. In addition, these efforts can help Regional Genetics Networks' staff members build trust with local community leaders. The U.S. Department of Health and Human Services Office of Minority Health provides a directory containing contact information for minority colleges and universities, which are institutions of higher learning whose principal mission is the education of racial and ethnic minority populations or institutions whose student bodies represent significant percentages of minority populations. These state-specific minority health contacts can provide resources on how to interact with or reach diverse populations.

By meeting with community leaders, program coordinators can hear directly from the community about their perspectives on genetic services and discuss ideas for projects that can help address barriers or gaps to receiving genetic services. In addition to having first-hand knowledge of genetic services as recipients of care, many community leaders are also familiar with obtaining and managing government funding. They recognize that funded projects can be constrained by the goals of the funding agencies and are often limited in how the proposed programs can be modified and implemented. Including community leaders and giving them a voice in program development can assist not only in completing the current project but in the design, funding, and implementation of future programs.

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Find and Engage Community Members

In *The Tipping Point*, Malcolm Gladwell indicates that within any group there are individuals who serve as "connectors." These are the individuals who know many people and are often the first ones contacted when someone has a problem or a question.[17] While these persons may not be experts in the program area, they are likely to have useful contacts for program staff. These are the people to identify and engage within communities. They are the most likely to already be familiar with healthcare, social services, financial, legal, and educational services both within and beyond their community and thus serve as key access points between outsiders and community members as well as allies for the program. Encouraging community feedback allows program coordinators to better tailor the program to the community, while also spreading awareness about genetic services.

Tools for Use - Capturing Community Feedback

There are online platforms that exist to capture community opinion. Many of these services integrate signage posted throughout a local area - such as outside of a restaurant or store - giving community members a number to text for them to share their opinion about a specific topic. Signage like this connects to various social media platforms, so information about programs can easily reach individuals of all demographics. Online community engagement tools can also be used by team members to better understand what community members want from their genetic services providers.

Participate in Community Events

It is important for the community to see program leaders and members, not just in the clinic or at leadership meetings, but on the streets, in the churches and at community events, such as holiday celebrations, pow-wows, and local festivals. This participation allows the community to view the program team members as part of the community, rather than outsiders.

TAKE A HOLISTIC APPROACH

Increasing healthcare access and participation among these ethnic and cultural groups is multifaceted and requires a holistic approach. This approach requires a comprehensive

understanding of the unique historical, cultural, demographic and situational characteristics of the population and how these factors shape the health-related beliefs and behaviors of its members. It requires the inclusion and participation of community leaders, healthcare agencies and providers who work with the community and individual community members in a collaborative working environment. And it requires careful attention to the unique, and often fluid needs of the community and its members.

Establishing and maintaining a working partnership with underserved communities requires a thorough needs assessment and, based on this assessment, a work plan for meeting the community's needs and goals. Specifically, this should include:

- Economic barriers to care
- Logistical barriers to care
- Sociocultural barriers to care
- Unique cultural practices

Economic Barriers to Care

Different communities have different needs with respect to healthcare coverage. For example, based on a needs assessment conducted by the Heartland RGN, many Marshall Islanders are ineligible for Medicaid because of treaty agreements between the US government and Republic of the Marshall Islands. The lack of coverage can make it difficult for the Marshallese to afford the care offered by local providers. For this population, therefore, much work is needed in state and local governments to raise awareness and change legislation so that they can receive this type of coverage and better access providers. Designing and offering any health-related program begins with an assessment of the financial landscape of the services provided and the priority population. When working with the Native American community, Indian Health Services, individual tribal governments, State and Local Health departments, and other agencies can help identify and meet the financial needs of their community.

Telemedicine Manual for Clinical Genetic Services

Telegenetic services provide remote genetic counseling for patients that cannot make an appointment due to logistic, economic, or other personal reasons. Telemedicine manual for clinical genetic services is a continuation of a Heartland Project that focuses on how to implement telehealth services. The implementation process, policies, procedures, and financial considerations are outlined within.

Logistical Barriers to Care

Many states have large rural populations and many underserved communities living well over 100 miles from available genetic service providers. For these communities, offering to pay for transportation to and from clinics is not sufficient, as this travel would require at least one whole day or longer. Individuals would have to take time off work, potentially find childcare and pay for food and lodging expenses. Any regular clinic visits would not be practical under these conditions, so other strategies must be developed, such as rotational outreach clinics and telehealth, or co-care provided by local providers and genetic specialists. Work in this area must begin with an assessment of the barriers preventing patients from reaching available services and the resources available—or able to be developed —for overcoming these barriers.

Sociocultural Barriers to Care

Language. Underserved communities are often faced with significant difficulties communicating with healthcare providers. While most healthcare services recognize this and have translation services or translators on site, the problems with these solutions are widespread. In the Heartland region, interviewees frequently indicated that they felt discriminated against or treated unfairly due to excessive delays waiting for translators. In addition, translators often did not tell them exactly what the healthcare provider said, nor did they explain things in ways that they could understand. Recommendations about translation services included the following:

- **Translation should be provided in a way that is best for the given situation.** Some suggested that translators should come from their local community, so that they would better understand the specific conditions and needs of patients from that community and be better at explaining complex medical issues.[12b] Some qualified this, however, by saying that if the nature of the medical condition was personal and perhaps stigmatizing then it might be better to have someone from outside, or even a telephone translating service where the patient does not have to look at the translator face-to-face when discussing deeply personal issues. Some said that translators (and healthcare providers for that matter) should be the same gender as the patient. Again, this is more important when the issues are more personal.[12b] Additionally, some members of other cultural contexts prefer to have male providers, believing males to be more authoritative, believable, and respectable.[11]

- **Translators should be familiar with medical and scientific terminologies in addition to the specific language and dialect of the patient.** One criticism by the Marshallese when attempting to use the Affordable Care helpline was that even though they did have a Marshallese translator, there are about 20 different languages spoken in the Marshall Islands and many could not understand the translator.[12b] Among Hispanic groups, many noted that Spanish spoken in different Latin American countries is substantially different. Within Mexico, there are differences between individuals from different areas, different social and cultural groups and even different age groups. Whether for translating spoken words or reading materials:
  - Translation services should not be limited to the medical examination only. Patients arriving at the clinic must be able to communicate with the clinic staff, complete medical paperwork (insurance forms, medication and prior medical conditions questionnaires, etc.), schedule appointments, and find pharmacists. When they get home and have questions, they must be able to call the doctor's office and get their questions answered.
  - Translations should reflect each reader's national, regional and local dialect.
  - Translations should be appropriate for each reader's level of education.
  - Independent of dialect and reading level, translators should be aware that medical terminology may be unknown by a reader and in some languages there simply are no words or concepts for what is being translated. In Marshallese, for example the body organs and systems known by English-speakers are thought about completely differently, so attempting to describe them would not be sufficient. For example, asking who one's "blood relatives" are is meaningless in Marshallese as relationships are not conceptualized that way.[12a]

- Regardless of whether a patient only speaks their native language or whether they are fluent in both English and their native language, there are many individuals who are illiterate in both languages.[18] In this case, providing written materials in one or both languages may not be sufficient. Interviewees suggested, whenever possible, to have video or picture-based media for communicating important health information to patients.

- **Non-verbal communication.** Although less evident than other forms of communication, non-verbal communication given by both patient and healthcare provider are influential to the patient's healthcare experience. The first moments of patient-provider contact are crucial, as this is the time when the patient generally expresses their concern and purpose for the appointment. Members of different cultures often misunderstand facial expressions, body language, gestures, and other non-verbal communication mannerisms. To minimize any potential misunderstandings, providers should adopt body positions that show they are focused on and listening to the patient, such as avoiding pager, phone, or computer distractions and maintaining open body positioning. Every culture is different; thus, it is important for providers to look for cues in what the patient values most. Repeated topics, emotional communication, facial expressions, and a change in speech can signify patient priorities.[19]

- **Culturally competent healthcare.** In order to provide culturally competent healthcare, it is first essential for providers to assess their cultural knowledge and own biases, as these might influence how they approach genetic testing services. Culturally competent healthcare does not require healthcare providers to know cultural beliefs prior to provider-patient interaction, but rather to be respectful and communicative with patients when given information about their cultural practices. In addition, it is important for providers to avoid categorizing or assuming healthcare expectations based on culture, as healthcare expectations are likely to differ on a patient-by-patient basis. Project Implicit provides a tool to help organizations and researchers identify existing biases.

- **Medical Knowledge.** One does not have to be foreign born or from another culture to have limited understanding of the biological basis of health and, more specifically, how changes in genes within a person's DNA affect health and how these changes can be passed on to future generations. Those who were raised in other cultures or attended schools outside of the United States are much more likely to have a completely different understanding of these concepts and their implications for human health.[20]

- **Failure to understand the basis for disease.** Many cultural beliefs include non-biological causes for disease. Whether this be magic, evil spirits, or other supernatural influences, many see disease and the treatment of disease as multifactorial, with western medicine as only one of these factors. While genetic counselors are often concerned with finding the best way to explain to a parent the risk of having another child with the same genetic condition as their newborn, they often overlook the fact that the parents believe that it was caused by, for example, astrological factors and not genetics, or that it was the "will of God." It is critical for programs and providers to understand a patient's beliefs before working with families to help them understand genetics and genetic diagnoses.

Account for Cultural Practices

Any genetic intervention program, in order to be effective, must take into consideration the culture-specific beliefs, traditions, and behaviors within a given community when developing practice models for that community.

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- Some cultures are collectivist – meaning that as a community, they emphasize and prioritize the needs and goals of the group over the individual. In many cultural contexts, the needs of the individual patient are less important than that of the family.[15] When providing a diagnosis and treatment plan or explaining the long-term needs of a child with special health needs, it is important to understand who must be involved in the decision-making process, how responsibilities for care are distributed, and how these decisions will impact not only the patient but the family— and perhaps extended family as well.

- Some patients use complementary and alternative medicine (CAM).[20] In addition to the use of traditional healers, many also use specific dietary and herbal supplements. Some of these may directly impact the efficacy of medications or even worsen their condition. When working with racial and cultural groups, it is critical to be familiar with their traditional medical practices, in order to know what questions to ask and what to expect when treating these patients.

Resources to improve cultural competency within the workplace include printable handouts that healthcare professionals can use to educate themselves, or detailed guides to religious, medical, and social beliefs of various cultures.

User Profiling

User profiling helps program coordinators identify how access to genetic services would improve as a result of their program. Creating a profile of a mock-community member that would benefit from genetic services, including their age, financial income, family history, emotional support available, career, and other factors, allows program coordinators to simulate how their experience with accessing genetic services would be. User profiling allows programs to identify how their program would benefit possible community members, while also identifying gaps in the program.

Fake Profile Generators

Online Fake Person Generators can help produce detailed profiles of individuals from various states. For example, a 22-year-old female from Russell Springs, Kentucky has a B+ blood type, black hair, a driver's license, $4,300 monthly salary, has $0.18 in their account, prefers to pay with a credit card, etc. Based on the designed program to increase access to genetic services in the area, how easily would an individual with this profile be able to obtain the genetic services they need? With $0.18 in their bank account they might not have enough gas to drive to their genetic counseling appointment.

COMMUNITY PARTNERSHIPS

The following section contains information, anecdotal evidence and links to external resources to support RGNs and organizations as they partner with diverse and medically underserved communities to improve the quality of and access to genetic services.

Preparing for Partnerships
Before forming community partnerships, it can help to ensure your region or organization is prepared. Although community partnerships ultimately reduce the resources needed to improve underserved populations' access to genetic services, initial resources are needed to form these partnerships. Transforming to an adaptive mindset to recognize that partnerships are needed, as no one organization or network can solve the shortage of genetic service access points alone, is a preliminary step to ensure preparedness. In addition, a commitment to investing resources and staff in the partnership is essential.[21] Company members dedicated to sharing organizational goals, beliefs, and expertise are helpful investments for collaboration. The March of Dimes and John Snow, Inc. have both created an assessment to determine how prepared an organization is for community partnerships.

Identifying Existing Resources and Building Collaborations
In many healthcare areas, including genetics, some service agencies are already in place and offering services to the community. Given current budget limitations, every effort to engage programs and personnel already active, rather than hiring new personnel to duplicate these services, is important. Often providing information about existing genetic services—having contact information of service providers and being a point of contact for community members—is the most cost-effective approach.

There are multiple types of collaborations that can be formed between existing organizations within the community. Gathering investors interested in funding similar causes helps pool resources to fund community access initiatives. Collaboration between government and nonprofit organizations, such as public schools and genetic testing companies, helps improve communication between nonprofit sectors and government organizations. In addition, partnering with a local nonprofit organization can increase awareness, inform underserved audiences, and increase customer bases.

Healthcare Partnerships
Hospitals are a leading provider of healthcare for communities. Forming hospital-community partnerships begins by identifying existing healthcare organizations serving the community and analyzing their data. Local community health workers, patient navigators, licensed social workers (LSWs), and healthcare advisors are trusted members of the community that can serve as intermediaries between the RGN and local community members.[22] Hospitals are required to perform community health needs assessments (CHNA) that identify healthcare needs of a community.[23] Using this information, rather than expending resources to gather new information, increases program efficiency. Once these data have been obtained and community needs are identified, the program can collaborate with local healthcare organizations to identify goals and outline strategies to reach those goals. The Creating Effective Hospital-Community Partnerships Manual provides more information on the usefulness of these collaborations and how to initiate them.

Leveraging Partnership and Needs Assessments to Improve Care

Indiana University Health (IU Health) and the Indiana University School of Medicine partnered on an initiative to improve the health of various communities throughout the state, both rural and urban. They conducted 18 needs assessments in various locations, specifically to measure access to affordable health care, obesity prevention, behavioral health services, and primary education. IU Health partnered with additional hospitals throughout the state to conduct these needs assessments. Through these collaborations, they shared data and resources. Specialized healthcare providers joined the initiative to provide their insight into how the program could develop a plan to reduce poverty and improve education throughout the state. As a result of this partnership, they increased students' average physical activity by 52%, delivered 450,120 pounds of food to neighborhoods, and distributed 2,200 nutritional education materials to the community. By working together, these organizations were able to combine their resources and data to create impactful changes throughout Indiana communities.[24]

Family-Led Organization Partnerships

The Health Resources and Services Administration (HRSA) funds a Family-to-Family Health Information Center (F2F) in each state, the District of Columbia, American Samoa, Guam, Puerto Rico, the Northern Mariana Islands, the U.S. Virgin Islands, and three F2Fs that serve American Indians/Alaska Natives.

These family-led centers are staffed by highly-skilled, knowledgeable family members who have first-hand experience and understanding of the challenges faced by families of children and youth with special health care needs (CYSHCN), including those with genetic disorders. These uniquely qualified staff, many of whom are bilingual and bicultural, provide critical support to families caring for CYSHCN, particularly families of children with complex health care needs and those from diverse and medically underserved communities.

F2Fs have built extensive partnerships with providers, state and federal agencies, legislators, and other stakeholders to better understand the needs of, and serve, CYSHCN and their families. These partnerships include collaborations with cultural brokers and community-based organizations, in particular, those assisting specific ethnic/racial groups.

Regional Genetics Network (RGN) partnerships with F2Fs can leverage the relationships the F2Fs have created with families and other organizations throughout their states and territories, and assist with outreach to, and development of relationships with, medically underserved and diverse communities. [Contact the F2F in each state and territory](#) to discuss partnership opportunities.

Communication Methods for Community Partnerships

Communication is key for ensuring lasting and effective community partnerships. The Center for Community Health and Development has created a detailed explanation, PowerPoint, and checklist to assess and build upon current communication strategies.

Communication is key for ensuring lasting and effective community partnerships.

Designating liaisons to meet with community partners and assess the ongoing status of the partnership is an important task. When collaborating with their partners, East Carolina University coined the phrase "partners and co-educators," showing that partners are instrumental in the university's mission.[25] In order to form lasting partnerships, it is important to recognize the expertise partners bring to the table. Foundations dedicated to a particular genetic condition may have better resources than a health center providing information for thousands of genetic conditions. DiseaseInfoSearch is a great example of a tool that patients and families can use to find organizations and resources for specific conditions.

Collecting and Allocating Funds

Various government and nongovernment sources are available to help fund regional genetic service efforts. Before asking for funds, it is helpful to know the exact resources needed, where they will go, and how the resources will be sustained over time. It may help to develop a committee for sustainable funding to ensure funding for program initiatives is adequate. As outlined by the County Health Rankings and Roadmaps Funding Guide, funding resources include federal and state governments, foundations specific to certain genetic conditions, corporate grants, and service organizations. The Prevention Institute additionally recognizes Accountable Care Organizations (ACOs), non-profit hospital community benefits, health impact bonds, and wellness trusts as possible funding sources.

The state of Texas' Interagency Council for Genetic Services created a Resource Allocation Plan that identifies their existing resources, available funding resources, and how funds are allocated to respective programs. The Grantsmanship Center provides state-specific government, corporate, and foundation funding options.

Partnering with United Way can provide necessary funding or connections with other funding organizations. Grants.gov and The Robert Wood Johnson Foundation are additional resources to help collect community health funds.

CONCLUSION

In order to better provide underserved populations with genetic services, it is critical to understand their healthcare needs and their community goals. Conducting a needs assessment requires programs to effectively gather population information, engage with the community, and build relationships. A needs assessment is essential to base a program around community needs. Data from a needs assessment can help RGN teams better understand the barriers/issues related to accessing genetic services that community members in a particular region are facing. In addition, having these data not only helps better address the needs of a community, but also helps in identifying the changes and outcomes derived from community partnerships. Collaborating with existing organizations and hospitals can help pool resources to easily conduct needs assessments and gather information. The resources linked in this document (Appendix B) can provide timesaving tools to support the completion of needs assessments in your region.

Additionally, to maximize success with diverse and medically underserved populations region should work to identify community leaders, establish relationships, and build trust within the communities. In order to develop long-term relationships and better understand impact of the work, regions should invest in early ground work to meet with and understand the needs of these communities. The Heartland Hispanic Access Project provides a great example of a successful regional project. This project built community relationships and increased provider understanding of barriers and issues faced when attempting to access genetic services.

After forming partnerships and gathering information, program initiatives should then be designed to better provide genetic services for underserved populations. RGNs seeking to build relationships with their own diverse community members can use the Hispanic Access Project as an example of how to avoid using practices previously proven to be ineffective. Some examples of ways to reduce inequitable access to genetic services that exists within the regions include:
- Ensuring primary care providers have the info needed to connect and consult with genetic specialists
- Providing tailored information for those with linguistic and/or cultural barriers to care
- Establishing community education programs

This document was developed by the National Genetics Education and Family Support Center to increase the capacity of RGNs to work with underserved communities. Key takeaways from the document include:
- Build relationships and collaborate with community members
- Don't recreate the wheel, identify and utilize existing resources and strengths
- Obtain accurate population estimates for underserved communities
- Identify and minimize economic, logistic, and sociocultural barriers to care
- Track program effectiveness

In order to maximize success, regional teams should work with the National Genetics Education and Family Support Center to identify and partner with their local family-led organizations. Regional family-led organizations, such as state Family to Family Health Information Centers, can help link regions with community leaders. The Family Center can also help with:

- Increasing reach and disseminating a needs assessment
- Reviewing materials to ensure family-centered language and approach
- Partnering to develop methods to reach underserved populations (e.g. creating materials in multiple languages or identifying innovative digital outreach approaches)
- Providing counsel around family engagement best practices

For more information or to involve the Family Center in your regional project, please email Joel Lopez (jlopez@geneticalliance.org).

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APPENDIX A: ISSUES AFFECTING THE AVAILABILITY OF MEDICAL SERVICES

Provider-side issues that impact the availability and uptake of medical services include:

- Workforce allocation- Financial resources must be available to cover salaries of physicians, service providers and support personnel. Trained and certified personnel must also be willing to practice in locations where these services are needed.

- Service-Point Allocation- Medical services must be offered in a location and at times to meet the needs of patients.

- Infrastructure Availability- Access to medical services via telecommunication, transportation, and telemedicine must be sufficient to meet patient needs.

- Sociocultural Conflict- In an increasingly intercultural climate, differences in age, gender, sexual orientation, social class, regional acculturation, ethnicity and race between healthcare providers and patients can cause challenges, including misunderstanding, distrust, reduced adherence to an agreed upon medical plan and patient loss. Providers must recognize the impact of these differences and be willing to accommodate the unique sociocultural characteristics of diverse patient populations.

Patients and their families have resources to access healthcare services, to varying degrees, based in part on the following issues:

- Economic- Having health insurance, a sufficient income to cover out-of-pocket medical expenses, sufficient sick leave or flexible work.

- Logistical- Having transportation (especially when specialty care or extensive travel for services is required), social support (childcare and assistance during hospitalization and recovery), access to medical facilities, medical supply services, and pharmaceutical services.

- Psychosocial- Access to social support networks (family & friends, religious, and counselors) to assist in coping with the emotional and personal impact of difficult medical issues.

- Sociocultural- In order to meaningfully participate in the healthcare system, community members must:

    - Trust the healthcare system and providers. They must believe that they will be treated fairly and that the healthcare options provided to them will be consistent with those offered to other persons or population groups. They must not fear that accessing the healthcare system will result in negative legal, economic or social consequences

- Have a basic understanding of the biological basis of health and the importance of preventive and emergency medical care.
- Recognize when medical attention is needed and be aware of how to access services.
- Be able to effectively communicate with healthcare professionals about their medical condition, ask questions, and understand the instructions given to them as part of their treatment plan.
- Understand that if they have special cultural, religious or personal beliefs and practices which contradict their provider's recommendations (i.e., special diets, complementary and integrative therapies, religious or cultural prohibitions about certain treatments, etc.) they must discuss these with their providers, so that they can help facilitate the development of equitable and effective treatment plans.
- Be aware of the benefits of informed consent and the patient's bill of rights
- Be willing and able to follow a treatment plan.

APPENDIX B: ADDITIONAL RESOURCES

NEEDS ASSESSMENTS

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APPENDIX C: SAMPLE RGN LOGIC MODEL

UNDERSERVED POPULATIONS: RGN Logic Model – Stakeholder Tasks: RGN	
Continuous Self-Assessment is key, as priorities, funding, communities, needs and personnel change. In any region, at any time, it is essential to: 1) carefully inventory currently available resources, the allocation of these resources; 2) identify the regional and community level needs and unmet needs within that region; and, 3) make changes to the existing system to maximize the fit between available resources and resource needs. At any time a RGN will be at either the Developmental, Implementational, or Participatory stage in this process.	
Development Stage	**RGC must determine:**
Community Identification	
	What underserved populations are there in coverage area?
Population Demographics	
	How large is each population? (is this known)
	Does population have known (specific) genetic issues?
	higher prevalence, severity, mortality of condition(s)?
Geographic Specifics	
	Where are underserved population centers (concentrations)?
	Do geographic conditions present a barrier to access?
	How far must patients drive to access services?
Resource Availability	
	Are there enough providers to meet community needs?
	If no, what alternative treatment avenues are there?
Cultural / Linguistic Barriers	
	Do members within this underserved community have limited English proficiency, both verbal and written?
	Do members within this underserved community have cultural, healthcare-related, or religious beliefs that may affect their desire and/or ability to access and utilize available healthcare resources?
	Have members within this underserved community experienced any past or present discrimination, stigma or prejudicial trauma that may affect their desire and/or ability to access and utilize available healthcare resources?
	Do members within this underserved community have

	limited access to education and/or have limited understanding of the biological basis of disease, the potential benefits of medical intervention?
	If yes to any of these, are there currently any educational programs within the community or interventions within the clinics to ameliorate these sociocultural deficits?
Economic/Legal Barriers	
	Are these Federally/Legally recognized groups?
	How many are uninsured?
	Are uninsured eligible for Federal/State programs?
	If no, why? (undocumented, treaty, etc.)
	Is population economically disadvantaged?
	Do local businesses provide insurance?
	What other assistance programs might be applicable?
	federal block grants, Title 9, HRSA, etc.
Available Health Agencies	
	What health agencies serve this population?
	Family-to-Family, AHEC, Early Childhood (etc)?
	Are there clinics and medical providers for population?
	Do available agencies and providers actively collaborate?
	Are agencies and providers available and accessible to all population communities?
	If no, what is available in each major population area?
Engagement	
	Once an Underserved Population has been identified and identified, an inventory of these six issues (Demographic, Geographic, Resource Availability, Cultural/Linguistic Barriers, Economic/Legal Barriers and Available Health Agencies) then work must be done to identification of key stakeholders service providers at the state, local and community level with the expertise and resources to assist in building collaborative service networks to increase healthcare/genetic service to community members with unmet needs. Identify funding and administrative (and manpower) streams and new technologies to increase service availability. Build access, trust and cooperation with community leaders and individual members to overcome historic and local barriers preventing access and utilization

		of available services.
Interactive Participation		
		As new services become available and existing services become more easily accessible (with better interpretation services, more service integration, etc.) these services must be regularly monitored to ensure that community members are getting the care they need in an efficient and cost-effective way. As needs and community characteristics change, these services must also change, so Development, Engagement and Participation must be seen as an iterative process.

UNDERSERVED POPULATIONS: RGN Logic Model – Key Stakeholders		
Stakeholder	**Perspective**	**Goals**
RGN:	Systems Level	Effective delivery of genetic services to all communities, and especially underserved populations across service region. Focus on identifying and engaging key stakeholders, building service coordination partnerships and increasing patient access to services.
Healthcare System	Systems Level	Effective Healthcare delivery at the community level. Focus on interaction/coordination between state, county, community and practice level services. Need to identify and overcome barriers to access and uptake.
Community Services	Community Level	Effective identification of and access to all available healthcare/Genetic services for community members. Developing service partnerships between federal, state, local and community providers and bridging the gaps between these service providers and community members who need their services.
Family/Individual	Personal Level	Recognizing the need for healthcare/genetic services and identifying the local, state and national agencies, programs and individual providers available to address these unmet needs.

UNDERSERVED POPULATIONS: RGN Logic Model – Developmental Stage		
Stage	**Goal**	**Activity**
Development	Self Assessment	Identification of unmet needs, inventory of available/accessible services and identification of barriers to service utilization
Engagement	Resource Development	Identification of key stakeholders service providers at the state, local and community level with the expertise and resources to assist in building collaborative service networks to increase healthcare/genetic service to community members with unmet needs. Identify funding and administrative (and manpower) streams and new technologies to increase service availability. Build access, trust and cooperation with community leaders and individual members to overcome historic and local barriers preventing access and utilization of available services.
Interactive Participation	Participatory Service	Leverage new collaborative networks, partnerships, technologies and community engagement activities to develop and increase healthcare/genetic services to all who need them.