PROJECT ABSTRACT

Project Title: HEARTLAND REGIONAL GENETICS NETWORK
Applicant Organization Name: University of Arkansas for Medical Sciences
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Medical Genetics has reached a field-defining point, facing significant challenges in workforce shortages and rapid advances in medical technology, service delivery technology and clinical practice. The Heartland Genetics Services Collaborative is one of seven regional groups, funded through HRSA, first to establish a regional genetics program (2004-2007), then to identify specific areas of need and develop strategies for meeting these needs (2007-2012) and in the current proposal to expand genetic service capacity to improve access to pediatric, metabolic and adult genetics services, targeting medically underserved populations. Targeted needs assessments have found that the Heartland region: 1) has too few medical geneticists, genetic counselors and related specialists to meet the region’s current genetic service needs; 2) has more residents living in medically underserved areas and rural communities, creating barriers preventing or delaying their access to available genetic services; and, 3) is home to several large ethnic and cultural groups (i.e., Native Americans, Hispanics and native Marshallese) who, because of their unique cultural, linguistic, socioeconomic and geographic characteristics, face increased challenges when seeking and utilizing available healthcare services, including genetics services. The current proposal will begin the task of meeting these needs by: 1) Creating new and enhancing existing access points or pathways to genetics services for children and adults by engaging and integrating primary care, home-visitors, and family support organizations, with a focus on improving genetics service delivery among the medically underserved populations; 2) Improving the quality of care for patients and their families accessing genetics services; 3) Implementing innovative telehealth clinical genetics service delivery models and providing technical assistance, education, and training in telehealth; and, 4) Providing resources to genetic service providers, public health officials, and families. This proposal builds on the strong foundation established by previous leadership and a large, committed and highly motivated network of genetics professionals, community leaders and family partners. The proposed work will focus on building partnerships between genetics providers, non-genetics healthcare providers and parent support organizations, and will implement or expand innovative models of care delivery, including telemedicine. In this way, we hope to better utilize the limited genetic service professionals’ expertise and more fully engage other healthcare professionals to increase the capacity to deliver needed genetics services. Additionally, by working directly with providers, community leaders and families within underserved, cultural and ethnic groups within our region, we will reduce barriers to their accessing and utilizing both new and existing services available to them. In all, we aim to increase access to by twenty percent over the proposed funding cycle.