

Introduction

Research in human and medical genetics promises to enhance the way medical care is provided in the future. The elucidation of how genes contribute to the etiology and pathogenesis of common diseases will hasten the development of new approaches to healthcare. As genetic testing improves, it will become possible to better diagnose patients, tailor treatments to a person's genotype and predict treatment efficacy. Unfortunately, such advancements may not immediately benefit many in the public. Most healthcare professionals have only limited genetics knowledge and do not appreciate how often genetic variation influences the morbidity and mortality of common diseases. Genetics professionals, such as medical geneticists and genetic counselors, have specialized training and routinely provide genetic services. However, clinical genetic services historically have been underfunded and a current shortage of genetic professionals has made access to genetic services limited in many areas.

The Heartland region of the United States includes North Dakota, South Dakota, Nebraska, Iowa, Kansas, Missouri, Oklahoma, and Arkansas and encompasses a population of nearly 21 million people spread across more than 548,000 square miles. Approximately 55% of the population is rurally located according to the 2006 US Census. Access to modern clinical and laboratory genetic services is a problem for many patients. Most clinical professionals, such as medical geneticists and genetic counselors, are located in urban areas where there are academic medical centers. In the Heartland region, there are significantly fewer genetic professionals compared to other areas of the country. On average, there is 1 genetics professional for every 175,000 people in the population.

The Heartland Genetics and Newborn Screening Collaborative (HGNSC) is a network of health professionals and advocates working together to promote and improve health through quality medical genetic services, clinical laboratory services, professional and public education, genetics research and public policy. The Heartland Genetics Collaborative is one of seven regional collaborative groups in the country created by the Genetics Services Branch of the Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB/HRSA) as a part of its ongoing effort to improve the health of children and their families. The HGNSC is made up of members from eight Heartland states. It consists of an advisory council and several individual committees.

The purpose of the Clinical Genetics Services Committee is to enhance existing services and increase the public's awareness of and access to genetic services. The committee has identified telemedicine as one potential solution for correcting the misdistribution of genetic services that currently exists. This manual is a collection of resources that can be used as a guide for establishing and sustaining a telegenetics program.