

Newborn Screening Workforce Background and Overview

Cynthia Powell, MD, MS, FACMG, FAAP
Chair

May 14, 2021

Newborn Screening Workforce

- **Many experts and professionals comprise the NBS workforce:**
 - Hospital staff
 - Genetics
 - Primary Care
 - Medical Specialties
 - Public Health—laboratory and follow-up
- **Today's focus:**
 - Genetics providers: Medical Geneticists and Genetic Counselors
 - Other specialty providers that serve a crucial role in NBS: Neurology
 - Advanced Practice Provider Model: Sickle Cell Disease
- **Future Conversations**
 - Public Health
 - Metabolic Dietitians
 - Audiologists
 - Other critical specialties



2020 Government Accountability Office Report

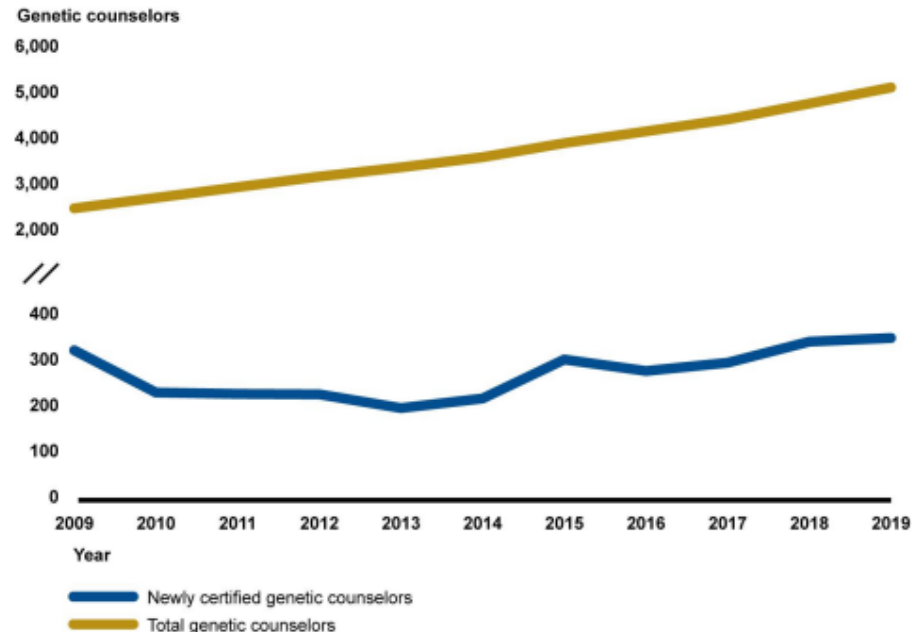
- Rep. Herrera-Beutler (R-WA) requested the Government Accountability Office (GAO) conduct a Medical Genetics Workforce study in 2019 HHS Labor appropriations bill
- The American College of Medical Genetics and Genomics and the American Board of Medical Genetics and Genomics partnered to survey the field of board-certified/eligible geneticists in the United States to provide information and data to the GAO
- The National Society of Genetic Counselors and The American Board of Genetic Counseling provided data and information to the GAO
- The GAO interviewed officials from HRSA, NIH, and BLS
- GAO interviewed 2 of the 7 HRSA-supported Regional Genetics Networks



GAO Report Findings

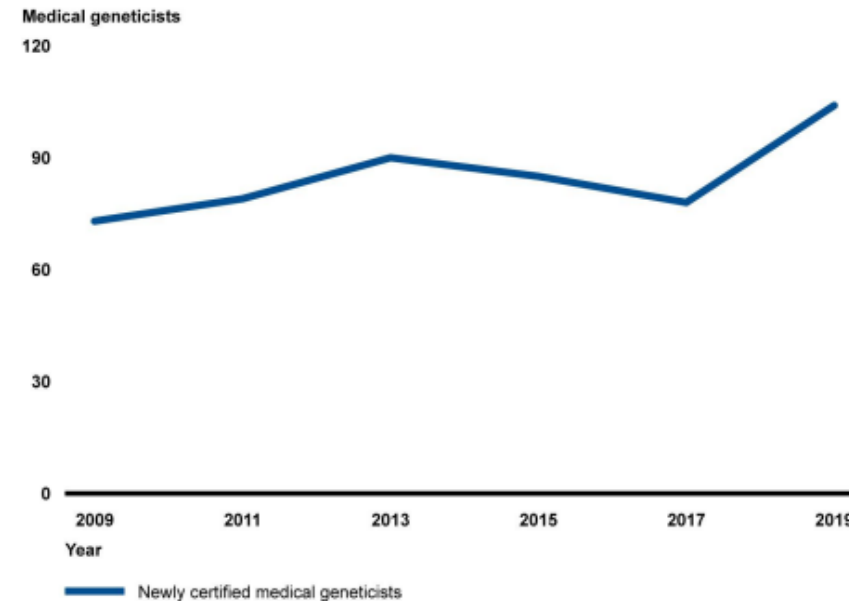
- There is an average of 7 genetic counselors per 500,000 (2019); and 2 medical geneticists per 500,000 (2020) in the United States¹.
 - The numbers of genetic counselors and medical geneticists have grown from 2009-2019 and are projected to continue growing:

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



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

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



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

(GAO, "Genetic Services: Information on Genetic Counselor and Medical Geneticist Workforces, pgs. 11-17)

GAO Report Findings (2)

- The numbers of genetic counselors and medical geneticists vary widely across states.
- Genetic counselors and medical geneticists primarily practice in hospital settings.
- Full report available: <https://www.gao.gov/assets/gao-20-593.pdf>

Implications for the Newborn Screening System

- GAO data represents data for both professional groups across all disciplines beyond newborn screening.
- Presenters today will share more details about:
 - Medical Geneticists, now and looking to the future;
 - Genetic Counselors, role and engagement in the NBS system;
 - Neurologists, innovative approaches to addressing challenges and gaps.
- Looking to other specialties for examples of successful engagement of providers to improve access to services:
 - Sickle Cell Disease—Advanced Practice Provider Training

