



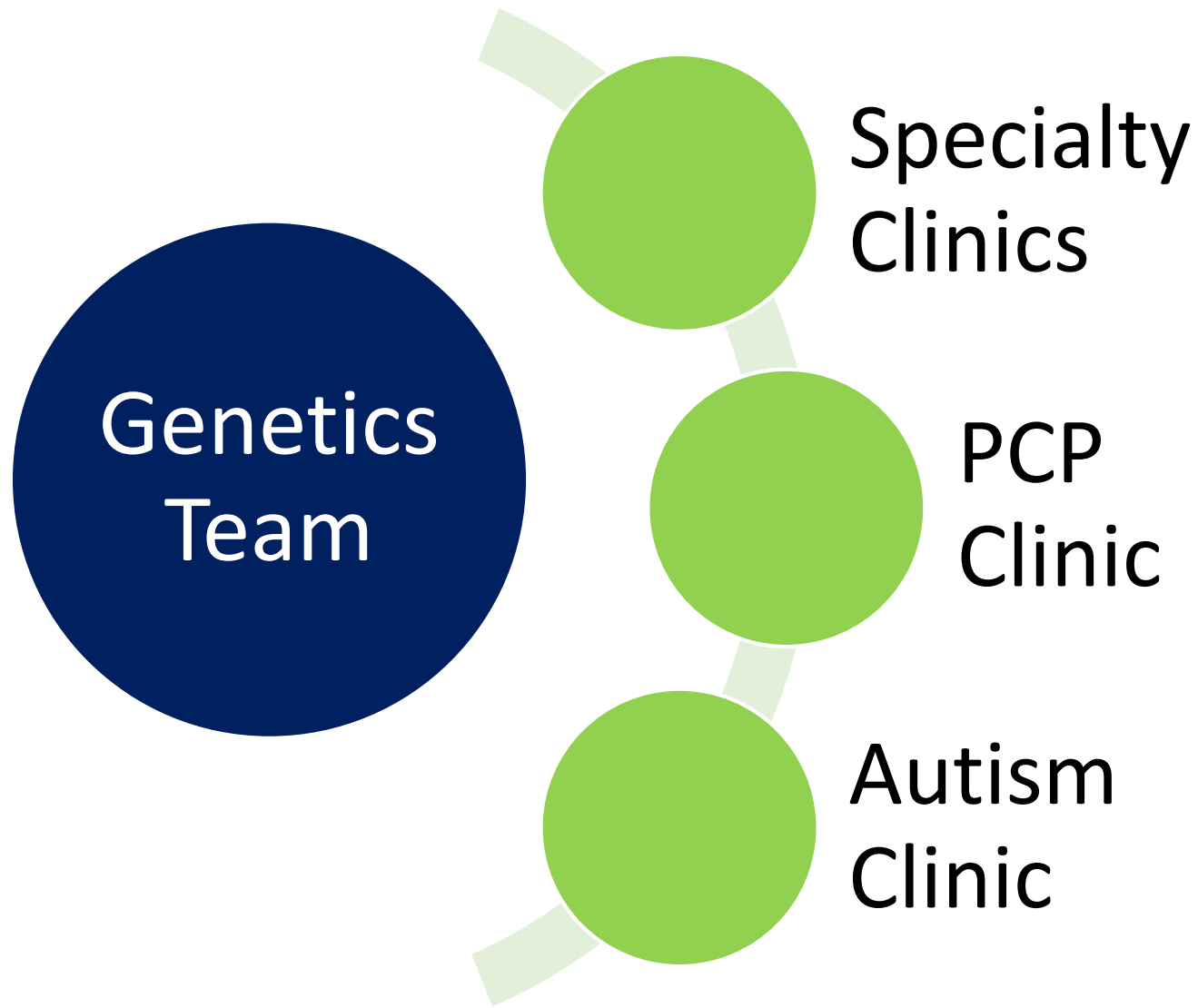
WHERE WE HAVE BEEN AND WHERE WE ARE GOING:
Evaluation findings from the 2017-2020



WHAT WERE OUR
STRATEGIES AND
RESULTS?



PARTNERSHIP TRIOS MODEL



UPTAKE OF
TRIOS MODEL
IN ONE
HEALTH CARE
SYSTEM



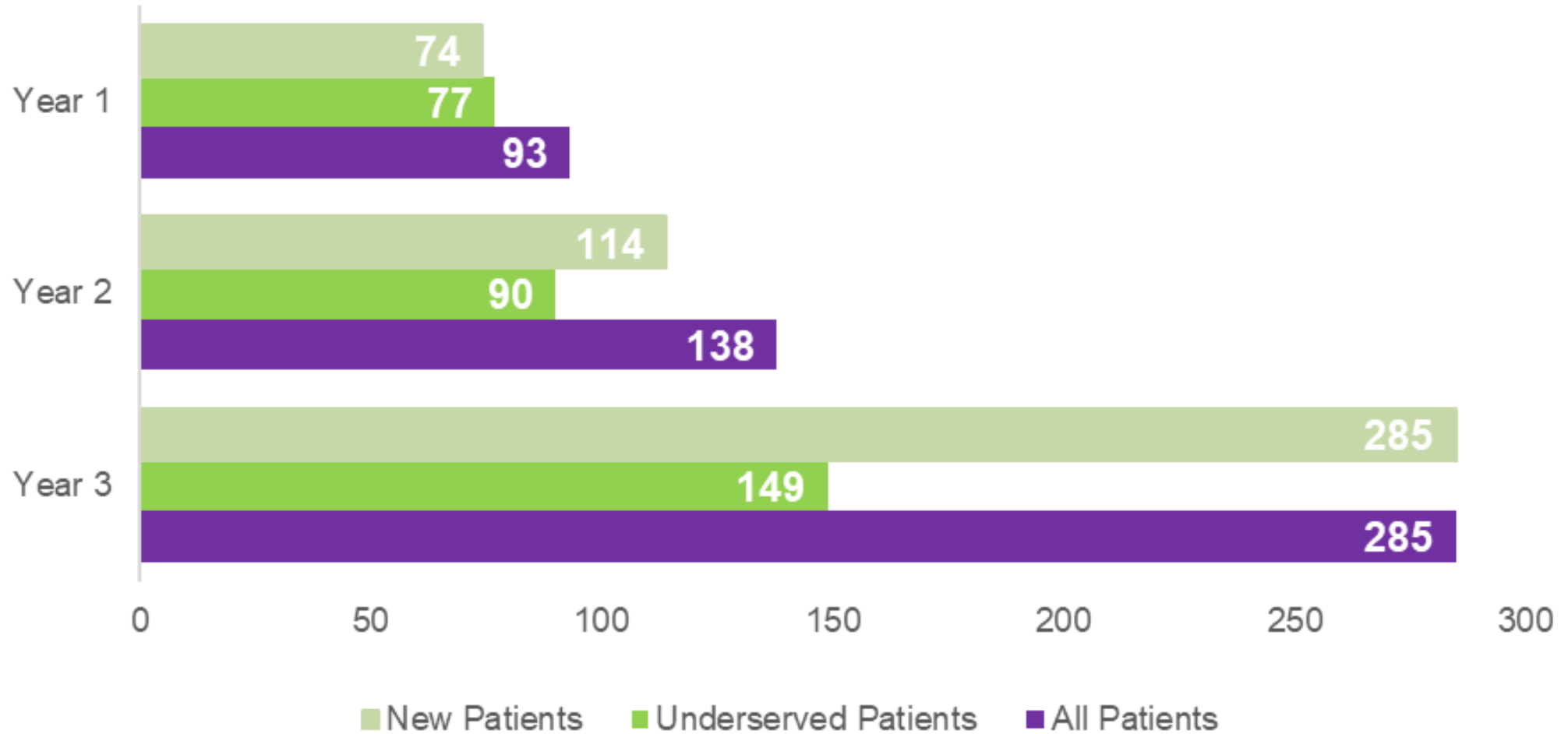
CLINIC VISITS AND FACILITATED CONNECTIONS

Facilitate Connections included:

- Connected with a geneticist
- Initiated a conversation about genetics
- Assisted with referral
- Provided information about an appointment
- Provided information on a condition or resource

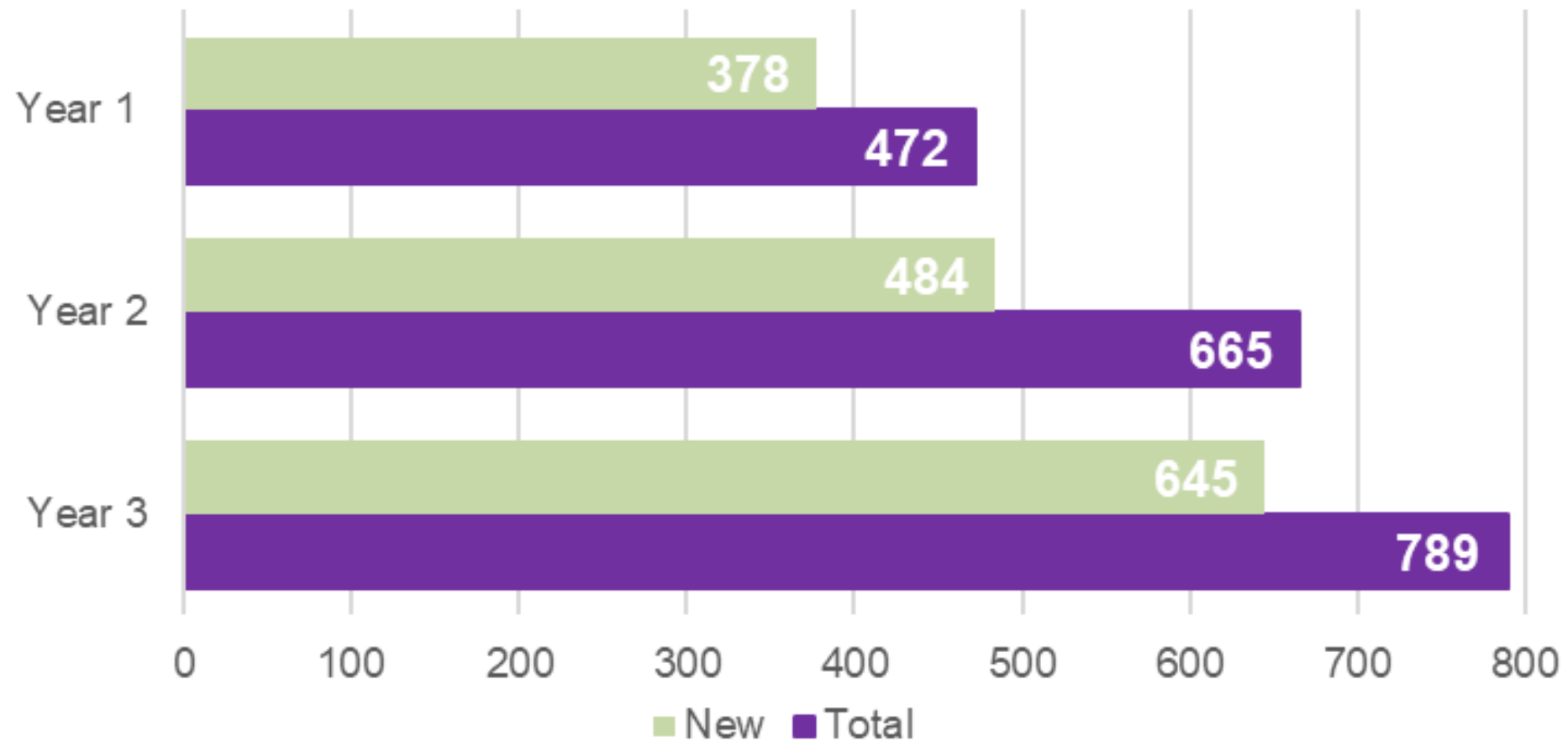


EARLY INTERVENTION AND FAMILY NETWORK PROGRAMS SUPPORT PARENTS' ACCESS TO GENETIC SERVICES*



*Includes Trios Partners Clinic Visits

NUMBER OF FAMILIES ACCESSING TELEHEALTH GENETIC SERVICES INCREASED EACH YEAR





COMMUNITY ENGAGEMENT

Marshallese

- Brochures for parents
- NBS video
- Publication (FHH)
- Tip sheet for providers
- Clinics devoted to Marshallese
- Community education and events
- Interviews
- Interpreter training

Spanish-speakers

- 3 videos:
 - NBS
 - Genetic Services
 - Use of interpreters
- Interpreter training
- Publication (HA project)

Native American / American Indian

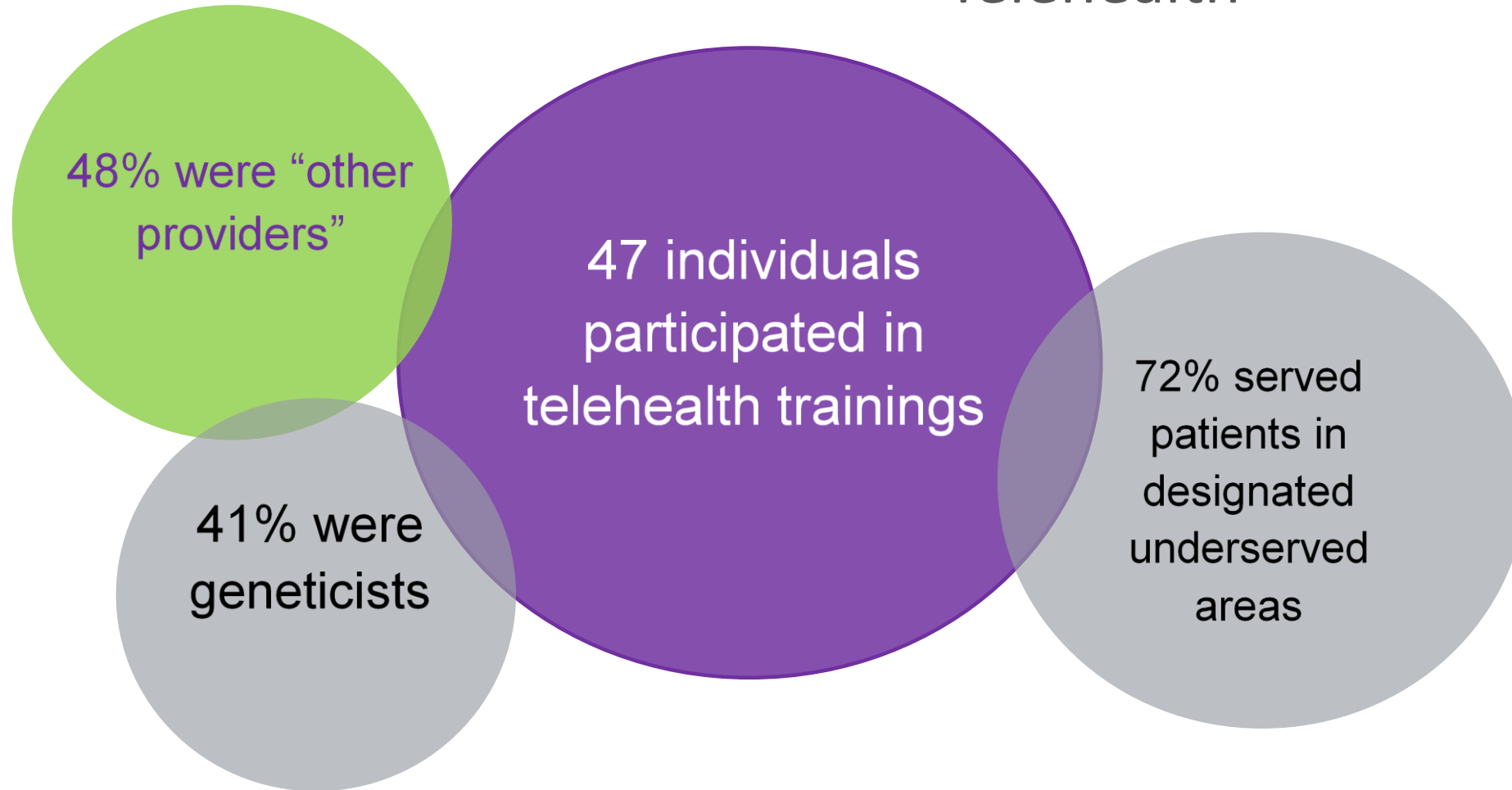
- Conducted parent trainings
- Presented at regional tribal public health conference
- Presented to tribal emergency preparedness board and regional conference

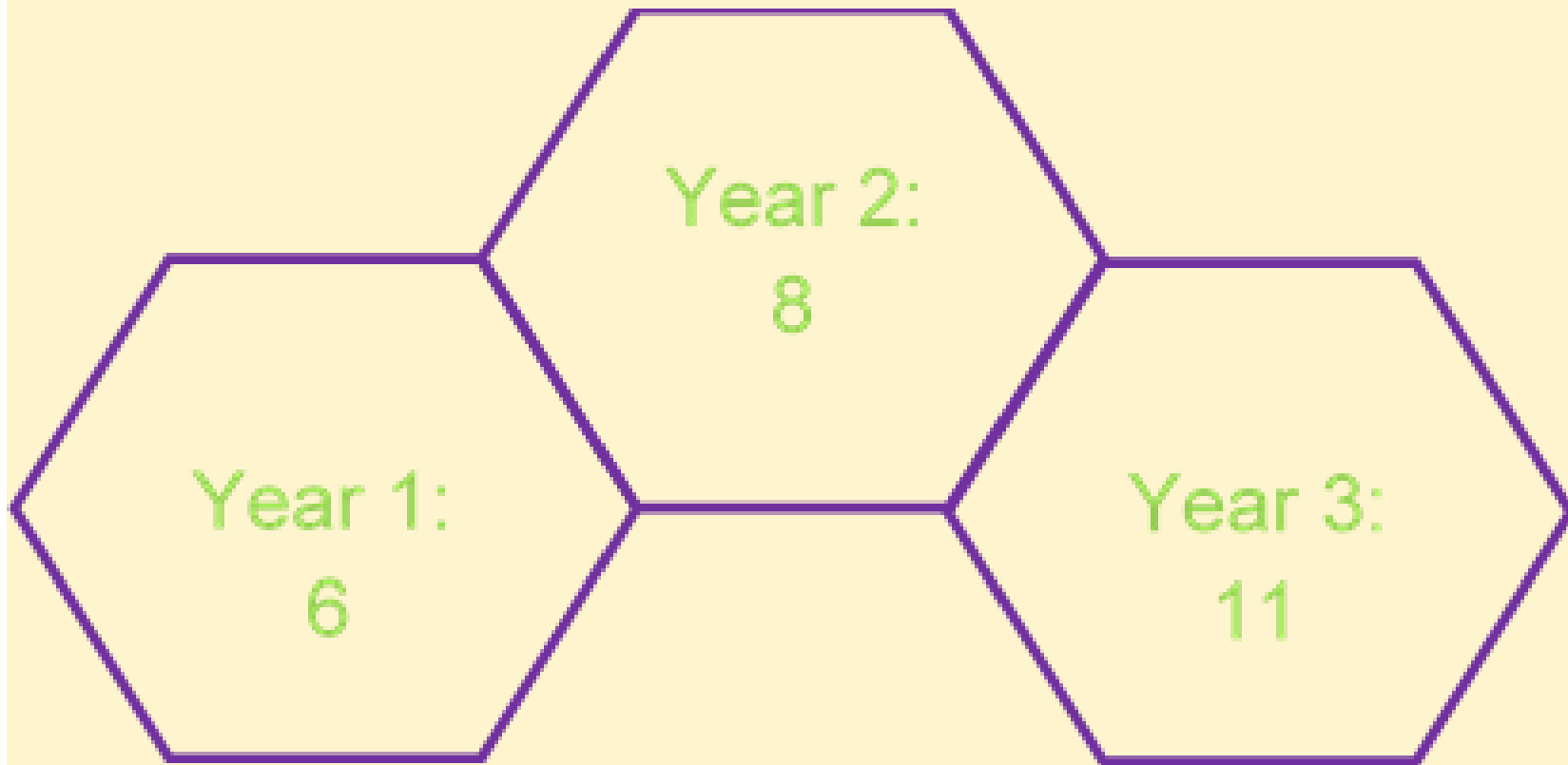
ACCOMPLISHMENTS



TELEHEALTH INITIATIVES

of Individuals Trained in Telehealth



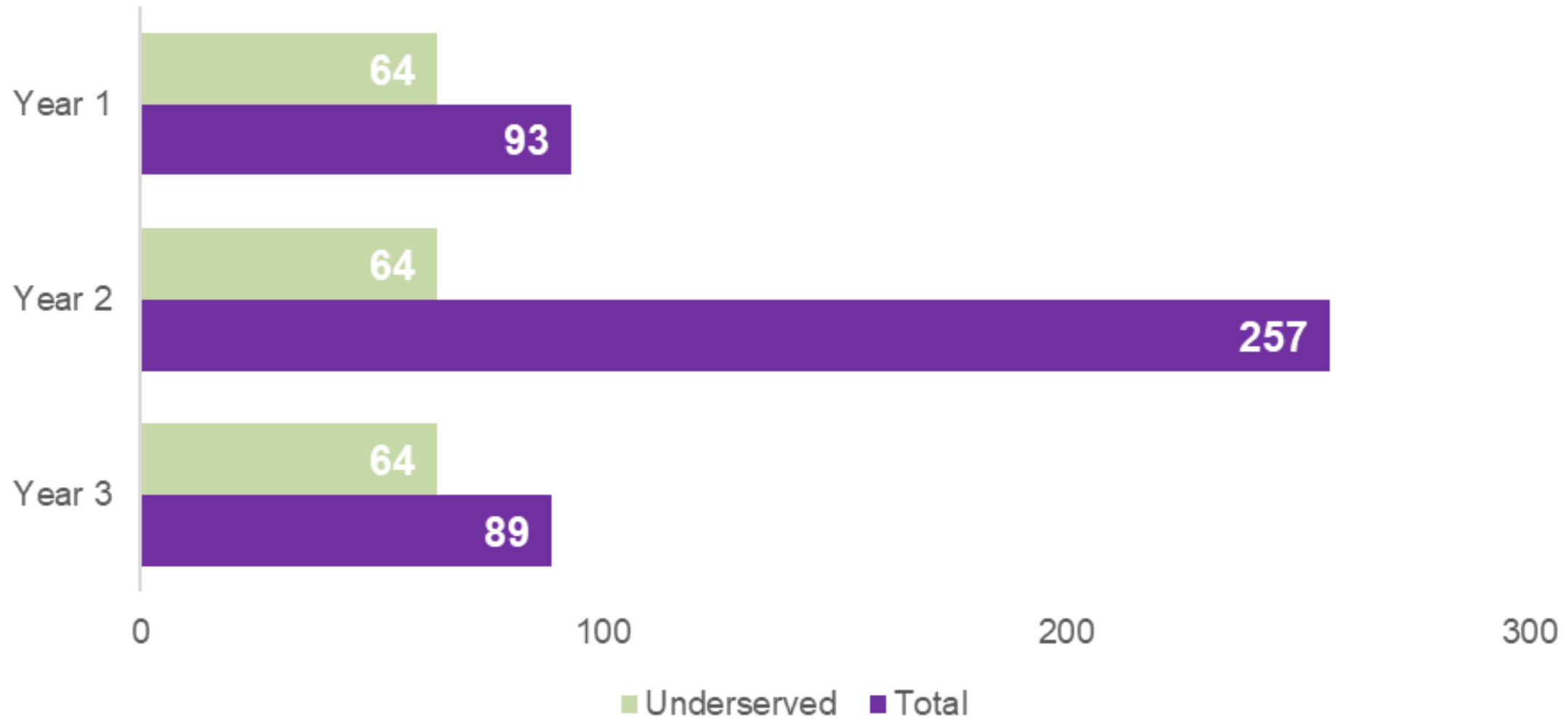


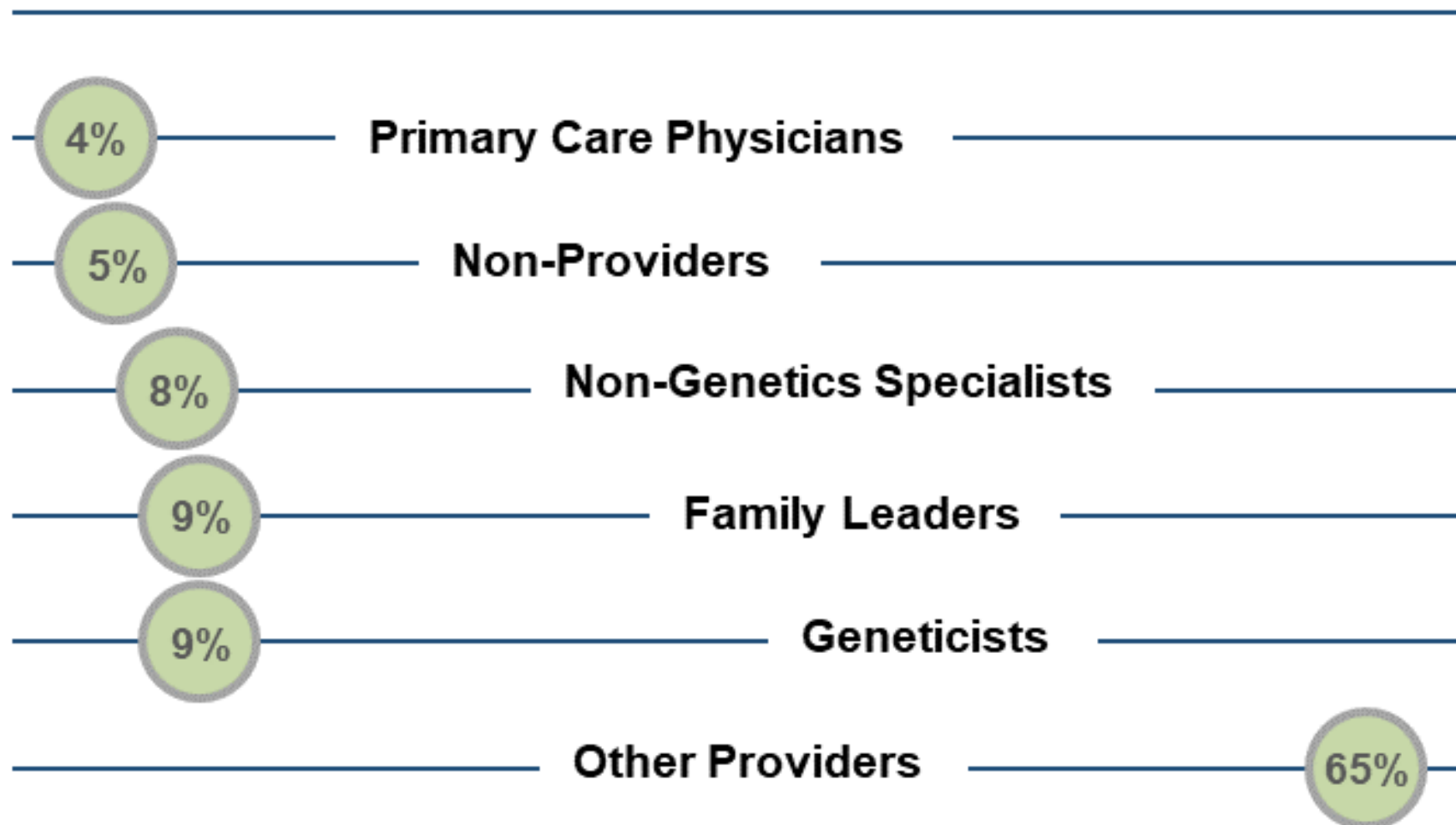
TELEHEALTH SITES
INCREASE SINCE
YEAR 1 BY 83%
WHICH RESULTED IN
AN INCREASE IN
NUMBER OF
PATIENTS SEEN
ACROSS THE THREE
YEARS.



TRAINING AND RESOURCE SUPPORT

PARENTS AND PROVIDERS PARTICIPATED TRAININGS THAT COVERED A BROAD RANGE OF GENETIC RELATED TOPICS





UPDATES 2020-2021

WORK GROUPS

- **Advocates**

- Individual health plan (IHP)
- App

- **Clinical Services**

- Pre-authorization sub workgroup: Creating a file to document pre-authorization requirement and medical necessity letters
- Telehealth sub workgroup

- **Community Engagement**

- Video
- App

- **Early Hearing Detection and Intervention**

- ECHO

- **Newborn Screening**



QUESTIONS?



WHAT HAVE WE LEARNED LAST YEAR?

BREAK

PLEASE RETURN IN 15 MINUTES

BREAK OUT SESSIONS



Caroline Statler Williams is a soon to be graduate of the UAMS genetic counseling graduate program. During her time at UAMS, Caroline worked with Heartland to connect with the Marshallese community and develop informational genetics videos in Spanish. In her master's thesis, Caroline explored the perspectives of Marshallese mothers, health care professionals, and Arkansas Newborn Screening staff in the hopes of finding ways to improve newborn screening for the Marshallese population. After graduating, Caroline will work as a cancer genetic counselor in Des Moines, Iowa and plans to submit her research for publication.



Bryce is a soon-to-be graduate of the Master of Science in Genetic Counseling program at the University of Arkansas for Medical Sciences. She will be joining the molecular laboratory as a genetic counselor at the University of Alabama Birmingham in June. Gene therapy has been a topic of interest to Bryce which was sparked during her undergraduate studies at Southern Arkansas University. This interest carried into her graduate research which assessed the autism community's views of it as a potential treatment for autism. Bryce plans to continue being involved in gene therapy and viral genetics throughout her career in research and education.



David Flannery, MD, is Director of Telegenetics and Digital Genetics in the Center for Personalized Genetic Healthcare of the Genomic Medicine Institute at the Cleveland Clinic. He was previously Medical Director of the American College of Medical Genetics and Genomics from February 2014 to May 2018. He joined ACMG from the Medical College of Georgia of Augusta University where he served in a succession of clinical, academic and medical staff leadership positions. Dr. Flannery has been a pioneer in telemedicine. At MCG he started telemedicine genetics clinics in 1995, which are considered to have been the longest continually running telegenetics services in the nation. He has published extensively in clinical genetics, telemedicine and dysmorphology and is a frequent presenter at national meetings. His expertise has led to his being appointed to national committees and workgroups developing standards and tools for implementation of telehealth, such as the Telehealth Committee of the National Quality Forum and the Digital Medicine Payment Advisory Group for the American Medical Association.



Tiffany is an Assistant Professor and the Assistant Program Director in the Department of Genetic Counseling at the University of Arkansas for Medical Sciences. In addition to teaching, she is the Genetic Counseling Discipline Coordinator for the Leadership Education in Neurodevelopmental Disabilities (LEND) program and is the genetic counselor in the Specialty Diagnostic Resource Center. Her area of expertise is in genetic counseling education, interdisciplinary training and service, and fetal alcohol spectrum disorders.

INTERSECTION BETWEEN GENETICS AND COVID-19



Aaron M. Wendelboe is Associate Professor, Edward E. and Helen T. Bartlett Foundation Chair in Public Health and Williams Companies Presidential Professor at the University of Oklahoma Health Sciences Center (OUHSC) in the College of Public Health, Department of Biostatistics and Epidemiology. Dr. Wendelboe is a nationally recognized epidemiologist and public health leader. He is an alumnus of the Epidemic Intelligence Service (EIS) program of the US Centers for Disease Control and Prevention (CDC), and he served with distinction in the uniformed Public Health Service Commissioned Corps, assigned as an EIS Officer for the CDC during 2006 through 2008. Dr. Wendelboe has made scientific contributions to the areas of infectious disease epidemiology, thrombosis disease epidemiology, disease surveillance methodology and outcomes for both of these conditions. Most recently, between March and July of 2020, Dr. Wendelboe was deployed to the Oklahoma State Department of Health where he served as the Interim State Epidemiologist in coordinating the epidemiology elements of the State's response to Covid-19. In this role, he served as advisor to the Governor and the Health Commissioner.

Dr. Wendelboe continues to pursue his passion of bridging academic and applied public health. He serves on OUHSC's Infection Control and Prevention Committee and the OUHSC's Emergency Response Committee. In these roles, he collaborates with national, Tribal, and local stakeholders, such as the Indian Health Service, CDC, the Oklahoma Area Tribal Epi Center, and the Oklahoma State and County Health Departments in preparing for and responding to pandemics such as 2009 influenza H1N1, Ebola virus, Zika virus, and COVID-19.

TO CONCLUDE...

THANK YOU FOR ATTENDING AND FOR YOUR SUPPORT TO THE HEARTLAND REGIONAL
GENETICS NETWORK