

The MSRGN Underserved Patient Populations (UPP) Project: A Systematic Approach to Identifying and Addressing Barriers to Accessing Genetic Services

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Introduction

- MSRGN's mission is to ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and information.
- Advancing access to genetics services is challenging due to provider shortages and geographic barriers including mountains and vast rural and frontier regions.
- The MSRGN region (AZ, CO, MT, NM, NV, TX, UT, and WY) covers almost one-third of the US and approximately 40% of its counties are rural or frontier.
- MRGN launched the Underserved Patient Populations (UPP) Project in June 2017.
- The primary goal of UPP was to identify barriers in accessing care at four initial sites (Tuba City, AZ; San Antonio, TX; Durango and Grand Junction, CO). See Figure 1. These sites were selected based on their populations, including large Hispanic or American Indian populations and rural communities with limited subspecialty care.
- UPP focused on identifying barriers to care such that clinic and/or community-level interventions could be developed to address those barriers.

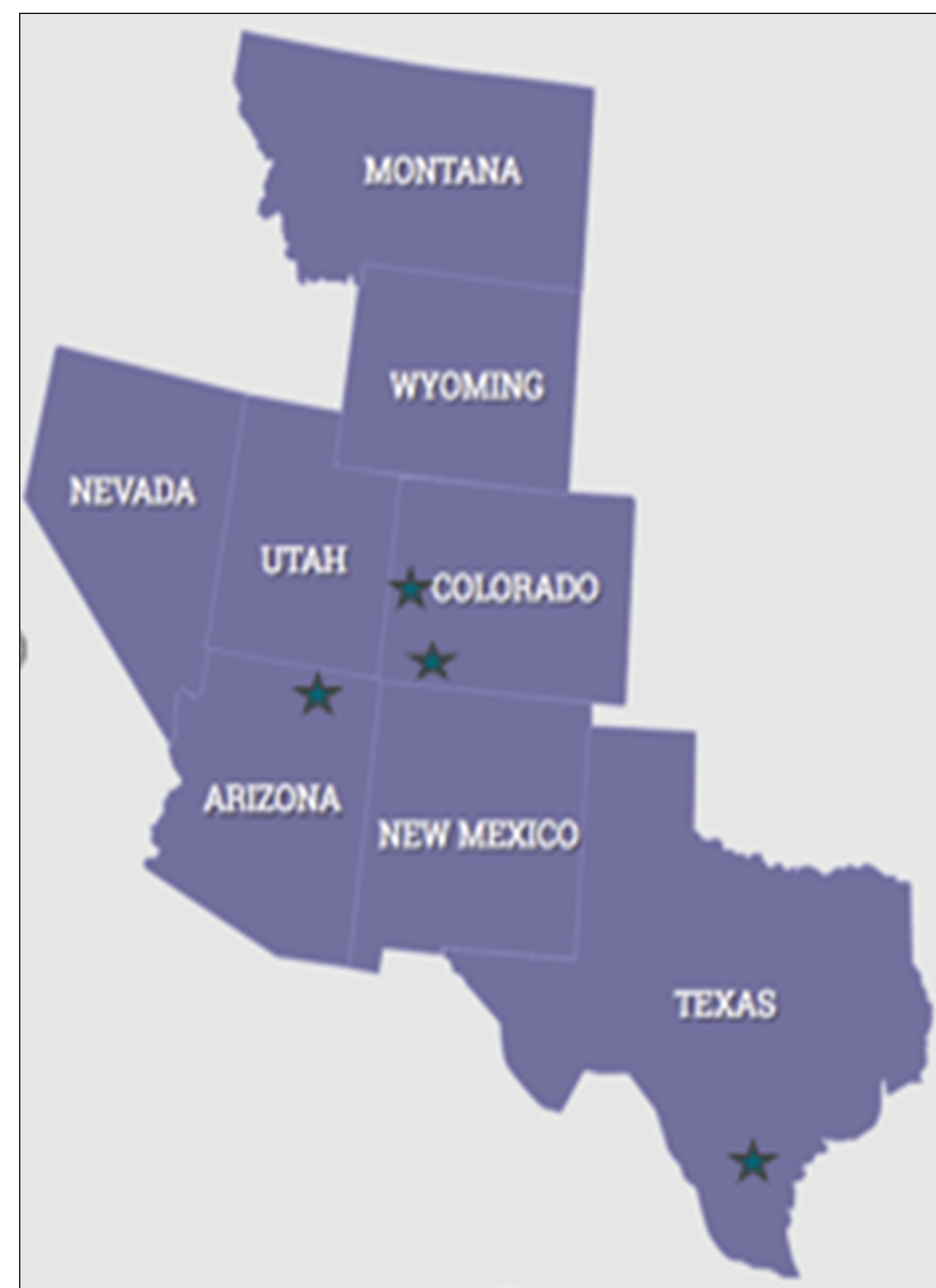


Figure 1. Selected sites for the UPP project.

Methods

- The UPP employed the Andersen Behavioral Model to guide identification of modifiable and non-modifiable factors that impact access to care.
- County-level demographic and socioeconomic data were extracted from data sources at the US Census Bureau, and data from the Health Resources and Services Administration (HRSA) were used to identify health system level resources available in each community.
- A literature review on barriers to access to care in American Indian and Hispanic populations and communities was completed.
- Interviews were conducted with families and consumers (n=8) and primary care providers (PCPs) (n=8) to gain better understanding of local barriers to genetic services.

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Key Findings

- Overall, the demographics and socioeconomic characteristics of the UPP sites demonstrates diversity and differing systems of care. See Figure 2 for an example of the types of data collected.
- The interviews revealed a number of challenges and needs among both providers and families:
 - Tuba City, AZ**
 - ❖ Tuba City general pediatric clinic provides the only pediatric clinic for approximately 80 miles in any direction
 - ❖ There are no genetic specialists at the site
 - ❖ Nearest genetic clinic is in Phoenix, AZ, about 250 miles away
 - ❖ Need is for MD genetic provider rather than genetic counselor
 - ❖ High incidence of SCID and Lynch syndrome in the Navajo population
 - ❖ Community Health Workers have limited genetics knowledge and no experience in assisting families with genetic disorders
 - San Antonio, TX**
 - ❖ Insufficient number of genetic providers
 - ❖ Wait time for genetics clinic appointment is over 6 months
 - ❖ Few PCP's order initial genetic tests because of the need for insurance pre-authorization
 - Durango and Grand Junction, CO**
 - ❖ Clinics (outreach and telegenetics) see general pediatric genetics patients (newborn screening typically seen in Denver first)
 - ❖ Nine month waiting list for new genetic patients
 - ❖ Laboratory testing for Medicaid patients facilitated by PCP ordering through Colorado Children's Hospital, which absorbs the cost if Medicaid does not pay
 - ❖ Adult genetics provider in Denver has 2 year waiting list

Census Topic	Coconino
Total Population	
Population Estimates (7/1/16)[V2016]	140,908
Age	
Persons under 5 years, percent (7/1/16)[V2016]	5.80%
Persons under 18 years, percent (7/1/16)[V2016]	21.20%
Persons 65 years and over, percent (7/1/16)[V2016]	11.90%
Race and Hispanic Origin	
White alone, not Hispanic or latino percent (7/1/2016)[V2016]	54.70%
Hispanic or Latino, Percent (7/1/2016)[V2016]	13.80%
Black or African American alone, percent (7/1/2016)[V2016]	1.40%
American Indian and Alaskan Native alone, percent (7/1/2016)[V2016]	27.50%
Asian alone, percent (7/1/2016)[V2016]	1.90%
Native Hawaiian and other Pacific Islander alone, percent (7/1/2016)[V2016]	0.20%
Two or more races, percent (7/1/2016)[V2016]	2.80%
Population Characteristics	
Foreign Born Persons, percent (2011-2015)	5.40%
Families and Living Arrangements	
Language other than English spoken at home, percent of persons age 5+ years (2011-2015)	24.30%
Health	
With a disability, under age 65 years, percent (2011-2015)	8.20%
Persons without health insurance, under age 65 years, percent	14.60%
Economy	
In civilian labor force, total, percent of population age 16 years+ (2011-2015)	64.60%
Income and Poverty	
Median household income (in 2015 dollars) (2011-2015)	\$50,234
Per capita income in past 12 months (in 2015 dollars) (2011-2015)	\$24,308
Persons in poverty, percent	19.50%
Businesses	
Total employment, 2015	50,051
Geography	
Population per square mile, 2010	7.2
HRSA FQHC	
Number of FQHC hospitals in county	3
Location of FQHCs and total patients served (as of 2015)	CANYONLANDS COMMUNITY HEALTH CARE 827 Vista Ave, Page, AZ 86040 Total Patients Served: 17,368 NORTH COUNTRY HEALTHCARE, INC. 2920 N Fourth St, Flagstaff, AZ 86004 Total Patients Served: 48,718 TUBA CITY REGIONAL HEALTH CARE CORPORATION 167 Main St, Tuba City, AZ 86045 Total Patients Served: 2,176
US Census Quick Facts Data	
HRSA Health Center Program Websites	

Figure 2. Demographic data related to barriers to care. Example of one community's data.

Conclusion

- The UPP project demonstrated that comprehensive community- and clinic-level assessment of barriers to accessing genetic services for underserved populations can lead to identification and implementation of specific interventions aimed at improving access to care. Basing the project on a well-established conceptual model allowed for identification of modifiable factors that facilitate improved access.
- Future work will determine if these interventions improve access to care for families. To measure their impact, MSRGN conducts rigorous evaluations of MSRGN-led interventions and offers technical assistance to state-based projects seeking to improve access to genetic services.

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