

Expanding the Public Health Workforce within the  
Administration for Community Living's (ACL's) Networks



Focus Group Summary

# **Future Planning for People with Intellectual or Developmental Disabilities**

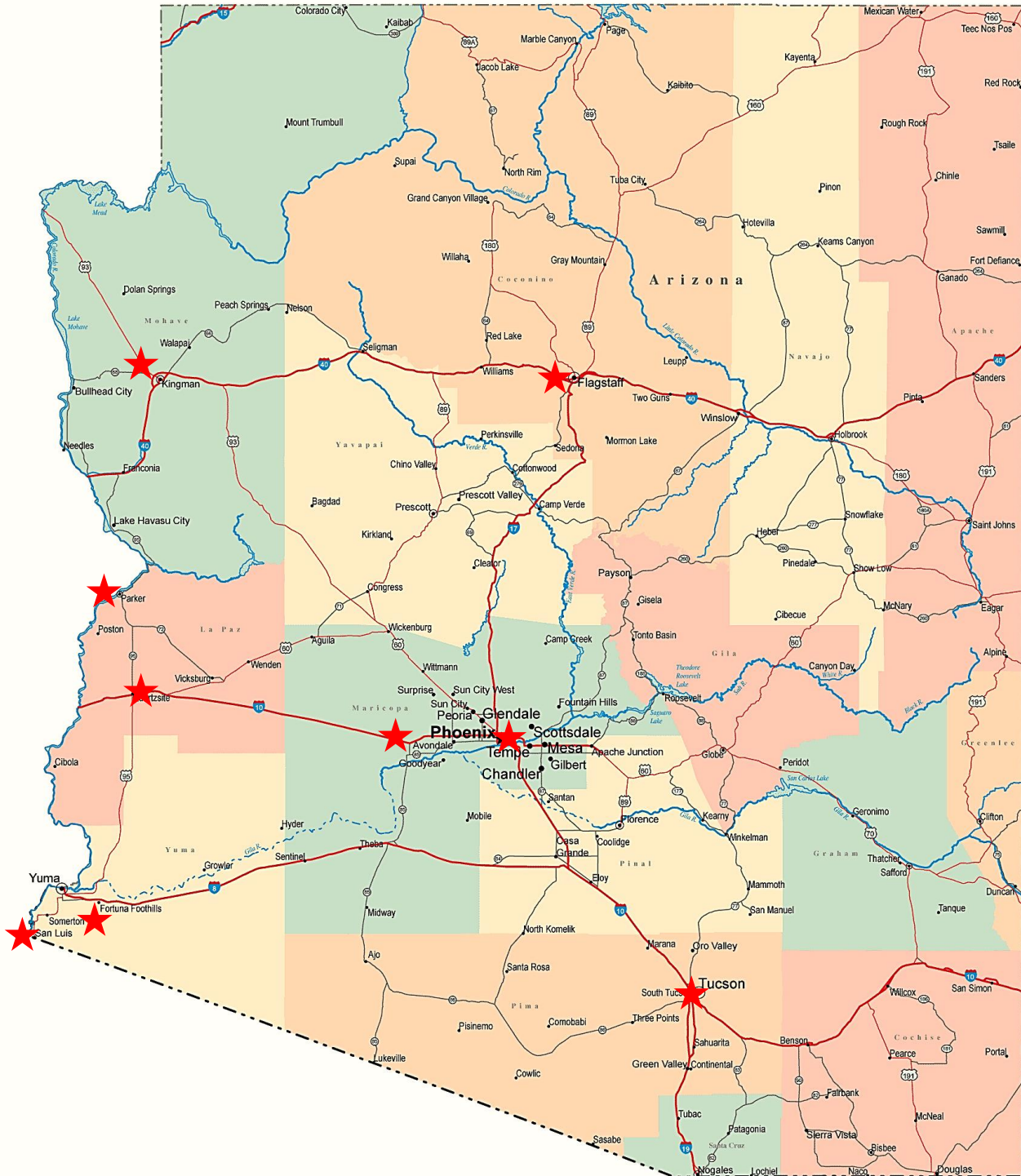
February 2024

*Prepared by: Regional Center for Border Health, Inc.*

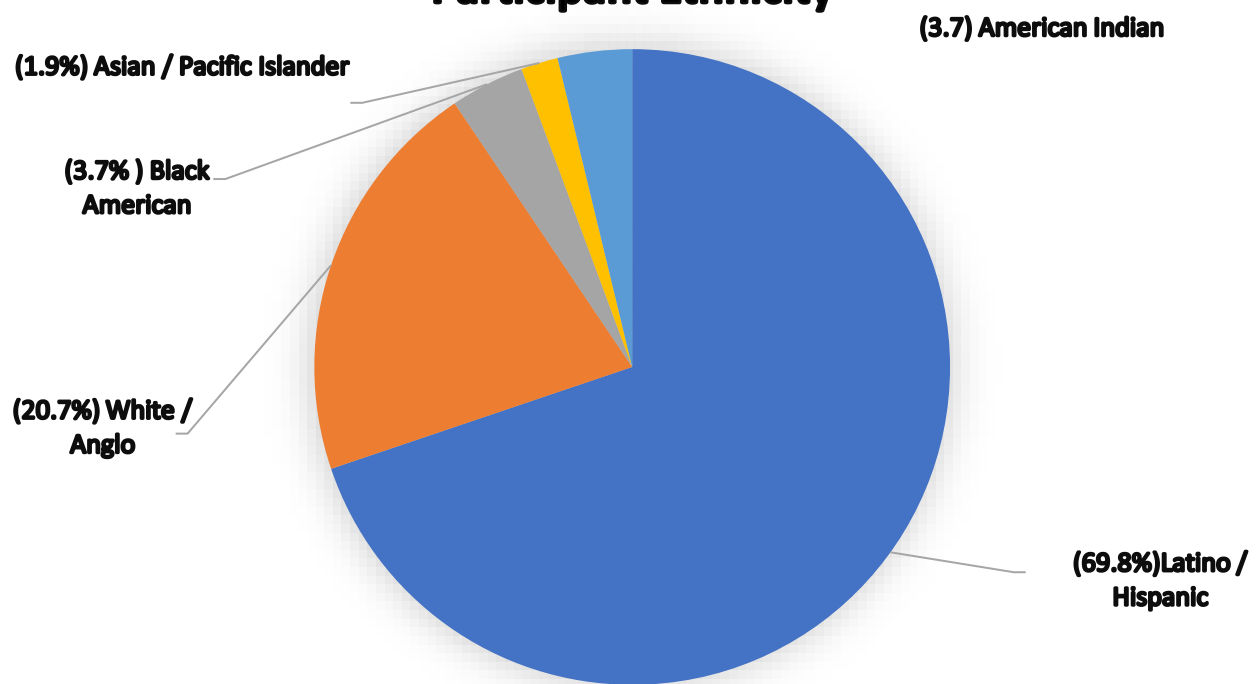


THE UNIVERSITY OF ARIZONA  
COLLEGE OF MEDICINE TUCSON  
**Sonoran Center for  
Excellence in Disabilities**

# Focus Group Locations; Yuma, Somerton/Cocopah Tribe, San Luis, Parker, Flagstaff, Kingman, Avondale, and Tucson



## Participant Ethnicity



This Infographic summarizes the results of eight (8) focus groups conducted in rural and urban communities around Arizona to better understand:

- ✓ The needs, desires, and goals of Arizonans with intellectual and developmental disabilities (I/DD) as they enter their elder years (roughly defined as age 60 and above), giving attention to both physical and cognitive changes.
- ✓ State-funded or private services currently helping people with special needs prepare for physical and cognitive changes they will experience in the future.
- ✓ New or adapted systems that are needed to better support individuals with special needs in the later years of their lives.

Focus Group participants expressed a sense of urgency and desperation in obtaining services for their family members, clients and themselves impacted with I/DD.

The feedback provided by the Focus Groups participants were similar for all sites, rural or urban sites. Although, the most impacted comments were from minority groups, Hispanic and Native American, feeling a sense of abandonment by state and local agencies or government entities.

The followings are several responses to the Focus Groups key questions developed for this study.

A blurred background image showing a group of children in a classroom setting. A young girl in the foreground is smiling and looking towards the camera. Other children are visible in the background, some looking towards the camera and others looking away.

**Future  
Planning**

**Workforce  
Development**

**Challenges  
and  
Opportunities**

**Services  
Accessible or  
Affordable**

**Services or  
Programs  
More Helpful**

*“Every day I pray that my child dies before me, because there is no one else is “gonna” take care of him. I don’t know who I’m going to pass along the responsibilities for taking care of my son”.*

Flagstaff Family Caregiver

### Concerns expressed throughout the Focus Groups:

Family caregivers are often overwhelmed by services barriers they experience, making it difficult to plan for the future.

Arizona’s workforce is insufficient prepared to address existing I/DD individual needs and help caregivers achieve future goals.

Many I/DD individuals and families experience social isolation and discrimination.

Resources should be available in local communities through coordination with state agencies.

Education and training opportunities should be available to people with I/DD.

Employment, Adult Day Care and Housing should be available for people with I/DD.

Develop a well trained workforce (primary care, behavioral health and home health care providers, legal, social workers, law enforcement, educators, first responders) to provide care in a compassionate, culturally, and high quality care to individuals with I/DD.



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## I/DD Families' Voices

*"There is a gap in services for the 10 years of age to 17 years of age population with development disabilities".*

*"Self-security and Home-based services 24/7 support."*

*"There is a waiting list to get Behavioral Health services and early intervention."*

*"It's a black dark side of disabilities community (due to lack of awareness)."*

*"Once you get in the DDD system and the Division of Developmental Disabilities receives your application it's OK, but getting approved is a higher barrier."*

*"Getting a Case Manager assigned is very difficult."*

*"Very hard to find medical personnel who have any knowledge of disabilities and I/DD, is not exactly helpful in pointing you for medical resources."*

*"It takes too long, 3-4 years to get services and being diagnosed. The process is too slow to get sponsored and no one takes actions."*

*"Most of the diagnoses are happening when the child enters the school system. If the child doesn't enter school at an early age, 6 years can go by without any services."*

*"The problems have been with us for years. When and what do we need to do to obtain a solution? Certainly, we have been expressing our needs and I believe it's important to do something. For me, it would waste everyone's time. These are problems we've seen for many years, and we can't find a solution. My question is, is there an opportunity to fix these conditions?"*

*"Ojalá que llegaran millones a la casa, para no pedir documentos, citas, pero por 1 dolar o 2 ya te excediste y te cierran las puertas". / ("I wish we could earn millions of dollars so we wouldn't have to apply for any services, appointments... but for an extra dollar or two you exceed, and you get doors closed (to apply for services.)"*

*"Y de repente sale una criatura bellísima con quienes tenemos mucha esperanza, mucho futuro y las escuelas y después empieza este comportamiento que lo único que podemos hacer o decir es que son delincuentes, no hacen caso, que tiene el diablo, supersticiones en familia". / "And all of the sudden a beautiful creature who we truly hope he will have a great future and will do great in schools, and then starts having this behavior that the only thing we can do or say is that they are criminals, they don't behave, they have the devil inside, family superstitions."*



# Social Determinants

## Safety Net for Families and Individuals with I/DD for All Ages

### Accessible and Affordable to Healthcare Services

- high quality health care
- timely access to mental health services
- well trained healthcare workforce
- culturally sensitive healthcare services

### Legal Services

- Legal Guardianship
- Estate planning
- Health directives
- Fiduciary services that are culturally sensitive to families and individuals with I/DD

### Inclusion & Civic Engagement

- Create environments that eliminate stigma that adversely affects people with I/DD

### Transportation

- Safe, accessible and affordable public transportation that connects with community services
- Safe walking, and biking routes to community services and resource centers

### Housing and Food Security

- support independent living for people with disabilities
- affordable, high quality, socially integrated housing
- access to affordable and nutritious foods
- supportive relationships and neighborhoods

### Education, Training & Economic Opportunities

- classroom settings conducive to delivering education and training from elementary school to high school
- early childhood education designed to address early intervention (Head Start programs, kindergarten)
- child and adult day programs designed to meet the needs of children and adults with I/DD
  - vocational education training centers
  - employment and living wages for people with I/DD



*Special acknowledgment to Regional Center for Border Health, Inc./ San Luis Walk-In Clinic, Inc., Western Arizona Health Education Center, League of United Latin American Citizens, Somerton Desert Valley Senior Center, Gadsden Elementary School District #32, Native Americans Community Action, North Country Healthcare, and Tucson Community Connections, for making this research possible.*

*This project was supported by the Administration for Community Living of the U.S. Department of Health and Human Services under the authority of Section 2501 of the American Rescue Plan (ARP) Act of 2021, PL 117-2, as part of an award totaling \$95,319, with 0% financed from non-governmental sources.*