

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



Focus Group Report

Future Planning for People with Intellectual or Developmental Disabilities

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Prepared by Regional Center for Border Health, Inc.



THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON

**Sonoran Center for
Excellence in Disabilities**

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I. BACKGROUND

The Arizona Developmental Disabilities Planning Council (ADDPC) contracted with Regional Center for Border Health, Inc. (RCBH) and the University of Arizona's Sonoran Center for Excellence in Disabilities (SCED) to organize focus groups that would elicit the perspectives of individuals with intellectual and/or developmental disabilities (I/DD), their family members/caregivers, professionals in the I/DD service system, and other stakeholders to better understand:

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

This Report summarizes the information collected during eight focus groups completed around Arizona, in rural and urban communities, during the summer/fall of 2023.

II. INTRODUCTION

Developmental disability (DD) is an umbrella term that applies to permanent disability, manifesting sometime before young adulthood, that impacts a person's intellectual or physical functioning (ADDPC, 2011). Sometimes developmental disabilities are visible, but oftentimes they are not, because the causes, severity, and types of disability differ.

Prevalence estimates for Arizona's disabled populations differ according to data source and definition used. The U.S. Census Bureau, a common reference, estimated in 2023 that 984,914 Arizonans (13.6%) had a functional disability (i.e., limited hearing, vision, cognition, ambulation, self-care, or independent living). This is an 11.2% increase in the number of individuals who reported having a disability during the 2010 Census. As the population of individuals with disabilities increases, so does the need for services. Data from the Arizona Long Term Care System (ALTCs) showed an 87% increase in DDD services spanning the 2009-2022 period; during the same period, Arizona's general population increased 17%.

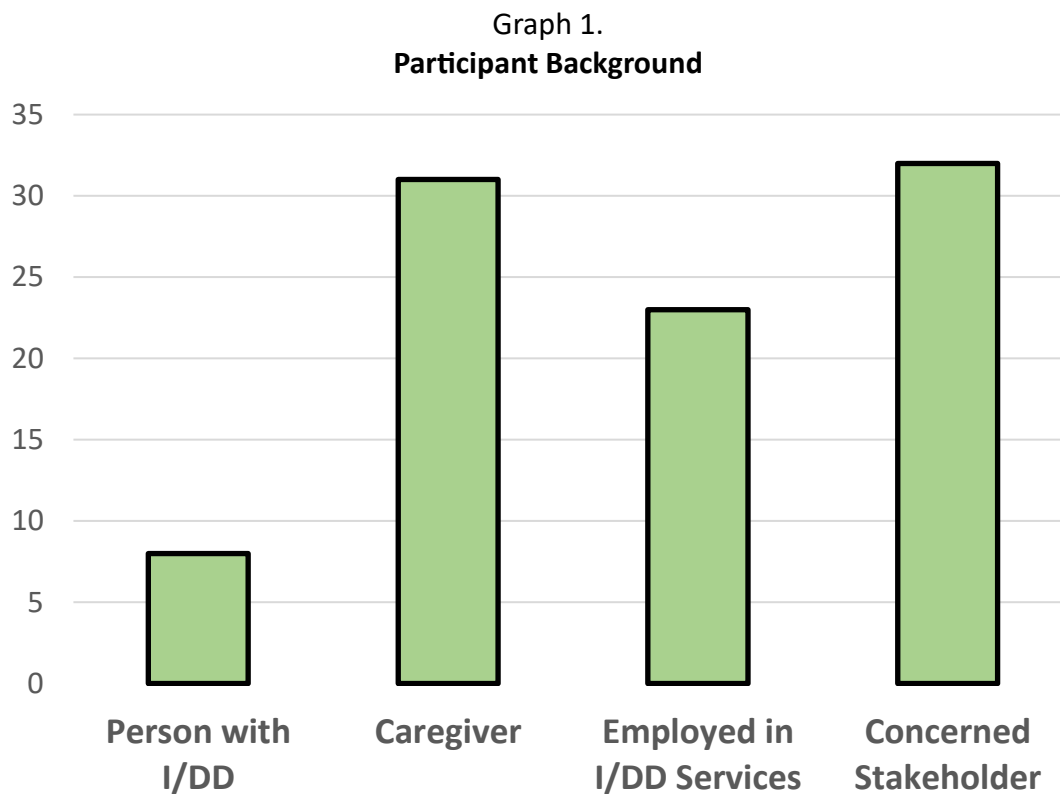
According to ADDPC, "individuals with intellectual and/or developmental disability (I/DD) are, on average, living longer and more fulfilled lives than at any other time in history. Yet these individuals are also in certain ways victims of the system's success, for as one emerges into 'elderhood' daily needs – including basic life activities, healthcare (both physical and behavioral), housing, and communication – can change dramatically." Individuals with I/DD are challenged by their chronic medical conditions but also by stigma, discrimination, and exclusion. Their caregivers, including many who left the workforce, are themselves aging and experiencing social isolation and burnout. The aging process has a profound impact on the individual with I/DD and their caregiver(s) who need to manage uncertainty with fewer financial and social resources as they look to the future.

III. Findings

The RCBH negotiated agreements with local community organizations to recruit participants and host focus group sessions. Attenders received a \$25 gift card for participation in the 90-minute sessions. Eight focus groups were organized, five in rural areas and three in urban communities. Out of the eight focus groups, five were conducted in English, two in Spanish, and one simultaneously translated (English/Spanish).

A limited amount of personal information was collected using an anonymous participant satisfaction survey that asked about the person's ethnicity and reason for attending. Sixty-one surveys were collected: thirty-seven (70%) participants self-reported as Hispanic; eleven (21%) as Anglo, two (4%) as Black American; two (4%) as American Indian and one (2%) as Asian/Pacific Islander.

Eight participants self-identified as having an intellectual or developmental disability; thirty-one as caregivers (most often a parent or sibling); twenty-three as service providers (most often a clinician, educator, or administrator); and thirty-three as concerned stakeholders. (Note: Individuals were allowed to choose multiple responses).



The following table identifies the Arizona communities where groups were organized, the number of participants in each group, and select indicators that describe community characteristics.

Table 1.
Focus Group Location, Participants and Community Characteristics

Focus Groups			Community Characteristics*					
Town / City (PCA)	County	# Participants (61)	Median Household Income (\$)	Community of Color (%)	Language other than English at Home (%)	Disabled Population (%)	Healthcare Shortage: Primary Care Provider ratio Pop:Provider	Less than 9 th Grade Education (%)
Somerton	Yuma	6	35,117	96.8	81.7	8.2	5,369:1	14.4
Somerton	Yuma	11						
Parker	La Paz	7	56,867	67.8	32.0	13.3	561:1	12.1
Flagstaff	Coconino	3	69,615	37.2	15.6	10.2	577:1	3.2
Avondale	Maricopa	5	68,636	73.1	40.3	10.9	1393:1	8.6
San Luis	Yuma	14	44,324	91.8	86.8	8.5	5938:1	17.3
Tucson**	Pima	11	38,137	48.5	28.1	15.3	272:1	7.0
Kingman	Mohave	4	45,939	24.0	7.2	23.9	534:1	8.9
Arizona State			62,115	46.6%	26.7%	13.2	747:1	5.0

* Data Source: Primary Care Area (PCA) dataset, Arizona Department of Health Services (May 13, 2022)

** Tucson Central PCA



Table 2.
Focus Group Questions

1. For individuals with developmental disabilities, when services are needed for health, education, housing and/or workforce training, which services or programs have been/are most helpful? Are they easily accessible and affordable?
2. Which needed services have been missing, less accessible, or unaffordable?
3. As individuals with developmental disabilities get older, their needs and circumstances change. What challenges have you experienced, or do you anticipate, as individuals with I/DD and/or their caregivers get older (say, older than 60 years of age)?
4. How do you think a person with disabilities and/or their caregiver(s) should prepare for the future as they age - say, get older than 60 years of age? What planning steps should be taken?
5. What services are now available, or what information do you find most useful in helping individuals with I/DD and/or their caregiver(s) to prepare for the future?
6. What would you tell community leaders (legislators or agency leaders) about the services or system changes needed to make certain future needs of Individuals with I/DD with I/DD are met?
7. Are there any recommendations that we haven't already discussed that you would like to add?



Key Themes

Table 3. identifies themes, sub-themes, and conclusions drawn from the focus group discussions. Participants were asked about information needs, how they were preparing for the future, and helpful services. Most comments, during all groups, related to participant needs and service barriers. When queried about future planning, some caregivers described efforts to create financial plans, establish trusts and legal arrangement for guardianship, and secure housing through long-term care or semi-independent living arrangements, such as small group homes. While some were taking action to prepare for the future, most were not. Many caregivers were anxious about future uncertainties due to diminished health and social support and lacking knowledge about alternatives. Many were not planning for the future, rather struggling to survive in the present.

Table 3.
Focus Group Themes, Sub-themes and Findings

Theme: Access to Services
<ul style="list-style-type: none">✓ Caregivers are often unaware of services and do not understand eligibility requirements.✓ Healthcare, dental, and specialty diagnostic services are often not locally available, require long distance travel, and experience excessive service queues (wait time).✓ Critical support services (i.e., respite, transportation, workforce, day program) and service networks (i.e., Areas on Aging, The Arc of Arizona, AHCCCS/ALTCS, DES-DDD) exist, however, access to their services varies by community. <p>Finding: Family caregivers are often overwhelmed by service barriers, making future planning difficult.</p>
Theme: Education & Training
<ul style="list-style-type: none">✓ Providers: Healthcare professionals, educators, state agency staff, direct care workers, etc., do not always understand specific medical conditions or communication needs of individuals with I/DD.✓ Caregivers: Often feel isolated and seek peer support and service outreach.✓ Law enforcement and emergency service providers need to more easily identify, and communicate with, Individuals with I/DD with I/DD. <p>Finding: Arizona's care workforce is not prepared to address I/DD personal needs and help caregivers achieve future goals.</p>
Theme: Social Isolation, Stigma, and Discrimination
<ul style="list-style-type: none">✓ Rural, low-income, and linguistically isolated Individuals with I/DD with I/DD and their caregivers are especially vulnerable.✓ Outreach and peer support services organized locally will help engage Individuals with I/DD with I/DD and caregivers. <p>Finding: Many Individuals with I/DD and families experience social isolation, stigma, and discrimination.</p>
Theme: Future Planning
<ul style="list-style-type: none">✓ Most caregivers and Individuals with I/DD have not developed formal plans to prepare for future circumstances.✓ Caregivers are interested in learning more about financial planning, supported decision-making & guardianship, trusts, housing and long-term care, eligibility restrictions and income limits. <p>Finding: Most caregivers are unprepared for future circumstances; however, they are interested in learning more about, and having greater access to, planning resources.</p>

Theme: Access to Services

Many of the focus group comments related to the barriers that caregivers experience when seeking services. A variety of obstacles were described; healthcare was a principal concern, however, other services including education, diagnostic testing, workforce development, transportation, respite, and housing barriers were also described. Many participants reported that services are not readily accessible.

While healthcare shortages exist in many communities around the state, these barriers were particularly difficult for individuals with I/DD due to the critical need for timely and specialized care. Delays in early diagnosis and intervention have profound effects on individual development and family wellbeing. In every focus group, participants described experiences of excessive service queues and/or long travel distances to receive diagnostic and clinical specialist care, routine dental care, physical, speech, and occupational therapy. For those caregivers who were employed, getting necessary care has to be synchronized with work and/or family obligations and often requires significant travel-related expense.

“My son did not know how to communicate, he was always crying when he was a kid and I put on his uniform and tennis shoes, and he always started crying, and I did not know what to do. One day, at 15 years, he said, he said he remembered back then he was crying because of a label in the tennis shoes [that] injured his feet.”

- Avondale Caregiver

Professional workforce shortages were identified as an important barrier; examples provided were especially evident in rural communities like Parker, San Luis, and Kingman. Access to healthcare is especially difficult for specialty and mental health, dental care, and pharmacy. Caregivers explained that workforce shortages were especially difficult due to the individuals' complex medical conditions that required timely intervention and specialized treatment, from multiple practitioners. Specialty and dental services are not readily accessible, but neither are ancillary services: speech, physical, and occupational therapy. Residents in the more geographically isolated communities must travel long distances. Dental care was identified as being a big challenge because of the shortage of providers and the training needed for sedation before preventive and restorative treatment. Caregivers feel that many practitioners do not accept patients who are considered “unusual” or difficult-to-treat.

Workforce turnover was another issue identified as particularly hard on individuals with I/DD and their caregivers due to the need to trust providers. Once a relationship is established, individuals with I/DD and caregivers try hard to maintain services. Care continuity can be a big challenge, especially for personal care/direct care workers and nursing assistants, where turnover is high (estimated to approach 30%). Frequent changes in personal care can be upsetting to the individual with I/DD, who has difficulty with social interaction, and for the caregiver, who needs to trust other people who are providing personal care.

Caregivers spoke of not having access to information to understand medical conditions, how to access services, or where to get assistance. Some caregivers knew about the local services available but were unaware of requirements for eligibility. During the Spanish-language sessions caregivers expressed concern about not having information available in Spanish.

"I wish we could earn millions of dollars so we wouldn't have to apply for any services,

One consistent message concerned not having sufficient information. However, when asked about services that were useful, participants identified state and local services including the AZ-211 information and referral service and the Department of Economic Security-Division of Developmental Disabilities (DES-DDD). State services were commonly identified as important, but participants also spoke of difficulty gaining access to information and receiving consistent guidance; services were often considered "distant" and difficult to access. Several participants identified the need for a local community resource center to make information more available and provide meeting space. Table 4 identifies the program services considered most useful. One specific issue identified by two caregivers in Flagstaff is that a local DDD Services Directory was unavailable due to concerns it would be construed by DDD as preferential treatment for service referral.

Table 4.
Services or Programs Identified as Most Helpful

• The Arc of Arizona – Tucson and Kingman Chapters	• Arizona Long Term Care System (ALTCS)
• Arizona ABLE	• AZ-211
• Arizona Center for Disability Law	• Chicanos por la Causa
• Arizona Department of Economic Security-Division of Developmental Disabilities	• Food Stamps (SNAP)
• Arizona Department of Economic Security	• Raising Special Kids
• Arizona Health Care Cost Containment System	• Regional Center for Border Health
• Western Arizona Council of Governments (WACOG)	• Saddles of Joy (Yuma)
	• Social Security Administration

Participants offered ideas about how best to engage individuals with I/DD and caregivers so they receive and understand information and can take appropriate action. Participants expressed strong preferences to receive information in-person, from people who have been trained in the specific disability condition, from outreach workers, peer specialists, or community liaison staff. Several participants expressed concern that agency outreach services have been reduced, either due to fewer community liaison workers being employed or because of increases in care manager workloads. Participants stressed the importance of community liaison and community outreach. Preferences were also expressed for peer support from individuals with direct knowledge of the I/DD experience.

"Caregivers can easily become overwhelmed by the service system."

When asked about internet-based information, several participants pointed out that many rural communities do not have adequate broadband internet service and that caregivers are often older and unfamiliar with computer technology. While challenges to over-reliance on web-based information dissemination were identified, participants also identified the internet as an important resource. A Kingman participant spoke about her experience with an “autism community of interest” that provides family support via Facebook, which she considered very effective.

“Every day I pray that my child dies before I do because I don’t know who I’m going to pass along the responsibility for my son.”

– Flagstaff Caregiver

Theme: Education and Training

Focus group participants emphasized that I/DD is not a uniform set of conditions or diagnoses. Participants suggested that clinicians, educators, and other service providers receive training to help them better address individual needs related to the specific medical condition. Concerns were identified about different types of service, from specialized clinical care professionals to direct care workers, educators to police.

“I feel bad, sick to my stomach when families struggle with disabilities and have to figure when they go a hospital and staff don’t know how to assist them, they don’t know how to communicate with our disabled children or disabled individuals to see what happens, is there any pain, where?”

– Flagstaff Caregiver

Participants suggested that provider education would improve quality of care. Service providers should have more knowledge about the specific medical condition underlying developmental disability and the best treatment practices. Providers should also be better informed about existing resources, insurance coverage, and service transition pathways. Participants identified the need for service providers to have better communication skills to interact with Individuals with I/DD. Suggestions were made to include I/DD topics into curriculum and during continuing education workshops. In some cases, more knowledge is needed; in others, providers should improve their customer service skills and capacity for empathy. During two groups, recommendations were made to establish emergency responder identification systems, for example, specialized license plates or home identification notices, for police and EMS providers to identify the person with special needs and communication difficulties.

“My son gets mistaken with an intoxicated person. Law enforcement, they need to be trained to be with people, with a person with disabilities. I have heard stories of police killing because they don’t know how to recognize them because they are aggressive and they are very vulnerable, we need to stop police and violence.”

– Flagstaff Caregiver

Education programs to help caregivers prepare for the future should be organized in accessible locations. Planning template tools can be more widely disseminated; however, their adoption is more likely if caregivers receive personal encouragement, are informed about the different financial planning tools, recognize trustee and guardianship options, and understand that options exist for housing and home care.

For professionals, web-based education and continuing education would be important. For family members, educational programs in the preferred language and appropriate literacy level are essential. Dissemination of information via web-based programs is acceptable although not sufficient, as many rural communities do not have broadband access and many caregivers are older and less comfortable with computer programs.

Theme: Social Isolation, Stigma, and Discrimination

Numerous caregivers expressed deep-seated feelings of anxiety and desperation, a sense of social and/or geographic isolation and wanting more social engagement. In several instances, participants spoke of poor treatment from school staff and/or bullying from other students. Several expressed concern about being excluded from community events. Having the opportunity to meet with other peers was considered important, during day programs, employment, or social engagement in local community sites.

“People must be approached and receive information in their language. It is cultural thing. For my parents and grandparents, it was taboo to talk about these issues. I still have friends that don’t take their kids for evaluation.”

– Somerton Caregiver

Program services more often identified for reducing isolation were respite care, transportation, and day programs. Respite care is highly valued, and participants want to increase the number of hours and allow more flexibility in respite service requirements. It was pointed out that overnight respite has been restricted by, among other requirements, home modifications intended to protect direct care workers during overnight stays. Caregivers also expressed concern about direct care worker turnover and whether they have the requisite knowledge about I/DD medical conditions.

“As we get older our circle of support is shrinking. Where can we get help, especially when there's limited respite?”

– Tucson Caregiver

Transportation is another service support that is considered a priority, especially by the rural participants. For example, a Kingman participant reported having to travel 90 miles, to Flagstaff, for dental services, and Somerton and San Luis participants reported traveling to Phoenix or Tucson, a round-trip that would last a full day. Public transportation is less accessible in rural communities, and when city buses operate, they are often difficult to use because of intemperate weather and infrequent schedules.

“Distance is a key barrier. Most people are 20 or 30 minutes away from any health care or services. People are homebound.”

- Parker Service Provider

Self Advocate (age 43) Wish List for Getting Older

1. *Old people want things to do, and they want to learn.*
2. *Sometimes old people don't want to work because they are tired, and sometimes they do want to work, but there are no jobs, or no one will hire them.*
3. *Sometimes they want to work because they don't want to get poor because of all the bills and the food.*
4. *Old people need health care and doctors need training.*

What I want to have and be when I am older:

- *Be Rich*
- *Have Love*
- *Do my own thing*
- *Have God in my life*
- *Have Housing*

Acknowledgements

This focus group report reflects collaboration among three organizations. The *Arizona Developmental Disabilities Planning Council (ADDPC)* is charged with advocacy, capacity-building, and systemic change activities that promote inclusion of people with intellectual and developmental disabilities (I/DD) across the lifespan. ADDPC is made up of individuals with disabilities, family members, professional stakeholders and state agency representatives appointed by the Governor of Arizona. The 23-member Council meets at least four times a year to discuss issues and vote on projects to support through its allocation of federal funds.

The *Sonoran Center for Excellence in Disabilities (SCED)* is an academic center in the University of Arizona's College of Medicine, Department of Family and Community Medicine. SCED's mission is to ensure individuals with intellectual and developmental disabilities have the supports they need to fully participate in the vibrant life of our community. The Sonoran Center has focused on capacity building, infrastructure development, and fostering leadership to establish itself as a recognized leader in disability within Arizona and across the nation.

The *Regional Center for Border Health, Inc. (RCBH)* has the mission to improve the availability and accessibility of education and health services in western Arizona's three counties (Yuma, La Paz, Mohave). The RCBH manages different community education and healthcare services including the Western Arizona Area Health Education Center (WAHEC); the San Luis Walk-In Clinic, Inc.; the Center for Children with Special Needs and Autism; and the College of Health Careers.

Table 5. identifies the local community organizations responsible for recruiting participants and hosting the focus groups.

**Table 5.
Community Host Organizations**

Host Organization	Location
• Western Arizona Area Health Education Center	Somerton
• North Country Healthcare / Colorado Plateau Center for Health Professions	Flagstaff
• Arizona Advisory Council on Indian Health Care (AIH-AHEC)	Flagstaff
• League of Latin American Citizens (LULAC)	Avondale
• San Luis Walk-In Clinic, Inc.	San Luis
• MP Consulting Services	Tucson
• Western Arizona Council of Governments (WACOG)	Kingman

