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A Day In Our Shoes

**Adults With Developmental Disabilities Share Their Experiences
Living In Small Cities And Towns**

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Adults with Developmental Disabilities
Share Their Experiences Living in Small Cities and Towns

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TABLE OF CONTENTS

| | |
|--|----|
| Executive Summary | 1 |
| Introduction..... | 3 |
| The State of Things in Arizona: Survey Findings | 4 |
| What Do Individuals with Disabilities Want? What Previous Studies Have Shown | 9 |
| Methods..... | 10 |
| The Stories That Were Told – The Results..... | 13 |
| Key Themes | 28 |
| The Disability Bubble | 32 |
| Study Limitations..... | 34 |
| Public Input | 35 |
| Next Steps | 38 |
| Appendix: Focus Group Questions | 39 |
| Glossary..... | 40 |

EXECUTIVE SUMMARY

Arizona adults with developmental disabilities (DD) have continued to face extremely high unemployment rates that have been trending upwards over the last 20 years. They also report greater isolation, fewer friends, and higher poverty rates than adults without disabilities. To address this sense of exclusion, many rely on state and federal programs; however, which programs and services should be offered remains an issue of considerable debate. Unfortunately, the voices that are too often neglected in this debate are those of individuals with DD themselves. Including the voices of those who best understand their own lives may offer options in policy and program development that have not received sufficient attention in the past.

To address these issues, Arizona State University's Morrison Institute for Public Policy conducted four focus groups in small cities and towns throughout the state with a total of 35 adults with different types of DD. Questions posed to them included: What are your goals and aspirations? What barriers have you encountered to reaching these goals? What can be done to help overcome these obstacles? Their answers identified both persistent barriers and potential solutions, while also identifying the themes that continue to shape the lives of this population.

A Day in Our Shoes, sponsored by the Arizona Developmental Disabilities Planning Council, finds that choices presented to individuals by the state system are limited, and can inhibit individual freedom and independence. Segregated day program and employment options are being utilized more than community-based options, which would promote these individuals' inclusion in the community. This segregation of services is called by some the "disability bubble." This bubble limits the promise, opportunities, and social networks of individuals who rely solely on a formal disability service system. The report also found that areas with limited resources spark creative opportunities for inclusion. In many cases, these opportunities were driven by the individual. A number of themes stand out from this research:

- **Choice or Inclusion?** Individual desires for inclusion vary. One person may want to live in his/her own apartment, while another would prefer a group home. Some prefer to stay to themselves, while others prefer to socialize. Some prefer group supported or center-based employment over competitive employment.
- **Options and Perceptions Limit Independence:** Most individuals desire to be independent. While their preferred options may be available, they are not always presented to them due to stigma or safety concerns. This was illustrated through the many negative experiences they encountered in their job search, as well as the limited options available to them to live on their own. Regardless, many said they were satisfied with what they currently had and were willing to settle for it. In some cases they had jobs in the community, lost them, and currently were participating in group supported and center-based employment programs.
- **Friends Like Me:** Most participants said they just wanted to feel normal. Those who had friends typically befriended others with disabilities like them who they met through providers. Those who did not receive services through providers either met friends through family or made their own friends in the community. In smaller cities and towns, often their friends moved away, so many had smaller social circles after high school.
- **Location, Location, Location:** While a few participants could drive, transportation still remains a significant barrier for the majority of participants in many of these areas due to cost, availability, and ease of use. The location of the individual's home determined how much freedom the person had to

see friends, run errands, and get out into the community. Those close to city centers either rode their bikes or walked, while those farther away depended on others, which limited their access.

- **Lack of Information, Lack of Access:** Those individuals who used wheelchairs reported consistent problems with physical access to businesses, houses, sidewalks, and roads. In addition, some participants in all four groups did not have access to correct information regarding transportation, available activities or employment. Further, there was an overall lack of knowledge regarding working while on Social Security Supplemental Security Income (SSI), how to access job coaches, and other work incentive programs. This lack of knowledge could help explain why so many are not in the labor force. It also affected how much or how little an individual was able to access the community.

Important questions remain concerning how Arizona can overcome these barriers and design programs that recognize individual choice, encourage active participation in the community, and burst the disability bubble. In order to build a more resilient support system for individuals with DD and their families, the answers must come from multiple stakeholders. This includes the individuals themselves, their parents or caregivers, the providers, government agencies, such as the Division of Developmental Disabilities (DDD), the Rehabilitation Services Administration Vocational Rehabilitation program (RSA VR), and the business community. Arizonans with DD are ready to organize and get to work to break through the barriers they experience daily. With their energy and ideas, Arizona can create a system that fosters their economic and social development, thereby enabling individuals to achieve the level of inclusion they desire.

INTRODUCTION

Isolation.

Resilience.

Dependence.

Pride.

Frustration.

Resignation.

More than 20 years since the passage of the Americans with Disabilities Act, these themes still resonate among Arizonans with disabilities facing persistent social and economic exclusion. Employment outcomes have also deteriorated over the years, despite programs targeted to improve them. Survey data has been helpful in understanding some of these barriers. But deeper questions remain: How are individuals with developmental disabilities (DD) striving to meet their aspirations, and why are some having a more difficult time than others in reaching them? How do they meet friends? What do they consider their ideal living situation? If they are isolated, how specifically does it affect them? How are they faring in the job search, and how do they feel about it?

To answer such questions, researchers often obtain family and provider perspectives through interviews and conduct brief surveys with the individuals themselves. However, these efforts seldom capture the actual voices of individuals with DD. As a result, we may set systemic goals to promote their inclusion without fully understanding what their own individual priorities are for being included -- or if they even feel excluded at all.

This study, commissioned by the Arizona Developmental Disabilities Planning Council, seeks to go beyond survey data to better understand the day-to-day lives of adults with DD living in Flagstaff, Prescott Valley, Sierra Vista, and Yuma. A focus group format was used in order to yield a better understanding of the experience of living with a developmental disability in Arizona, so that programs may be designed to yield better individual outcomes. The focus group format helps participants gain confidence in a group environment by validating their common experiences and providing opportunities for peer support, as well as providing the opportunity to learn from one another. The general public may also learn from the resilience of this population.

THE STATE OF THINGS IN ARIZONA: SURVEY FINDINGS

In 2011, 364,485 out of an estimated 3.8 million Arizonans between the ages of 18-64 were individuals with disabilities, representing about 10 percent of the population.¹ Approximately 150,000 of these individuals have a cognitive disability. According to survey data, this large group of adults with disabilities faces serious challenges living in Arizona. Barriers exist in many areas, including employment, socialization opportunities, and transportation. The following section provides an overall status report of Arizonans with DD via topics that were discussed in the focus groups.

Unemployment and Not Looking

People with DD continue to be excluded at a substantial rate and face large disparities when compared to people with no disabilities. In 2011, the state's overall high unemployment rate meant that workers with disabilities tended to be last hired and first fired.² Looking from the opposite perspective, the employment rate of 20.7 percent for people with disabilities was only about one-third the 60.6 percent rate for people without disabilities. However, most people with disabilities were not actively looking for employment. Nearly three-quarters (73.9 percent) of those ages 16 and older with disabilities were not in the labor force, more than twice the percentage of people without disabilities (32.3 percent).³ Why is this?

Nearly three quarters, 73.9 percent, of those ages 16 and older with disabilities were not in the labor force...

Confusion over eligibility for Supplemental Security Income (SSI),⁴ as well as systemic issues could be partially to blame. The Institute for Community Inclusion (ICI) recently published a wealth of state and national data on employment services and outcomes. This report found that in 2011, there were 98,908 Arizonans with disabilities receiving SSI benefits – with the largest number of these beneficiaries nationally being people with intellectual disabilities (ID).⁵ Social Security Administration (SSA) work incentives, such as the Plan for Achieving Self-Support (PASS), Impairment Related Work Expenses (IRWE), and the Student Earned Income Exclusion (SEIE) support employment by allowing individuals who receive SSI to exclude money, resources, and certain disability-related expenses from total earned income, so their SSI payments will not be affected. The SSA also administers the Ticket to Work program, which provides beneficiaries with a ticket to purchase vocational rehabilitation, employment, and other support services from any participating employment network or state VR agency. However, despite the SSA's initiatives, work incentives and the Ticket to Work program remain underused. Only 74 SSI beneficiaries in Arizona used these programs (not including Ticket to Work) in 2011. In fact, in Arizona, only 3.6 percent of SSI beneficiaries were working at all, which was lower than the national average of 4.6 percent.⁶

¹ U.S. Census Bureau, American FactFinder. (2011). 2009-2011, American Community Survey 3 year estimates. DP02: Selected social characteristics in the United States.

² U.S. Bureau of Labor Statistics. (2011). Unemployment rates for states.

³ U.S. Census Bureau, American FactFinder. (2011). 2009-2011, American Community Survey 3 year estimates. S1811: Selected economic characteristics for the noninstitutionalized population by disability status.

⁴ SSI is a Social Security program that pays monthly benefits to those with limited resources who are 65 and over, have blindness, or have a disability. The maximum monthly benefits are \$710 in 2013 – less than poverty.

⁵ Butterworth, J., Hall, A.C., Smith, F. A., Migliore, A., Winsor, J., Domin, D., & Sulewski, J. (2013). StateData: The national report on employment services and outcomes. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

⁶ Social Security Administration. "SSI Disabled Recipients Who work."

The Rehabilitation Services Administration's (RSA) Vocational Rehabilitation (VR) system assists people with disabilities in finding jobs and obtaining information and resources to help them get back to work. Unfortunately, Arizona has the only VR agency in the country to not have an employment outcome for those with DD after one year. Further, only 2 percent of those of any disability were able to become employed after one year. Ultimately, in 2011, only 22.9 percent of individuals with ID who had cases closed obtained employment. This demonstrates a clear lag in serving people with DD in the VR system.

ICI also demonstrated that the Division of Developmental Disabilities (DDD) did not fare much better in employment outcomes. In 2011, among the 6,821 individuals with DD who received services, 81 percent obtained outcomes in day treatment non-work settings or facility-based work settings alongside others with disabilities. Only 19 percent obtained employment in the community in integrated employment settings alongside workers without disabilities. Overall, facility-based non-work made up 80 percent of total DDD day and employment spending, whereas integrated employment only made up 14 percent. Furthermore, individual supported employment, such as job coaching, was only provided to 1 percent of individuals who had obtained employment outcomes in 2011.⁷

Isolation

Survey data also indicated that individuals with disabilities often feel isolated. In 2010, the National Organization on Disability and Harris Interactive found people with disabilities on average are less satisfied with their lives than people without disabilities. The survey findings also revealed barriers in transportation, socialization, and employment, which are similar to the findings in Arizona. DDD participates in the National Core Indicators (NCI) program, which is a voluntary effort by state developmental disability agencies to track and measure their own performance in advancing community inclusion and other outcomes for adults with developmental disabilities.⁸ The 2011-2012 face-to-face survey found that compared to the national average, participants with DD in Arizona reported fewer friends, less ability to date, more loneliness, more circumstances of having no one to go to if they were afraid, and less participation in self-advocacy. The reasons for this isolation were not uncovered in the survey.

Disability Benefits 101
(<http://az.db101.org/>)

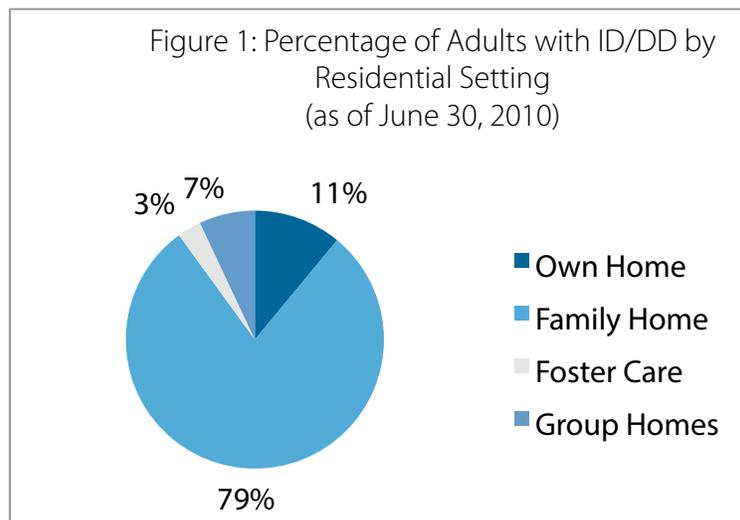
This website helps individuals understand how work and benefits go together and how much SSI they would receive while working. It also answers many questions related to SSI, health insurance, and other work incentive programs that can increase income for the worker with a disability.

⁷ Arizona Department of Economic Security. (2011). Division of Developmental Disabilities. Individual/Group supported employment report, 12/1/2011.

⁸ The NCI report can be found here: https://www.azdes.gov/uploadedFiles/Developmental_Disabilities/consumer_survey_summary.pdf

Living with the Family

Arizona is a national leader in promoting community living. United Cerebral Palsy (UCP) confirmed this with its 2013 report, *"The Case for Inclusion,"* in which Arizona was found to offer the best Medicaid services in the country for persons with ID/DD and did so at maximum efficiency. Some criteria used to evaluate each state included lack of waiting lists for home and community-based services (HCBS), the availability of programs that support families who care for loved ones with DD, and residential services provided in small group settings.⁹ Indeed, Figure 1 indicates that Arizonans with DD are living with family more than any other option. However, the question remains of whether this is what individuals actually want.¹⁰ The NCI survey found that 96 percent were satisfied with where they lived, but when it came to choice, only 25 percent stated that they made the choice, and 36 percent said they had some input.



Stuck at Home or Out and About?

Transportation barriers are frequently cited in literature pertaining to passengers with disabilities, especially in rural or outlying areas. A national poll conducted by Harris Interactive in 2010 found that 34 percent of people with disabilities found their transportation options to be inadequate - up from 30 percent in 2004.¹¹ Furthermore, transportation difficulties were more frequent among those with severe disabilities and/or lower income. The same trends were also found in Arizona. In 2010, when compared with those without disabilities, Arizonans with disabilities were almost four times more likely to report that a lack of transportation was the primary reason there was a delay in getting the care, tests, or treatment a doctor believed was necessary.¹² And of those with disabilities reporting problems, 45 percent were living at or below the federal poverty line.

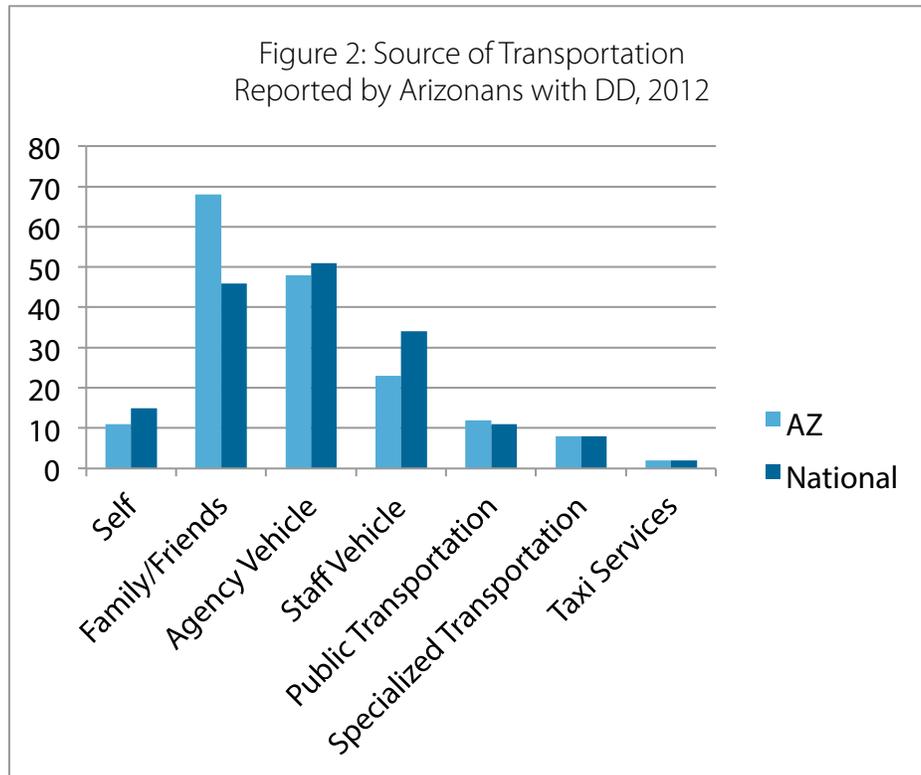
⁹ United Cerebral Palsy. (2013). *The case for inclusion*. http://www.ucp.org/the-case-for-inclusion/2011/images/The%20Case%20for%20Inclusion%202012_Full%20Narrative_final%20.pdf

¹⁰ Source: S. Larson, A. Ryan, P. Salmi, D. Smith, & A. Wuorio, Residential Services for Persons with Developmental Disabilities, Status and Trends Through 2010, 2012.

¹¹ Kessler Foundation/National Organization on Disability, 2010. *2010 Survey of Americans with Disabilities*. www.2010DisabilitySurveys.org.

¹² St. Luke's Health Initiatives, 2010. *Arizona Health Survey, Adult Survey*. Proxy measures for disability were 'Not Looking for a Job Due to a Disability,' 'Receives SSI But Less than 65,' 'Receives SSDI,' and 'Difficulty Going Outside Home Due to Physical/Mental Condition.'

Alternatively, individuals who were clients of DDD reported better results. The 2012 NCI Survey reported that 81 percent almost always had a way to get where they wanted to go, and 19 percent reported sometimes they did. As noted in Figure 2, the top sources of transportation were family and friends (68 percent), agency vehicle (48 percent), and staff vehicle (23 percent). Reliance on family for transportation was well over the national average of 47 percent, indicating that those with less family support would rely more on professional and agency staff to get around their communities. The national average also showed that fewer sources of transportation were being utilized in Arizona. Because of these conflicting findings pertaining to Arizona transportation, more needs to be understood about how existing transportation options shape the lives of adults with DD.



Disconnected and Not Engaged

Over the years, the high school graduation rates of youth with disabilities have increased.¹³ In 2011, 78 percent of Arizonans with disabilities ages 25 and over had at least a high school degree;¹⁴ however, employment outcomes continue to be poor. Arizona’s special education system, Exceptional Student Services (ESS) partnered with Arizona schools to administer the Post School Outcomes Survey (PSOS).¹⁵ This survey tracks the progress of high school students with disabilities, who were served by ESS one year after graduation.

¹³ Butterworth et al. (2013).

¹⁴ U.S. Census Bureau, American FactFinder. (2011). 2009-2011, American Community Survey 3 year estimates. S1811: Selected economic characteristics for the noninstitutionalized population by disability status.

¹⁵ Arizona Department of Education. (2012). 2012 Arizona PSO Survey Results & Accessing Local PSO Data. <http://www.azed.gov/special-education/files/2012/07/2012-pso-results.pdf>

The most recent survey was administered to 1,423 students who exited high school in the 2010-2011 academic year:

- 34% obtained competitive employment (at least 20 hours per week);
- 26% went on to college or university;
- 26% were not engaged;
- 8% were in postsecondary education or training;
- 6% had some other employment (i.e. self-employment or work for pay not at minimum wage in day programs or center-based employment settings).

When results for students with ID (128) were broken out, outcomes were not as positive:

- 53% were not engaged;
- 17% were in postsecondary education or training;
- 14% obtained competitive employment;
- 13% had some other employment;
- 3% went on to college or university.

And for students with autism (72):

- 40% were not engaged;
- 31% went on to college or university;
- 12% were in postsecondary education or training;
- 11% had some other employment;
- 6% obtained competitive employment.

These surveys demonstrate that there is a real gap in services for people with DD that have impeded their ability to find employment and to expand their social networks. Other studies have derived similar findings.

WHAT DO INDIVIDUALS WITH DISABILITIES WANT? WHAT PREVIOUS STUDIES HAVE SHOWN

Only a handful of studies have conducted focus groups or interviews with people with disabilities to understand barriers to community participation. One such study of individuals with aphasia reported that individuals wanted to be respected, and – although they felt isolated and couldn't work – they wanted to be engaged in their communities in some meaningful way. They craved a feeling of belonging and social connection and were more interested in the quality of activities than the quantity of them.¹⁶

They also wanted to define and participate in activities on their own terms, not because society expected them to. Hammel et al.

additionally found that among people with all types of disabilities, meaningful participation, access, opportunity, choice, and control impacted the individual's feelings of value, purpose, personal responsibility, and need to give back and support others.¹⁷

...meaningful participation, access and opportunity, and choice and control impacted the individual's feelings of value, purpose, personal responsibility, and need to give back and support others.

Using a format similar to that of this study, Abbott & McConkey conducted a focus group with 68 individuals with ID/DD, who lived in group homes in the United Kingdom to determine what social inclusion meant to them and to identify perceived barriers.¹⁸ The participants felt separated from the general public and perceived that this separation was due to the location of the house, lack of transportation, the frequent inability of support staff to go with them to activities, and negative attitudes felt from the public. They all desired reciprocal relationships with those without disabilities, acceptance, and not being recognized for their differences. They also wanted access to activities, individual choice, and available support that would allow them to be independent.

In all of the above studies, an individual's environment played a key role in determining how much or how little the individual participated or was involved in the community. However, there have been no studies conducted with adults with DD in multiple living arrangements that have talked about their day-to-day lives – both challenges and successes – and what they perceive to be important.

¹⁶ Dalemans, R., deWitte, L., Wade, D., van de Heuvel, W. (2009). Social participation through the eyes of people with aphasia. *International Journal of Language and Communication Disorders*, 45, 5, 537-550

¹⁷ Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., et al. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30, 19, 1445-1460.

¹⁸ Abbott, S. & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, 10, 3, 275-287.

METHODS

Participants

Morrison Institute for Public Policy conducted four focus groups with a total of 35 adults with DD in areas of the state not typically heard from, including Flagstaff, Prescott Valley, Sierra Vista, and Yuma. The age of the participants ranged from 19 to 68. Individuals in each community were recruited through non-profit and governmental organizations that serve people with DD; however, in some communities, DDD was the primary recruiter in the absence of other organizations. The individual had to have acquired his or her disability in childhood to be eligible for the study. Those who participated were reimbursed with a grocery gift card and lunch. Transportation expenses were also paid for those who needed it. Efforts were made to obtain a representative sample of the area population, thus in most cases, demographic information about the individual was obtained beforehand. At times, this information was provided by the parent, the provider, or DDD when the individual was unable to do so. The individuals who participated were able to communicate or communicate with the use of assistive devices. Family members and personal care workers were also invited to attend, but the purpose of the group was to hear directly from the individuals with DD. The caregivers present included seven family members, two providers, and a worker with DDD. Table 1 gives the demographic profile of the participants.

| | Frequency | Percent |
|-------------------------------|-----------|---------|
| <i>Age (n=34)</i> | | |
| 18-25 | 9 | 25.7 |
| 26-33 | 8 | 22.9 |
| 34-41 | 3 | 8.6 |
| 42-49 | 6 | 17.1 |
| 50-57 | 5 | 14.3 |
| 58-65 | 2 | 5.7 |
| 66+ | 2 | 5.7 |
| <i>Gender (n=35)</i> | | |
| Female | 14 | 40 |
| Male | 21 | 60 |
| <i>Race/Ethnicity (n=35)</i> | | |
| African Americans | 1 | 2.9 |
| American Indian | 4 | 11.4 |
| Hispanic | 5 | 14.3 |
| Other | 2 | 5.7 |
| White Non-Hispanic | 23 | 65.7 |
| <i>Education (n=35)</i> | | |
| Less than High School | 7 | 20 |
| High School or GED | 14 | 40 |
| Some college/Technical School | 14 | 40 |

| Table 1 (Continued): Participant Demographics (N=35) | | |
|--|-----------|---------|
| | Frequency | Percent |
| <i>Primary Disability (n=35)</i> | | |
| Autism | 4 | 11.4 |
| Intellectual | 14 | 40 |
| Cerebral Palsy | 6 | 17.1 |
| Epilepsy | 1 | 2.9 |
| Multiple | 3 | 8.6 |
| Physical | 6 | 17.1 |
| Psychiatric | 1 | 2.9 |
| <i>Employment (n=35)</i> | | |
| Center or Group-Based | 10 | 28.6 |
| Competitively Employed | 1 | 2.9 |
| Retired | 4 | 11.4 |
| Self-Employed | 5 | 14.3 |
| Student | 1 | 2.9 |
| Unemployed | 14 | 40 |
| <i>Living Situation (n=35)</i> | | |
| Adult Developmental Home | 2 | 5.7 |
| Own Apartment/Home | 13 | 37.1 |
| Family | 13 | 37.1 |
| Group Home | 7 | 20 |

FOCUS GROUP STRUCTURE AND PROCEDURES

Focus groups were chosen to give individuals an opportunity to be actively involved and invested in the research, as opposed to being a subject. These groups allowed individuals to flesh out and build ideas off of each other, so that both individual and shared perspectives could be obtained, including both agreements and disagreements. The goals of this project design were not only to learn from the participants as a group, but to also give participants and family members the opportunity to network and offer peer support to each other. Exploratory questions were derived from the National Core Indicators survey and a literature review to determine how individuals in Arizona perceived leisure activities, transportation, employment, friendships and family, housing, and overall community involvement. A copy of the questions used can be found in the Appendix.

The groups were held at accessible sites, including Northern Arizona University's Institute for Human Development in Flagstaff (a University Center for Excellence in Developmental Disabilities (UCEDD)), New Horizons Independent Living Center in Prescott Valley, as well as the Sierra Vista and Yuma public libraries. The focus groups were held on a weekday during the day for between 2½ and 4 hours. One focus group was broken out into two groups for part of the day due to its size. The same moderators were present at each focus group. The principal moderator played a key role in ensuring that the discussion proceeded and that core questions, prompts, and probes were covered. The second moderator raised questions, prompts or probes omitted by the principal moderator, ensured that everyone was included in the discussion, and provided an oral summary. Each interview was recorded and later transcribed verbatim by a research assistant.

Participants were also asked to fill out a sheet called *A Day in My Life* that described how they spend a typical day, starting from when they wake to when they go to bed, and the kinds of support they need to complete these activities (see Figure 3). This gave the research staff a better understanding of how individuals perceived their daily lives, if they were engaged in the community, and how they were engaged. A staff member from either ADDPC or the ASU faculty assisted participants and each group with note-taking.

Figure 3: A Day in My Life

| A Day in My Life (list activities and any support needed) | |
|---|-------|
| 6:00 | _____ |
| 7:00 | _____ |
| 8:00 | _____ |
| 9:00 | _____ |
| 10:00 | _____ |
| 11:00 | _____ |
| 12:00 | _____ |
| 1:00 | _____ |
| 2:00 | _____ |
| 3:00 | _____ |
| 4:00 | _____ |
| 5:00 | _____ |
| 6:00 | _____ |
| 7:00 | _____ |
| 8:00 | _____ |
| 9:00 | _____ |
| 10:00 | _____ |

Data Analysis

The data were analyzed using a constant comparative approach. The transcripts were imported into Dedoose analytic software and open coded to identify key themes. The coding team included the moderators for each group. The codes that were developed represented overall content themes, ideas, and feelings that emanated from each group. Dedoose was used to analyze the codes between the four groups – how they were interconnected, how often they were mentioned, and whether or not there was agreement or disagreement in each thematic area. As patterns and themes began to emerge across transcriptions, and relationships between categories became apparent, each one was revisited using axial coding, memoing, and other inductive analytical strategies. Using a constant comparison method of interpretation enabled us to revisit and locate a conceptually relevant literature to make sense of the patterns and themes captured.

THE STORIES THAT WERE TOLD – THE RESULTS

Not surprisingly, because the participants were of different ages, ethnicities, and locales, they told different stories. Nevertheless, there were also consistent themes reported that are not reflected in Arizona’s current survey outcomes, including transportation barriers, pride in their accomplishments, the importance of friends and family, fear of losing SSI if employed, and the need for independence. The Code Cloud gives a graphic display of the description and frequency of topics discussed (see Figure 4). In general, the participants had disappointing stories to tell, but in doing so, the resilience of this population also became clear.

Figure 4: The Code Cloud



Location, Location, Location

Transportation barriers throughout the state are commonly reported by people of all disabilities. Transportation is critical to seeing friends, going to work, going to medical appointments, running errands, and being self-reliant. Only eight individuals from these groups could drive, and among these individuals, high gas prices and maintenance costs were a problem. Thus, transportation was the most frequently mentioned barrier to living their day-to-day lives.

In some areas, public transportation is not available. These areas only provide taxi services with \$30 - \$40 monthly discount vouchers to seniors and people with disabilities. However, these vouchers help minimally, as a ride into town can still cost an average of \$20 each way. Some areas provide limited public transportation and do not operate during evenings or weekends. Door-to-door service for riders with disabilities may cost as much as \$5 one way, which was also too costly for most of the participants. For those who didn’t drive, they often relied on family, walking, or biking to get around and to visit friends; however, when these options weren’t available, participants felt “stuck.”

My mom used to drive me around, but now I can’t go where I want to go anymore. Mom is still alive and lives close by, but now she has a hard time getting around like I do.

After I had the operation on my foot, I couldn’t get the cast off because I couldn’t get transportation to Flagstaff. I had to wait 2½ months, and I was only supposed to wear it for a month just because we couldn’t get transportation.

My dad won’t give me a ride. When I asked him, he said I should walk or find my own ride. And my mom is working. If I don’t walk or find a ride, I would be stuck at home.

“When deciding on where to go, for us in the group home, it really depends on what one person wants to do. Four people don’t want to go to the same place.”

Those who had to rely on professional caregivers experienced a loss of control and choice.

My staff in the evenings can’t drive at night. I can’t really go do something or see a friend because it gets dark early. I can’t really get the transportation to do what I want to do.

When deciding on where to go, for us in the group home, it really depends on what one person wants to do. Four people don't want to go to the same place.

A minority of participants used public transportation. Reasons why many others did not use it included that it was confusing, expensive, the person could not ride unassisted, and there was just too much walking.

"When you get home you just want to sleep, because with [public] transportation and groceries you walk and wait, walk and wait."

You're putting in a lot more energy when you are taking public transportation. You are walking so much during the day. When you get home you just want to sleep because with transportation and groceries you walk and wait, walk and wait.

I've tried public transportation and it doesn't work for me. I have to walk two or three blocks because the bus doesn't stop at the door and cabs are so expensive.

Because so many walked or used a bike, location was extremely important in determining if an individual was isolated or not.

The house [group home] is by a grocery store and Hastings is down the hill. Everything is right there. A lot of people in the other homes don't have that advantage.

I live on the main boulevard now. If I need something, I just take my backpack and drive my bike to go to Safeway if I don't have my truck. I am very lucky, because where I used to live is 7 miles from the town, and I used to have to walk all 7 miles with a bum foot.

I personally am just in the right area. I can get to everything with my scooter, so I'm very fortunate.

I like walking. I walk everywhere when my parents are busy. On Saturdays, I like to walk from my house to this library, which is 2½ miles away.

Because many rely on transporting themselves, weather and structural barriers play a large role in determining whether or not the individual is able to get out. Ice, snow, and extreme heat become extra hazardous for those with mobility issues.

Structural Barriers Persist

Design and infrastructure issues can impede access. Some rural areas have few sidewalks and a large number of wheelchair-inaccessible businesses and houses.

There are no sidewalks or streetlights by my house. I can't go anywhere at night.

There are some roads that are still dirt, and when it's raining or snowing, you can't get in there. Wheelchairs get stuck in the mud.

Everywhere I go there are marks on the door from me trying to get in [with a wheelchair].

At restaurants, their bathrooms are too small. You can't even get in there, or stores, where you want to get into. It's an old town, but there is always a step.

Feelings of Disrespect and Exclusion

Several spoke about the overall lack of respect and general negative attitudes they received from the community. They felt that they were continually limited by the perceptions of others about their disabilities. They did not feel that people tried to empathize with them or allowed them to have a voice.

I was beat up and bullied so much in school that I fell behind in my class work and had to drop out.

The doctor told my dad I needed to be in an institution because I was retarded.

I was told that because of my disability, I would not be able to do anything, because I was slower and I had no eye-hand coordination.

Probably what I experienced, everyone has experienced - more of a lack of respect with disabled. You run into it with cashiers. They take a look at you when you're not walking normally. You get a feeling that they haven't gotten the message of equal access.

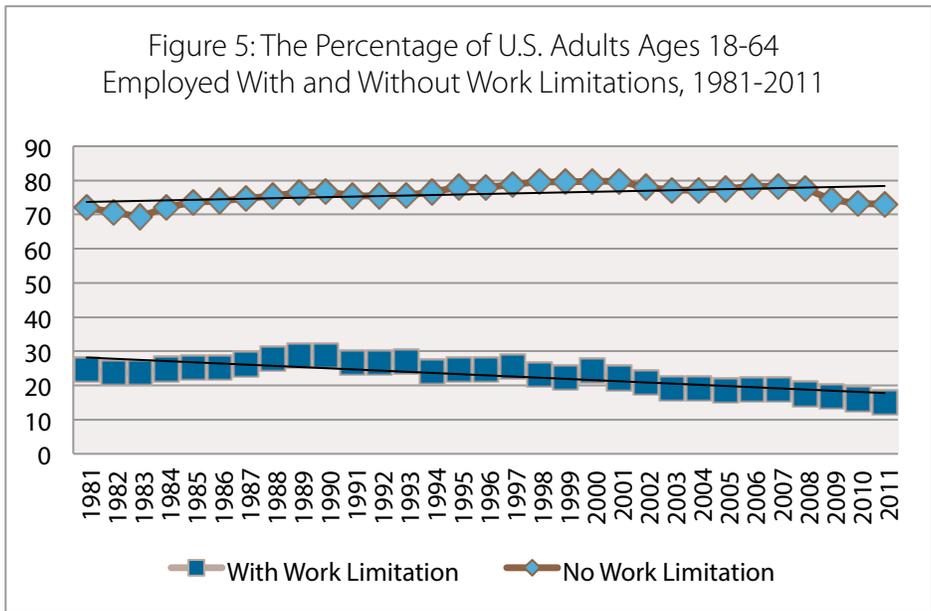
I ran into negative attitudes growing up on and off the reservation. I still run into it sometimes. I just have to take it I guess. I can't do anything about it.

I have a lot of friends out in the public. Not everybody in the public is negative, but some people that just the way it is. They don't understand people with mild disabilities. The real world is cruel to people with disabilities. I stay away from negative people as much as I can.

"I was told that because of my disability, I would not be able to do anything, because I was slower and I had no eye-hand coordination."

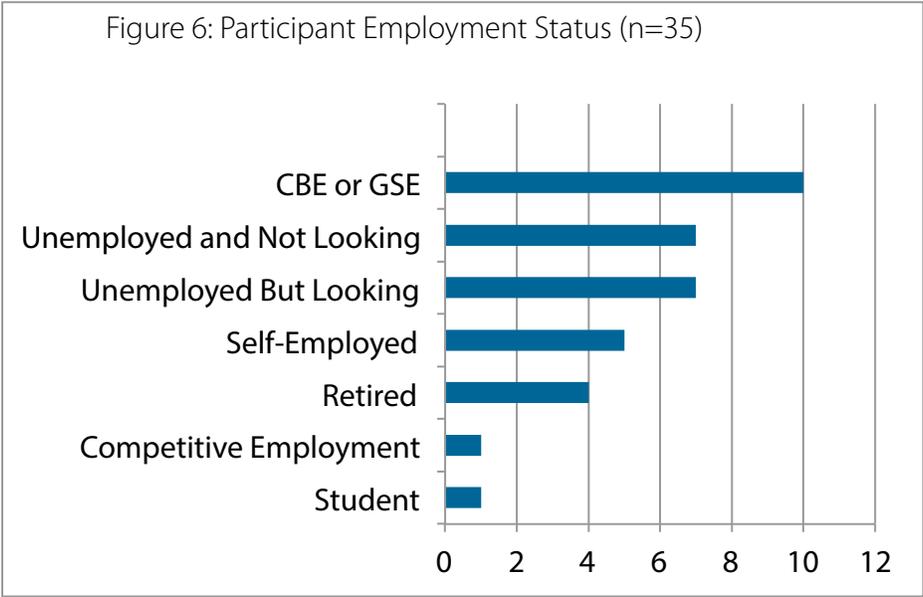
Employment through the Eyes of the Individual

Nationally, employment outcomes among people with disabilities have been deteriorating over the last 20 years. The highest reported percentage was 28.8 percent in 1989, one year before the passage of the ADA; the most recent percentage was 15.2 percent in 2011. Figure 5 demonstrates that the disparity between workers with and without limitations is significant and has been increasing over the years. In 1983, there was a 45.7 percent difference between workers with and without limitations; however, this disparity reached an all-time high of 60.1 percent in 2008. In 2011, there was a 57.9 percent difference between the employment rates of both populations. The ADA guarantees that people with disabilities have the right to equal access to employment free from discrimination and the right to reasonable accommodations to be able to do a job successfully. Theories have been posited that the reasonable accommodation mandate has discouraged employers from hiring workers with qualified disabilities.



Source: Disability Statistics from the Current Population Survey (CPS). Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and

Some of the focus group recipients may agree with this theory. As Figure 6 shows, the majority of participants are unemployed. Individuals who are employed are primarily in group supported or center based employment. In our sample, only one person was competitively employed. Almost all participants received SSI benefits. To qualify for SSI, individuals cannot have resources more than \$2,000. SSI maximum monthly payments are only \$710, causing many to live well below the federal poverty line or to rely on their families for support.



Career Aspirations and Desired Places to Work

When asked what their ideal jobs would be, many respondents initially responded with where they would like to work that was in close proximity to their homes and what they could do based on what positions they had held in the past, such as a janitor, dishwasher, food service worker, courtesy clerk, or stocker. Desired places of work included Walmart, Fry's, Wendy's, Safeway, the mall, the movies, and the bowling alley. When asked why they chose these places, many stated they liked going there, "they hired the handicapped," or they were familiar with the location and felt they could do the jobs. Most, however, were not picky. They just wanted a job that paid and kept them busy. Some needed a paycheck to stay independent.

Any kind of job I would like to have. If there was an opportunity, I would apply. And I can have friends to hang out with.

I would like any job to keep myself busy. I would like to help people.

I'm actually on my own now and not under dad and mom's wing anymore, and I would like to work at Walmart. I get \$700 and have to live off of that, and it is getting very hard. If I ran over that money, they could help me out, but not anymore.

I would like to work somewhere where I can do something I know how to do.

If I can work, I can make my life so much better. Then I won't have to worry so much every month about paying my bills.

Probed further about what their dream jobs would be, some gave different answers. Responses varied significantly, and included positions such as a chef/restaurant manager, software developer, handyman, teacher's assistant, motivational speaker, landscaper, artist, veterinarian, courtesy clerk, retail, office worker, business owner, mason, woodworker, and park service worker. Some already dabbled in these areas as a hobby or were investigating how to do them as a career; however, many seemed to be unsure what they wanted to do and were brainstorming career possibilities during the discussion.

Previous Experience in Competitive Employment

Many of the participants had held jobs in the past, but had bad experiences or had been terminated. Job retention among those with intellectual disabilities was very low, and individuals with all types of developmental disabilities did not feel understood or supported by their supervisors.

It was very discouraging that the only thing they had me doing was stuffing envelopes when I was qualified to do so much more.

People don't accept you with certain issues. I have to use large print. I was too slow and made some mistakes. I was gone in no time.

I was doing my best. It was really stressful. They said I wasn't tagging right. They had a lot of management changes. I don't know what was going on there.

Help Wanted... But Not from People with Developmental Disabilities

Although it was clear that most of the participants had career aspirations, very few were applying for jobs, partly due to past negative experiences. Those who tried to apply for jobs ran into significant barriers,

ranging from unreturned phone calls to inability to accommodate a position for the individual to flat-out discrimination.

"I had the manager tell me that I couldn't work there because I was retarded. I work harder and do more than other people, but I never get the opportunity."

They walked me into the kitchen. They have a small dish washer thing. They said "Can you read the menu on that TV set." And I said "No, I can't do that. I can't read or spell." They said "Why we are going to hire you if you can't do the stuff we want you to do?"

I put in like 13 applications, nothing. No one called me back. Housekeeper, dishwasher, nothing.

He was close to getting a job once, and then the assistant manager said he had his application on his desk. He said that all he wanted to have was a drug test. Then we never heard from him anymore.

I had the manager tell me that I couldn't work there because I was retarded. I work harder and do more than other people, but I never get the opportunity.

They encourage you to go to school to improve yourself, and work to apply, but then you never get the job. It's frustrating.

One participant was upset that the business wouldn't hire him without the help of a job coach.

I put in an application but they said I need a job coach. It got me upset. I can do stuff. I'm a good listener. You just need to tell me what to do. It takes a little bit of time to get things settled in my head. I can do better without a job coach - slows me down. They write down everything you are doing wrong.

The participants said the job market had changed since the recent recession to the detriment of people with disabilities. They found that there are now more workers than jobs, so employers are more selective.

Ok, they should have workstations - jobs for the handicapped like they had years ago.

At jobs that I would normally get like fast food, people who are overqualified are applying. At fast food, you now need a degree to get hired.

Even though some government jobs encourage people with disabilities to apply, there are so many requirements that no one could fulfill them.

Thoughts on Group-Supported and Center-Based Employment

Participants who worked in group-supported and center-based employment had concerns, but overall they were thankful for the opportunity.

Most of us stay at center-based – they don't go anywhere. They sort paperwork out. They can't go out and do stuff. They have to stay inside at all times. It is not our favorite, but it is what we have right now. At least we have a job where we can earn money.

Some participants preferred center-based employment over community-based employment, because they did not have to deal with harassment.

If I work out in the community, I would just be picked on and made fun of. I would rather work with others like myself where I won't get teased.

The real world thinks that people with disabilities are not normal. I've learned to deal with that because I'm just me. People tend to think they know everything more than people who don't know everything. The state and the federal [officials] don't see it that way, but that's the way it is in the disability world.

"Most of us stay at center-based – they don't go anywhere. They sort paperwork out. They can't go out and do stuff. They have to stay inside at all times. It is not our favorite, but it is what we have right now."

It is no surprise that individuals who have experienced negative interactions with the general public are more likely to be satisfied in a center-based or group-supported work setting. Although some of them want to work in the community, they usually do not have the support needed to keep a community-based job and have had to return to center-based employment.

For example, a mother shared her son's experience with losing his job coach.

He actually had a job at border patrol as an assistant for a year or year and a half with assistance over there. The problem was he didn't have enough assistance. Because he didn't have that kind of support, he couldn't keep that job.

Ability to Maintain a Job and Fear of Losing SSI

Other barriers to employment stem from individual perceptions. Many people with disabilities said they hesitated when searching for employment because they did not want to risk losing SSI by working too many hours.

A lot of employers like to have full time, and due to the fact that I'm on SSI, that is not an option. If I didn't have to rely on government assistance every month, I could work full time. The biggest barrier is being on SSI.

I always talk about my government check [SSI] when I apply for jobs. If they are not friendly with that, then they won't hire me... In my eyes, I just want a job, but in their eyes I am just bugging them. It is hard.

"I always talk about my government check [SSI] when I apply for jobs. If they are not friendly with that, then they won't hire me. In my eyes, I just want a job, but in their eyes I am just bugging them. It is hard."

When you work too many hours a year, you lose your benefits. When you lose your benefits, you have to start the whole process over again if you ever need it again.

The state is saying, "Our goal is for you to be as independent as you can," but there are still some limitations where I can't be as independent as I'd love to be. The whole idea is to be as independent as possible, but it seems to be no matter where I turn there is some type of barrier.

A few said they were self-employed, if informally. They kept their SSI, but received a little extra income from their business.

I do landscaping. I have my truck and my own tools. I go around to my neighbors and cut their yards.

I sell my artwork at art shows.

And still others thought that they wouldn't be able to work anymore due to their disability.

Having seizures the way I do with memory problems is still a barrier.... I don't know if I could ever really get a job like that [waitressing]. I'd love to, but I don't know if ever could because of the stroke I had.

I used to work at Safeway as a bagger, but I can't work at Safeway now after I hurt my arm. I don't think there is anything anyone can do to help me.

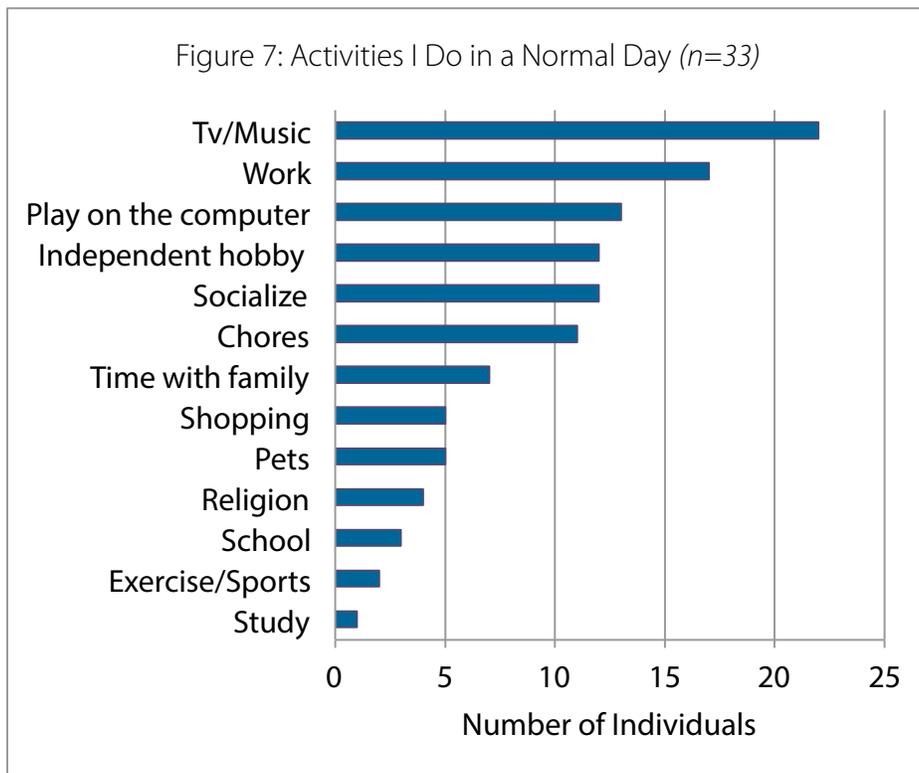
"I used to work at Safeway as a bagger, but I can't work at Safeway now after I hurt my arm. I don't think there is anything anyone can do to help me."

In one of the groups, several parents expressed confusion over the general issue of employment; more specifically, the role, value, and cost of job coaches for their children. In general, there seemed to be a lack of knowledge regarding work incentives, SSI, and state-funded support among most of the participants. Many individuals with DD left the job market after negative experiences, believing that they couldn't do the job or fearing they would lose SSI. Therefore, despite many having aspirations, most are sitting at home or working in segregated jobs where they will at least get paid something.

Leisure Time and Friendships

Another key question is what barriers shape how people with DD spend their leisure time and nurture friendships. Focus group participants completed a sheet called *A Day in My Life* to help understand how they spend their time. Figure 7 gives an overview of how many individuals mentioned doing that particular activity in a given day. The activities varied widely, but the most consistent activity listed by participants was watching TV or listening to the radio.

- Out of 33 individuals, 2/3 watched TV or listened to music on an average day.
- A little over half (17) said they worked.
- A little less than half (13) used the computer, playing video games and chatting with friends. Those who used the computer were typically younger, indicating that the digital divide (i.e. the lack of access to computers for people with disabilities) may be improving for people with DD.
- Having an independent activity and socializing were the next most listed activities (12). This often occurred on the computer through texting or at work. Only 1/3 of the participants listed it as something they did on a normal day.
- Spending time with family (7) was also low.



Six of the 33 individuals reported that a caregiver helped them do some of these activities. In reality, this number is much higher, as assistance by day treatment, employment support and group home staff is not always recognized by the individual. At least 17 individuals are in center-based or group supported operations or group homes with professional staff. Thus, almost half of the group experiences some interaction with professional staff on an average day.

What participants enjoyed varied from the social butterfly to the introvert.

I enjoy people and I have people over all the time.

Read and be alone. I like my alone time.

I keep my apartment clean. That's what I do.

I really do enjoy the day program there. We do art there and hang out with friends there.

Those who lived in group homes seemed to have social lives interconnected with their staff. The professionals were viewed as friends.

When we go out to dinner or go out in public, we go with staff out and eat and see friends. We will go out once on the weekends. We do a lot of stuff in the house a lot more. I hang out a lot more with my staff than anything else.

I don't have the opportunity, but would like to go on the Internet with my staff.

"We do a lot of stuff in the house a lot more. I hang out a lot more with my staff than anything else." - Group home resident

A few experienced a loss of things that they would like to be able to do, but couldn't because of their disability.

When I want to do something at home, ceremonial thing, it gets difficult for me because I really can't participate because of my disability.

Having CP, I can't get a driver's license to drive a car, so that right there stops me from going to see a lot of my friends.

And still others complained about their rural area's lack of people to date, and recreational and social opportunities.

There's not much to do around here. I hang around now with most of the roommates.

I am thinking about moving back to Phoenix. Phoenix is a better place than here. There are more girls.

Many of their friends had moved away after graduating from high school to pursue different opportunities.

I went to high school with her. Then she moved to Idaho for her mom's medical reasons. I do have high school friends here, but I haven't seen them.

I usually hang around with my friends. Most of my friends have moved out, but I still have a few here.

Once people graduate school, they move away to Phoenix.

Even if the person just moved to the other side of a small town, visiting became difficult with transportation barriers.

They used to live on the same street when they were in high school – they used to walk to school together. But, she moved to the other part of town, so they have lost contact.

Those who lived in their own apartment or in group homes tended to socialize with their roommates and staff or neighbors. Likewise, those who lived with family typically socialized with family friends.

I'm friends with my mom's friends. I hang out with them.

I have one good friend for about 10 years, and she is friends with the whole family. She lives on the same street as me. She has been pretty busy. I saw her three or four times in three or four months.

I met him through my sister. He taught me how to spray paint and showed me his motorcycle.

Those who made their own friends did so while out in the community.

I go to college. I like to meet new people. I have already met new friends.

I like to hang out with my friend who I met at work.

Some said they didn't have a lot of friends by choice, in some cases because they had been taken advantage of.

I don't usually hang out with my friends very often because I am sort of alone. I would rather have more friends who would not take advantage of me. They give me trouble a lot, and they kick me when I am down.

Throughout all four focus groups, most of the individuals in each group knew each other from high school. In many cases, they had not seen each other since. Scheduling issues and transportation barriers were common complaints among participants about why they couldn't see their friends that often. Those who were friends in the groups met each other through programs that built bonds between like-minded people. These included Special Olympics, day programs, center-based and group-supported employment programs, disability advocacy organizations, and public housing. Some had friends who did not have a disability, but their closest friends tended to be others with similar disabilities.

Their Support System

In most cases, an individual's success in achieving their goals depends on how connected they are to others who can offer support, information, and somewhere to turn when they confront barriers. Such support systems differed among those who lived with their families and those who did not. In most of the former cases, primary support came from an immediate family member. However, the situation was much different for individuals who lived in group homes or their own homes or apartments. Individuals in group homes tended to rely on their counselors or providers, while those in apartments tended to rely on friends, neighbors, and service and/or religious organizations.

I tremor so much that it is hard for me to write. Friends help me. They are very good about it. They ask me, "Want me to fill this out for you?" And I sign it and whatever.

I help a lot at the church, where I can get help and I can help them.

One older gentleman, who used a wheelchair and lived on his own, commented on his shrinking familial support system.

I get help from the church for the most part. I am on their grounds keeping team because I can still do a few things. [I'm also helped by] next-door neighbors. My parents passed away, so my family is getting very small.

A few who were living on their own simply said they only rely on themselves. For some, it was a scary proposition.

I used to go to my aunt's house or call my dad. But now my dad is living in California, so I have to figure it out on my own. I got my dad on my back. He says that even if you live off your government check, you don't have that much of money for bills. Your bills are \$300 already. I need to prove to my dad that I can do it.

Parental Concerns

Parents who are their children's primary source of support worry about what will happen to their children if something should happen to them. They are plagued by doubt that their child can make it on their own. In the following example, a 55-year-old with autism moved out against his mother's wishes.

My biggest problem as a parent is what is going to happen to him when I am gone. My husband passed away two years ago.... I always took him everywhere. We exposed him to everything. He can read and write.... It was his idea to move to an apartment. We were against it, but it has worked out very well. He keeps his apartment very clean. He does all my chores. Comes over to my house every day. He shops by himself.

Another father worried about the fate of his 24-year-old daughter who lived with him and his wife. This exchange reflects the dichotomy of a father wanting to protect his daughter, and proud that she knows how to take the bus by herself.

Father: We all have the same problem. When we are gone, what's going to happen to her? She doesn't even know how to count money. She never goes anywhere on her own. My wife didn't want to take her to college because we lived so far, so she had to take the bus back and forth every day. She only took the bus when she had to go to college.

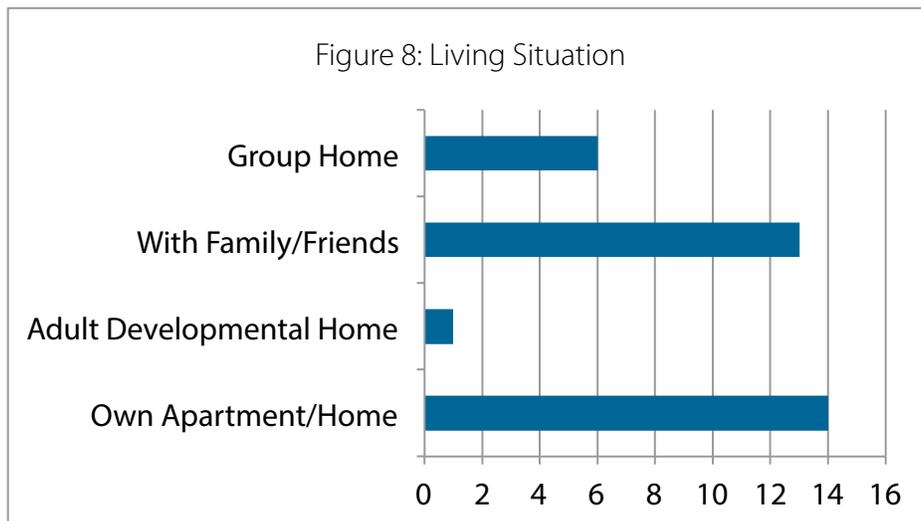
Daughter: I have this little sticker. They give you this from the Arizona Western College, and I think you have to pay them. When you show this sticker to the bus driver, then they take you anywhere you want anytime. Father: Other than that, she can't go out by herself.

"It was his idea to move to an apartment. We were against it, but it has worked out very well. He keeps his apartment very clean." - Concerned parent of 55-year-old son

In the seemingly inevitable balancing act between safety and independence, many parents prefer to err on the side of caution.

Housing and Desire for Independence

While nearly all participants enjoyed their current living situation, they didn't necessarily consider it their ideal option. Figure 8 provides a breakdown of participants' living arrangements. Living with family, and living in one's own apartment with/without roommates were the most popular options. Only a handful of participants live in group homes. Although residents complained about issues with roommates, constant staff turnover, and a lack of control over the screening process, they were generally satisfied.



Some said they enjoyed living with their families and would not change anything. However, the majority of those who lived with their families also said they wanted to be on their own, so that they would have the freedom to do what they wanted to do, including dating and having relationships.

My ideal living situation is living with my girlfriend, if I find one.

The reason I want to live on my own is so I can be happy, feed myself, pay the bills myself, try on and get clothes by myself, and get a pet.

Living with my grandmother is not like having freedom. We want to be able to spend time with our friends, invite people over, and get away from our parents.... Hopefully, my mom will help me to get my own place.

I want to get married when I'm 29 (age 24). I want to live in Yuma.

"Living with my grandmother is not like having freedom. We want to be able to spend time with our friends, invite people over, and get away from our parents..."

Those who moved out were happier to be on their own. Some preferred roommates, while others did not.

I've lived on my own since I was 23. I love living with somebody, but having the freedom to come and go as I choose.

I like living by myself in low-income housing because I can do whatever I want. I used to have a roommate, but it drove me crazy. It took me 1½ years to move.

My mom and I were like two cats in a cat carrier. We became closer after I moved out. When I came here [group home], I met a lot of people. It's just been wonderful.

There was a wait list in all of the groups for public housing, ranging from 10 months to more than a year. The participants said that was too long and that there didn't seem to be any priority as to who is selected for available slots. Because of this universal shortage of affordable housing, many are only able to live in group homes, in adult developmental homes or with their families.

Loss of Control and Voice

Not surprisingly, many participants felt a loss of control over their lives with parameters dictated by people in authority, who they felt did not really understand them. Some felt that they could not change this pattern of control, while others were too embarrassed about their disability to speak up.

You don't want to have to depend on people. You want to be able to be independent - to do these things for yourself.

I have a memory problem. When people talk to me, I don't hear everything they say, from here to my brain it gets lost, but I can't process what they say. I hate to ask people to repeat things.

My guardian is very smart, but she goes too fast for me. I'm used to doing these things for myself. I don't want to slow her down, but I don't understand what she is doing.

We do have a voice, but we keep getting ignored.

"You don't want to have to depend on people. You want to be able to be independent - to do these things for yourself."

Feelings of loss of control and not having a voice were consistent across all disability types, living arrangements, and ages. Participants unanimously felt that they had limited options.

Resilience, Group Cohesion, and Advocacy

Resilience

Many have found a way to live satisfying lives in spite of having a formal support system in need of significant repair. They have relied on their own resourcefulness, as well as the support of family members and friends. They are proud of their accomplishments and approach life with a positive attitude.

Some people in my school used to think of me as a role model. I won three-class awards. Biggest oddball, class clown, the homecoming king, and the biggest flirt.

All I can do is try to do the best I can with what I got and try to make it work.

But still, you know I say that even though I'm like this, but even though I still say nothing is going to get me down. I just keep going. I have a positive attitude.

You can't change people, but you can change perception.

Group Cohesion

In each group, participants formed quick bonds, and shared information with each other. Information exchanged included transportation, housing, employment rights, college access, home modifications, sports, and leisure. This demonstrated that an individual's access to the community was bounded by an individual's access to information.

Responses varied when asked where they normally went for information on activities or events in which they would like to participate. Most participants mentioned the Internet, television, radio, and the newspaper. Others mentioned family members, case managers, the library, the Special Olympics calendar, social service agencies, day programs, and disability organizations, like The Association of the Severely Handicapped (TASH). There was no "one-stop shop" for information. However, some individuals said they didn't really need to locate information.

You just figure it out. You hear something here, you hear something there or you learn from others.

I hear through my family members. I get to hear things through a lot of people about life.

I have all of the information I need. I don't need to find information on anything.

Advocacy

Participants also expressed a strong desire to help others, including family, friends, church members, or others within the disability community. They unanimously wanted to join a local disability advocacy group. They were excited by the possibility of making a change, as well as being part of a group, which they could identify.

You have to be part of it to make better change for yourself and the cause you are trying to fight for.

That would be cool to be a part of something. You don't know that many other people with disabilities.

In unity, there is strength.

Specific advocacy topics cited by the participants were individual support, socialization, information sharing, and advocacy.

Where can we go to get better information to help us along? How to get Social Security, how to get benefits, a support system. That would be really great for us. We don't need to be alone.

Would be interested in learning about specific issues, and having a support system since some of us have been abandoned by their families.

Have self-advocacy on Facebook to build social networks. Possibilities for good are endless there. You can have ride-sharing on there.

"That would be cool to be a part of something. You don't know that many other people with disabilities."

One individual commented on the need to change procedures, so that communication was locally between members instead of top-down from a central office.

It could be good to have a self-advocacy group. Help us start a group, but then change the procedures to how to communicate with each other, how to help each other, whoever has a problem or has something to say or needs help, we can change things a little bit and work things out to help this individual. Help them and they can help us in a way too.

However, some concerns were voiced by participants over whether or not these groups would be effective.

I [a parent] understand their need. I like to hear their voices, but they always don't have the skills to solve these problems on their own. Without a support coordinator there, it would just be a party.

There's a difference between talking about it and actually doing something about it. We talk about these issues all of the time, but then people at the top sit on it.

Transportation will be a barrier, so you need to plan [a meeting] at least a month ahead of time.

All participants thought that the meetings should be held at least monthly in-person in their communities, in order to maintain momentum. They felt the meetings would be a way to provide members with important information. In addition, they would help participants gain confidence and find their voice, so that they will have access to more opportunities in community life. The only concern among the participants was obtaining transportation to get there.

KEY THEMES

After analyzing the survey data cited at the beginning of this report, it became clear that serious barriers exist for Arizonans with disabilities in employment, social networks, and ability to make choices in housing. But, the existence of barriers in transportation and housing preference wasn't so clear. The findings from these focus groups pick up where the surveys left off, answering some of these questions, and revealing several major findings.

Choice or Inclusion?

It was clear that all Arizonans with DD could not be lumped together when setting state goals. Each individual had different interests, aspirations, and needs. While some viewed friends as important, others preferred keeping to themselves. Some preferred to live with others, while others preferred to live alone. Some preferred to work, while others preferred not to. Thus, at times our systemic idea of inclusion conflicts with individual choice.

Options and Perceptions Limit Independence

In addition, individuals desire to be independent, and while their preferred options may be available, they are not always presented to them. This creates an obstacle to the goal of independence.

- Many who were living with families desired to live in their own apartments, so that they could have the freedom to live their own lives, see their friends when they wanted, and/or have the opportunity to date or marry. While shared living, such as living in an apartment with a roommate, is supported by DDD and is less costly than group homes, it is an option rarely offered by most DDD agencies. Nevertheless, shared living is used in rural areas with limited housing. Further, there is a shortage of available, affordable accessible housing that limits these options.
- Although many aspired to perform certain types of work, they did not feel that employers would give them a chance. As a result, many were content to be placed into "jobs for the handicapped." Many individuals not in these centers were not looking for work because they had given up or felt that they could not work.
- Individuals who had to rely on caregivers to get around found themselves limited to when and where the caregivers could take them out. Many participants resorted to walking if they lived in a location that had amenities close by.

In addition, individuals said they were limited by what others perceived that they could do. The automatic assumption by many is that they need support, or they aren't capable of doing something by themselves, or of doing any higher-level work. Even a job coach can be perceived as a barrier by those who just want to work in the community and receive direction from a workplace supervisor like everyone else.

Taking What They Could Get

These lowered perceptions by others ultimately impacted participants' self-confidence and sense of self-efficacy. Opportunities for training or education in areas that interest them are minimal at best. Their employment desires tend to be shaped by their own perceptions and the system's perceptions of what they can do, where they normally go, if they can walk there, and if the business hired people with disabilities. In effect, many take any job they can get to keep them busy and to earn a paycheck – not necessarily because

it is something that they actually want to do. The general expressed belief was that the job market changed after the recent recession to the detriment of job seekers with disabilities.

The Backward Slide from Independence

Further, those in need of more assistance to be independent and successful are often unable to receive it. For instance, families have stated a problem with securing job coaches to help individuals maintain jobs. Those individuals who qualify for Arizona Long Term Care System (ALTCS)¹⁹ automatically qualify for DDD services that would pay for a job coach or someone to assist them on the job for up to one year if it is in their support plan. After one year, if needed, DDD would pay for an Employment Support Aide to promote job retention. However, those who do not qualify for ALTCS would have to go through RSA's VR program. Those with less significant disabilities would be placed on an indefinite wait list. As a result, the lack of information or the lack of access has caused many individuals to regress from independence in employment. Those who were employed in the community and lost their jobs either remained unemployed or went to work for a disability service provider in a center-based or group-supported option.

Who does VR currently serve?

Due to a budget shortage, Arizona's RSA-VR program operates by an order of selection, meaning that those that are deemed to have the most significant disabilities are served first. As a result, VR services for those with less severe disabilities are closed indefinitely.

While an individual who lives in a group home may aspire to be out in the community pursuing his or her own interests, the current system does not support that. Group needs of staff time supersede individual needs. A constant turnover of staff also affects the ability for some residents to form relationships with their staff members, which also inhibits the ability of individuals to pursue their own interests in the community. Some participants expressed frustration with this lack of support. However, others accepted these limitations and set the bar lower for what they could accomplish.

Transportation Still a Barrier, But Location Plays a Mitigating Role

Those with no transportation barriers were able to have the freedom to go where they wanted when they wanted. They often walked or rode a bike. They only encountered issues with ice, snow, or extreme heat. As a result, the location of one's home has everything to do with how included a person may feel in the community. Many of those facing transportation barriers simply befriended their family's friends or their house staff – the people that were able to see them in their own homes.

Physical Barriers and Fewer Opportunities in Less Populated Areas

Participants noted that many of their friends moved away after high school because individuals with DD often rely on informal support. The choice of whether or not to move is not an option for many. They often choose to stay where their families live. Consequently they encounter limited opportunity and fewer friends in less populated areas of the state. Some of these areas have limited transportation, as well as, significant physical barriers, including dirt roads, inaccessible businesses and houses, and lack of sidewalks.

¹⁹ A customer who is eligible for ALTCS will have a functional and/or medical condition that is so impairing as to interfere substantially with the individual's capacity to remain in the community, and results in long term limitation of ability for self-care. ALTCS services would allow the individual to remain in the community, as opposed to an institution.

Friends Like Me

In many cases, the individuals were not connected to others outside of their families and provider groups, such as group homes, day programs, or sheltered workshops. Some individuals preferred to be solo, due to the discrimination they felt from society. They said they just wanted to feel normal. Those in day programs or center-based employment settings enjoyed spending time with others who could identify with them. Those who did not participate in these programs, however, rarely saw others with disabilities, although they wanted to meet others like them.

Lack of Information, Lack of Access

Many group participants used technology to obtain information, indicating that the digital divide, while still present, is gradually diminishing among the younger population. However, a lack of information persists across all of the groups. There was a consistent fear of losing SSI if they obtained a job. Therefore, many were satisfied living on just their SSI payment – a maximum of \$710 a month.

The reality is individuals can both earn wages at a job and maintain some or all of their disability benefits. Someone receiving SSI will generally lose only \$1 of their benefit for every \$2 they earn by working. As a result, even if their disability benefits get reduced, their overall monthly income is still more than it would be by not working. Many individuals can use special programs available to them under the SSI program to further limit the impact of income on their benefit. For example, many individuals are able to work and continue to get their healthcare coverage under SSI. They can also own a home and a car, and not have their values count against their disability benefit. Should individual earnings go over the maximum allowed to retain benefits, individuals would lose SSI, but they would be able to get back on SSI if their wages dropped or if they lost their job.

Because of the confusion and misinformation about the impact wages have on disability benefits, a resource was created specifically to answer questions for beneficiaries and their supporters. Arizona Disability Benefits 101 (AZ DB 101). In addition to income and benefits calculators, AZ DB 101 has an extensive index of general resources of interest to individuals with disabilities and their families and friends. This resource is available at <http://az.db101.org/>.

Therefore, the fears that many will lose their SSI if they work too many hours and that it is too difficult to get back in the program are unfounded. There was also a lot of misinformation regarding transportation, what employers could and could not do, and a general lack of knowledge about available resources and activities. Without this knowledge or even recognizing that having it is important, individuals rely on others for information, which limits their choices.

Family Fears

In a state policy environment grounded in self-reliance, families have had to expend substantial effort and resources to support their loved ones. They worry about what will happen when they are gone. Who will their loved one depend on? A small social network, a social environment that many consider hostile, and limited state support pose significant barriers to individuals who desire to be independent, and heighten the concerns of families who worry about their safety.

Desire for Self-Advocacy Group

Although focus group members all faced barriers in their daily lives, many had become resigned to them. However, after hearing from others who encountered similar barriers, participants became interested in change. In the face of shared barriers, these individuals desired to come together to build their own support network, advocate to remove some of these barriers, collect information, and socialize. Many recognized that they needed do something in order to improve their present situation and that there was strength in numbers if they came together.

THE DISABILITY BUBBLE

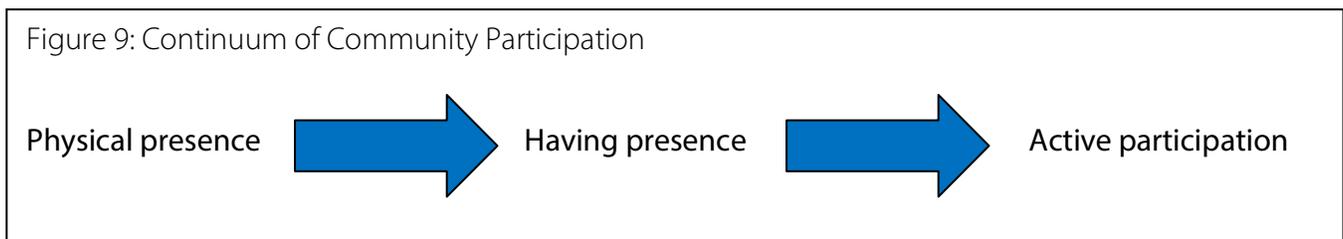
Common to most of these themes is the shortage of needed services provided by DDD, VR, Social Security, transit agencies, housing authorities, and provider agencies. People with DD often receive support within a human-services system that allows few opportunities for social participation with others outside the system. This network of formal supports is called the *Disability Bubble*.²⁰ Importantly, this bubble shapes the self-perceptions of individuals' capabilities. The community falls outside of this bubble.



Although individual choice is part of professional service plans, there are caveats to these choices: They ultimately must meet the expectations of the professionals or fit within the list of limited options. Thus, professionals often make the final decision on how people with DD are included in their communities through the services that are rendered. As an unintended consequence, many people with DD and their families become captured by this system, which often guides decision-making and limits their opportunities for social inclusion.²¹

People within this bubble of formal services find that those in the bubble with them, like providers, facilitate little interaction with others outside. Certainly, many individuals prefer to bond with others like themselves. However, the danger of not networking and developing reciprocal relationships with “outsiders” is that the individual with DD can end up being segregated or excluded.

Figure 9 describes how this can be changed. There are three types of community presence that suggest different ideas of inclusion.²² The first notion of physical presence is often what occurs among people with DD. Providers often coordinate community activities for individuals in a group. They visit the mall, go to movies, and participate in leisure activities. While individuals enjoy these outings, such group “visits” -- simply being there -- do not necessarily provide them with opportunities to have meaningful social contact with others.



The last two notions of community presence introduce quality of relationships and interconnectedness between individuals with and without DD. As individuals with DD venture more into the community and socialize with other community members who become acquainted with them, they will begin to have a

²⁰ Gardner, J. & Mathis, E. (2009). Inclusion: progress and promise. Beyond the disability bubble. *The International Journal of Leadership in Public Services*, 5, 38-45.

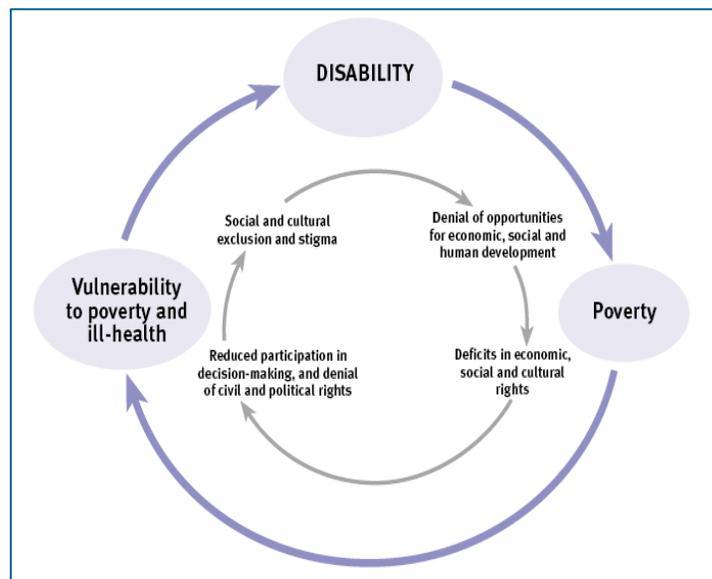
²¹ Abbott & McConkey, 2006; Bates, P. & Davis, F. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability & Society*, 19, 3, 195-207; Gardner & Mathis, 2009.

²² Smull, M., & Sanderson, H. (2001). *Essential lifestyle planning: A handbook for facilitators*. Manchester: North West Training and Development Team.

presence. In active participation, they are not only present and interacting with others, they are also actively participating in their community through work, voluntarism or play. In active participation, they are appreciated for contributing to their communities. Researchers believe that increased presence and contact by those with DD in the community should result in their participation in more valued activities, and generate more positive attitudes from the community.²³

Furthermore, because social and employment opportunities are often facilitated by colleagues, friends, and mentors,²⁴ a lack of social connections and networks outside of familial or professional-service connections can be a barrier to achievement. A vicious cycle can emerge, as marginalized individuals remain excluded, and this in turn affects their self-perceptions and efforts to direct their own lives.²⁵ Figure 10 demonstrates how exclusion in decision-making, social opportunities and individual economic development opportunities can impact quality of life, resulting in vulnerability to poverty and ill health.

Figure 4: The Code Cloud



Arizonans need to help individuals with DD and their families step out of the *Disability Bubble* by developing a network of opportunities, both formal and informal, that will help individuals with DD emerge from the bubble and expand the quantity and quality of their life opportunities.

²³ Abbott & McConkey, 2006; Booth, T. & Ainscow, M. (2002). Index for inclusion: Developing learning and participation in schools. CSIE. Retrieved from <http://www.eenet.org.uk/resources/docs/Index%20English.pdf>;

O'Brien, J. (1987). A guide to lifestyle planning: Using the activities catalog to integrate services and natural support systems, in B. Wilcox & G. T. Bellamy (Eds.) *A comprehensive guide to the activities catalog: An alternative curriculum for youth and adults with severe disabilities* (Baltimore, Paul H Brookes).

²⁴ Granovetter, M. (1974). *Getting a job: A study of contacts and careers*. Cambridge, MA:

Harvard University Press; Portes, A. (1998). Social capital: Its origins and applications in modern sociology. *Annual Review of Sociology*, 24, 1-24

²⁵ Atkinson, A. B. (1998). Social exclusion, poverty and unemployment. In A. B. Atkinson and J. Hill (Eds.), *Exclusion, opportunity and employment*. London: Center for Analysis of Social Exclusion.

STUDY LIMITATIONS

It should be noted that this study is based on the perceptions of individuals with various types and severities of DD, who live in smaller towns and cities across the state. Therefore, the findings may not necessarily be generalized to all people with DD across Arizona. In addition, the perceptions of these individuals may differ from the perceptions of their family, case workers, and friends. Nevertheless, it is their perceptions we were interested in obtaining, since they are often left out of the discourse. Furthermore, some individuals may not have been able to attend. The focus groups were held during the day when those who are competitively employed may have had to work, and recruitment included assistance by non-profits, government, and provider organizations. Therefore, those who were disconnected and not involved with any organization may not have received the information to participate. Regardless of these limitations, the findings validated the results from the few similar studies completed. In addition, participants from all four focus groups reported consistent themes and barriers to inclusion, and the public forums corroborated these findings.

PUBLIC INPUT

The three public forums held in Prescott, Yuma, and Mesa hosted approximately 120 providers, family members, government workers, and individuals with DD. After presenting the report results, the public was invited to ask questions and/or to make oral or written comments. Overall, the audience agreed with the findings of the report. Some even offered assistance in creating groups or offering opportunities for networking among people with DD.

Other issues brought forward covered several areas, which are divided by topics listed below:

Information and Advocacy:

- Some were upset by the complacency of the community reflected in the low turnout in Prescott (approximately 30 attendees). The audience suggested conducting more outreach to raise awareness of disability issues.
- Bring awareness to all other groups outside of the DD world, especially if you are seeking community inclusion.
- In order to raise awareness of disability issues, attendees suggested advertising in the newspaper, through cable and on local community internet sites, as well as employing high school transition teams to pass out informational flyers and put up posters. Some attendees with DD stated that they would like a support group for people with DD and more activities.
- We need to educate at an earlier age for self-advocacy. Things will go smoother if we know what they want, and they know what they want. Even if they cannot verbalize, they can use their body, their eyes, etc. Parents need to be advocates – not protect the individual – but help them to be independent.
- You need to consider issues of liability when organizing an advocacy group.
- We have to get active with our legislators.

Education:

- There is a shortage of special education teachers.
- There was a lack of information by a number of parents and caregivers regarding the services available and the rights of people with DD to reasonable accommodations, specifically in higher education.
- Social and communication skills need to be emphasized in schools and also in our adult community to help with employment.
- Bring disability awareness into all schools.
- Some individuals expressed concern that there were few vocational options for people with DD outside of higher education.

Transportation:

- Some considered transportation as not an issue, since they relied on others to get around, or there were various other public transportation options that could be used. However, the problem was getting the information to the individual about these options.
- Others stated that transportation was an issue and a barrier for people with DD to be able to go to events and be included in the community.

Inclusion:

- Individuals with DD stated that at times they feel that they are not part of the community. Some surroundings are unfamiliar and they don't understand them. They end up hanging out with family a lot.
- Utilize community organizers and help get the DD population in the community.
- One individual with DD stated that she did not choose to hang out with others that are higher functioning since they hurt her and leave her out of things. People with DD are individual and normal, but people with disabilities can also be bullies like everyone else.
- People with DD need to cultivate stronger friendships and be accepted and respected for who they are, regardless of behaviors.
- We (people with DD) experience discrimination daily in employment, getting a bank account, driving a car, being allowed to be recruited into the military. We don't enjoy the same privileges that others without disabilities have.

Housing:

- Many don't understand budgets or what they can afford. They can work with independent living centers to help set up a budget. They do need continued supports to keep housing. There also needs to be a grant leveraged for housing those with DD without mental illness. Those who live by themselves may need assistance setting up a structured routine and schedule. There should also be someone who has daily contact with the person.

Employment:

- Reach out to local employers (top 10 employers) to discuss the benefits of hiring a person with a disability: i.e. Banner airlines, Intel, Amazon, AVNET. Bring other partners to the table: health plans, St. Luke's Health Initiatives, faith-based organizations, municipalities, non-profits.
- We are slow to react to the employment issue and people with disabilities.
- There is a lack of awareness of state and federal government actions to promote employment among people with disabilities. There are federal tax breaks to promote employment in the private sector. Also, a U.S. Department of Labor rule was issued this summer mandating federal contractors to have a workforce that includes seven percent of workers with qualified disabilities. Further, Arizona is working towards becoming an Employment First state. This means that programs, funding, and services would be prioritized to ensuring that people with disabilities have the choice of employment first, before other options are employed.

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- I need a job coach to do my job, but when they did budget cuts, the first cut made was my job coach. There are no options that support people with DD, who want to work, but need some help.
 - Some groups of employers have come together across the state to address the disability employment issue.

Funding:

- Fund the individual and not the program. For example, in Pennsylvania, an assessment is done and based on individual needs, abilities, and interests. At the end, one would qualify for \$50K a year and that person could go out and purchase pieces of a service plan, like buying a job coach service or interview skills training. So the individual can purchase pieces of an employment opportunity and they don't have to be part of a program.

Benefits:

- More resources are needed for adults who do not qualify for services under DDD.

Technology:

- There needs to be better use of technology to increase access to public meetings.

NEXT STEPS

This report sought to listen to the voices of Arizonans with DD to gain a better idea of the day-to-day lives of those living in less populated towns and cities in Arizona. People with DD have made their voices heard. They have fewer resources in these less populated areas of the state, yet they are flexible, creative, resilient, and have learned how to enjoy life in the face of scarcity. They are also a group that desires more out of life than outings to the mall or the occasional visit with a friend. Some desire careers. Some want to help others. Others want to date or to marry, to have a house with a dog, or simply to live independently – to live their version of the American dream. While the current system offers some assistance to individuals with DD and to families in need of respite, much more needs to be done to help these Arizonans get a fair shot at life.

To this end, important questions remain concerning how we can design our programs and services to recognize individual choice, encourage their active participation in the community, and burst the *Disability Bubble*. In order to build a more resilient support system for individuals with DD and their families, the answers must come from multiple stakeholders, including the individuals themselves, the parents or caregivers, the providers, government agencies, such as DDD and VR, as well as the business community.

- **Self-Advocacy:** How can we start self-advocacy groups that touch on the needs of individual communities and connect individuals with needed information and social contacts?
- **Community Participation:** How can individual interests and dreams be supported with a shortage of resources and transportation?
- **Independence over Dependence:** How can individuals with DD be offered more opportunities to make friends outside of the disability bubble, learn independence, and learn from failure, while still remaining safe?
- **The Role of Family and Friends - Building a System Outside of the System:** How can informal systems be expanded to provide mentoring networks, ride sharing, etc.?
- **The Role of the Provider:** With limited funding available, how can providers facilitate more meaningful community interaction of individuals that attend their day programs, and how can they individualize employment opportunities?
- **The Role of Government:** What can agencies such as DDD and VR do to increase the choices and options that promote community participation by individuals with DD like housing, employment, transportation?

Arizonans with DD are ready to get to work to find answers to these questions and to break through the barriers they experience daily. With their energy and ideas, Arizona can create a system that fosters their economic and social development, thereby enabling individuals to achieve the level of inclusion they desire.

APPENDIX: FOCUS GROUP QUESTIONS

Inclusion

- What activities do you enjoy doing or would like to do near where you live? Why is this? (CHOICE)
- What helps you to get involved in these activities? (SUPPORTS)
- What stops you from participating more in these activities? (BARRIERS)
- What can be done to give you access to more of these activities? (IDENTIFYING UNMET NEEDS)
- How do you find out about different activities or other information you may need? What other information could help you to get out and about more? (IDENTIFYING INFORMATION NEEDS)
- Describe your friends. What are they like? How do they make you feel? How often do you get a chance to socialize with them? (BELONGINGNESS, RELATIONSHIPS, VALUE)

Employment

- How do you feel about getting a job? Why? (PERCEPTIONS OF EMPLOYMENT)
- Describe your dream job. (CHOICE)
- How would you go about getting your dream job? (PROBLEM SOLVING, KNOWING HOW TO ACCESS RESOURCES)
- What kind of problems have you encountered trying to get a job or keeping a job? (BARRIERS TO EMPLOYMENT)

Housing

- Describe your ideal living situation. Where would you live? With whom would you live, or would you live by yourself? Would you have pets? Why would this situation be ideal for you? (HOUSING PREFERENCE)

Self-Advocacy

- Who do you talk to or where do you go when you have problems? (SUPPORT NETWORK)
- Suppose there was a group of people with disabilities that talked with each other about how to solve problems and barriers for themselves and the whole group. Would you be interested in joining a group like this? Why or why not? (NEED FOR SELF ADVOCACY GROUP)

GLOSSARY

Adult Developmental Home: Paid for by DDD through federal Medicaid waivers. Up to three individuals with ID/DD live with a family other than their own. These “foster” homes provide care for adults 18 years or older.

Arizona Long Term Care System (ALTCS): It provides medical care and supportive services, such as in-home attendant care, case management, or costs of institutional living. To qualify for ALTCS, individuals may live at home, but they must be determined to be at risk for, or in immediate need of, an institutional level of care, if assistance is not provided through ALTCS.

Center-Based Employment/Sheltered Workshops: These programs offer skills training, special certificate commensurate wage rate work (i.e. sub-minimum wage), prevocational services, group work placements, and recreation and leisure activities in segregated settings with other workers with disabilities.

Competitive Employment: Self-employment or work alongside others with no disability in a community, non-segregated setting that is performed on a full- or part-time basis that is at least equal to the higher of the federal or state minimum wage.

Group Home: This option is paid for by DDD through federal Medicaid waivers. They are typically smaller, more “home-like” settings offering resident supervision and the opportunity to live in a neighborhood setting. This is the most popular residential option in Arizona, housing primarily adults at least 22 years old. Group homes house as many as six people with developmental disabilities; however the majority in Arizona house up to only three people. Average costs are \$400 per day per resident.

Group-Supported Employment: Groups of people with disabilities that work together to perform the same job in a community, non-segregated setting with a job coach.

Impairment Related Work Expenses (IRWEs): Documented expenses for services or items that are related to a serious medical condition or impairment and needed in order to work. Wheelchairs, physician visits, copayments for prescriptions, and other medical expenses are some examples of IRWEs. These expenses are subtracted from your countable income for SSI.

Job Coach: State and federally funded staff persons who provide assistance and training to workers with disabilities while on the job. This type of support is extended to individuals, as well as to groups of people with disabilities working together in the community.

Plan for Achieving Self-Support (PASS): This program is for people with disabilities on SSI who want to save money for a work-related goal that will help them become self-sufficient. By setting up a PASS, the individual can keep full SSI benefits to pay for basic living expenses, like food and rent, while he or she sets aside money from other sources to achieve work-related goals.

Rehabilitation Services Administration (RSA): Under the U.S. Department of Education, RSA defines and evaluates employment outcomes for state vocational rehabilitation (VR) agencies across the country.

Shared Living Arrangements: People with ID/DD are given the opportunity to choose their own roommates and live in their own houses/apartments together. Supports from the state are through personal attendant support.

Student Earned Income Exclusion: Allows students under the age of 22 to make more money without having their SSI benefits reduced.

Supplemental Security Income (SSI): SSI is a Social Security program that pays monthly benefits to those with limited resources who are 65 and over, have blindness, or have a disability. The maximum monthly benefits for individuals are \$710 in 2013 – significantly less than the federal poverty guideline.

Supported Employment: This is individualized supervision on the job according to the individual's abilities. This can be offered either through natural or formal supports. Natural support tends to be a preferred option as on-the-job assistance and role modeling is offered by peers, supervisors and colleagues, thus there is no differential treatment based on disability. Formal support is offered by state and federally funded job coaches.

Ticket to Work: This is a voluntary federal program that helps individuals between the ages of 18 and 64 on SSI get back to work. A variety of services to help get a job are offered through an employment network, including vocational rehabilitation, training, referrals, job coaching, job counseling, and placement services.

University Centers for Excellence in Developmental Disabilities: These centers facilitate the flow of disability-related information between community and university. Centers work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens. The national network of UCEDDs is authorized under Public Law 106-402 (The Developmental Disabilities Assistance and Bill of Rights Act of 2000 or "DD Act") and their core funding is administered by the Administration on Intellectual and Developmental Disabilities (AIDD).

Vocational Rehabilitation (VR): Agencies that coordinate and provide programs and services that help individuals with disabilities achieve the ultimate goal of obtaining and retaining employment.