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COMPREHENSIVE REVIEW AND ANALYSIS

SECOND EDITION

Arizona's Services, Supports, and Unmet Needs for Individuals with Developmental Disabilities and their Families

Prepared for the Arizona Developmental Disabilities Planning Council

ARIZONA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL℠

ASU Morrison Institute for Public Policy
ARIZONA STATE UNIVERSITY

Comprehensive Review and Analysis

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INTRODUCTION

The Arizona Developmental Disabilities Planning Council (ADDPC) tasked Arizona State University's Morrison Institute for Public Policy with completing a Comprehensive Review and Analysis (CRA) of Arizona's services, supports, other assistance, and unmet needs for individuals with developmental disabilities (DD) and their families. The contents of this document will help guide ADDPC in selecting its priorities for the 2017-2021 five year strategic plan. Members of ADDPC and community stakeholders assisted in establishing the direction and strategies for data collection.

Methods of data collection and sources used were diverse and extensive; they sought to uncover the trends locally, statewide, and nationally in community inclusion among individuals of all ages with a broad range of developmental disabilities. The following is only a partial list of methods used:

- Literature review: best practices and trends in specific topics, such as aging with DD, housing, employment, transportation, education, self-advocacy, self-directed and peer supports, and assistive technology.
- Existing data: U.S. Census; federal agency data; state agency reports (national comparisons made where available)
- Secondary research: National Core Indicators (NCI), Native American Disability Law Center, United Cerebral Palsy (UCP) Case for Inclusion, Institute for Community Inclusion State Data
- Service Inventory of existing DD services and waitlists

In an effort to reach underserved and un-served populations, the research team traveled to both urban and rural areas of the state and used translators when necessary to interview individuals with DD, their families, and providers to determine attitudes, perceptions, and barriers to day-to-day life, work, and play. Following are some of the methods used:

- 36 focus groups: parents, adults, high school students with disabilities, providers
  - 22 of these focus groups were conducted in 2015 with 153 adults with DD, family members, and providers:
    - Six groups with people with behavioral health issues and their families;
    - Six groups with adults with DD ages 40 and over and their family members;

    - Four groups with Spanish-speaking adults with DD and family members
    - Six groups with providers
- 939 surveys in 2014 with high school students with disabilities and their guardians
- 898 general population survey in 2015
- 140 provider surveys in 2015
- 326 consumers with disabilities surveys in 2015
- Employment provider survey (pilot survey of 28 providers, 2013)
- 75 key informant interviews (35 completed in 2015)

The data reported is corroborated from multiple sources. In the event that the data only exists from one source, it will be indicated. Despite all of the data reported in this CRA, there will be some data points omitted that the Council may find necessary in goal-setting. This document is a working document and can and will be revised based on feedback from ADDPC, stakeholders, and constituents.

The CRA is primarily laid out in two parts, as defined by the federal template, which State Councils are required to submit. The first section is the "Portrait of State Services" that provides an overview of state services in specific areas, including strengths, weaknesses, opportunities, and threats. The second section is an "Analysis of State Issues and Challenges," which discusses issues related to eligibility, un-served and underserved populations, the availability of assistive technology, adequacy of health care in institutions, and an overall assessment of Home and Community-Based Services (HCBS) waivers. In the Appendix are the acronyms used in this report, state demographic information, 2015 survey instruments with raw data, and notes/references.

Key findings indicate that the state continues to rank high nationally in supporting individuals with DD to live at home with their families, but it is deficient in supporting other areas that promote community living. Employment and community inclusion indicators lag behind other states, and individuals and families consistently report a lack of individualized, supported employment, recreation, transportation, access to healthcare, and supported living options. A majority of individuals with disabilities report not speaking up for themselves in a system and a society that overall expects less of them. Families are overwhelmed, feel that they lack information and choices, and have to make do with what they are able to receive. Many rely on providers to fill the gaps for their child. By and large, the disability bubble in Arizona remains intact. Individuals and families report very few authentic relationships between people with and without disabilities. In this system barriers are magnified in rural areas and amongst those who do not speak English – 9.5% of the population in Arizona.

PORTRAIT OF STATE SERVICES

HEALTHCARE

Access to quality health care is very important for people with disabilities, not only to maintain their current health status but also to ensure quality of life. The issue of health care accessibility ranges from physical inaccessibility of care providers to failure to receive health care in a timely manner, to failure to have health insurance coverage, to lack of access altogether. In response, various government agencies and programs aim to provide quality health services to people with DD in Arizona to improve access to care and remove some of these barriers.

Access to Public/Private Health Insurance

Affordability of health services is a substantial barrier for people with disabilities, and why many do not receive needed care. Health insurance is an effective mechanism to improve health care access by addressing affordability. According to the U.S. Census, many people with disabilities in Arizona had some type of health insurance coverage in 2013. About 84% of people with disabilities ages 18 to 64 had health insurance coverage, outnumbering the 76% of people without disabilities who also had it. Among people with disabilities with health insurance, 49% were covered through private insurance and 64% had public health insurance coverage. The uninsured rate for working-age people with disability in Arizona was 16.3%, almost equivalent to the national level of 17.4%.

For older populations, the vast majority had health insurance coverage in 2013; 99% of those who were 65 years and over with a disability were covered by health insurance; 56% had private insurance and 99% had public health coverage. However, for those under 18 years with disability, those who have no insurance coverage is twice higher than the national average. In Arizona, among those under the age of 18 with a disability, about 9% did not have any health insurance coverage in 2013 while the number nationally was only 5%. For people without disability, the rate of uninsured in Arizona (12.7%) was higher than the national level (7.4%).
As for type of insurance, 38% reported that they were covered by Medicaid (or other government-assistance plan for those with lower income or a disability), 34% by a current or former employer/union, 22% by Medicare, and 10% were covered by Military/VA. Nine percent of working-age people with disabilities in Arizona were covered by private insurance either throuhg their own or through family members. Although there are a significant number covered through health insurance in Arizona, there are still around 15% people with disabilities who are uninsured.

Health insurance (HI) coverage by age (Arizona)				
	with disability		without disability	
	with HI (private/public)	without HI	with HI (private/public)	without HI
Under 18 years	91.2% (43.4/65.8)**	8.8%	87.3% (61.6/42.2)	12.7%
18 to 64 years	83.7% (48.8/63.9)	16.3%	76.1% (85.1/18.1)	23.9%
65 years and over	99.1% (55.9/99.0)	0.9%	98.9% (62.0/96.9)	1.1%

**** Note:** Total percentage of those who have private and public insurance may exceed 100% because of those who have both insurance coverages.

Source: American Community Survey 2011-2013. (B18135)

Medical Assistance Programs

The Arizona Health Care Cost Containment System (AHCCCS) is Arizona's state agency that administers medical (i.e. Medicaid), nutritional, and other assistance programs, some in collaboration with other state agencies. For people with disabilities, there are several major programs through which AHCCCS provides medical assistance:

- AHCCCS medical assistance programs (e.g. Medicaid, CHIP, etc.) provide access to service packages covering a wide range of care including doctor/specialist visits (including transportation), prescriptions, hospital services, immunizations, emergency care, rehab services, behavioral health, 90 days of nursing care services, surgery, medical supplies, etc. for eligible adults and children.
- Arizona Long Term Care System (ALTCS), a division of AHCCCS, provides services including case management, medical services, behavioral services, family planning services, and long-term care services to those who need a level of care provided in an institutionalized setting. As of November 2015, 57,646 Arizonans are eligible for ALTCS (3% of total AHCCCS recipients). Among the ALTCS population, 49% (28,511) are those who are DD and 51% (29,135) are elderly and people with physical disabilities.
- Freedom to Work (FTW) is an underutilized program. It allows people with disabilities who work between the ages of 16 and 64 to maintain their AHCCCS medical insurance. Eligibility requires that the person with a disability make $4,989 or less a month. The person can also receive ALTCS services if they have medically diagnosed eligibility in need of long-term care services or if they live in an institutional setting providing such

services. There were only 2,149 FTW enrollees in November 2015, 97% receive FTW acute care and 3% receive ALTCS.

Residential/Institutional Care

Institutionalized care facilities provide more intensive care in residential settings for relatively longer periods of time. This service is administered by ALTCS. AHCCCS administers ALTCS for those who are elderly or with a physical disability (EDP), and Arizona's Department of Economic Security – Division of Developmental Disability (DES-DDD) administers ALTCS for people with DD. As of November 2015, there were 29,135 EDP populations enrolled in ALTCS. Residential settings for long-term care include Assisted Living Centers, Adult Foster Care Homes and skilled nursing facilities. In 2014, the total number of residents in certified nursing facilities was 11,118. It has been slightly but steadily decreasing since 2010 – and at a rate of 1.2% between 2013 and 2014. In fact, Arizona showed the largest decrease in the country of nursing home occupancy rates (10.6%).[i]

Among 33,933 individuals with DD who enrolled in ALTCS in 2014, 12% received long-term care in residential settings. For people with DD who need residential options, adult/child developmental homes and group homes are available. Adult/child developmental homes are licensed private residential care facilities for up to three individuals with DD. In 2014, 4% received long-term care through adult and child developmental homes; and 7.7% did so through group homes. As residential settings in the community, group homes (can house up to six people, but in Arizona, usually 3 residents or less) provide supervision, room and board, and 24 hour staffing. For DD populations who need more intensive care in residential settings, there are two institutional care options: Medicaid certified nursing facilities and intermediate care facility for persons with intellectual disabilities (ICF/ID) (AZ DES, 2014). Only 0.5% of the DES/DDD population was served in such settings in 2014; the trend is for more community-based care options.

The Arizona Early Intervention Program (AzEIP)

Early intervention has resulted in improved school performance, with children mastering life skills and gaining confidence as a result of these programs. The sooner the interventions can take place after a diagnosis of disability or risk factors are identified, the more developmental gains and the less developmental problems children are expected to have. Secondly, early interventions are also effective in cost reduction. Cost and benefit studies show that overall costs are less if the services begin at birth.

AzEIP supports and provides services for families with children with developmental delays and disabilities who are ages 0-3. Children under the age of 3 who fall below 50% of developmental progress criteria based on a doctor's diagnosis are eligible to receive services. In 2014, 5,363 infants and toddlers ages 3 and under received early intervention services. The number of families served by AzEIP have steadily decreased from 2008 (5,783) to 2013 (4,611). In 2014, however, it jumped again to 5,258, due to an increase in birth rate.

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Infant and toddlers who received AzEIP services in 2014 - *by age group and setting*				
Age group	Home	Community-based setting	Other setting	Total (%)
Birth to 1	750	2	14	766 (14.3%)
1 to 2	1,671	1	30	1,702 (31.7%)
2 to 3	2,837	6	52	2,895 (54.0%)
Total	***5,258***	***9***	***96***	***5,363 (100%)***

Types of services provided include physical and/or speech therapy, developmental special instruction, social work and/or psychological services. The program aims to provide supports and resources for children born with developmental delays so that children can fully exercise their educational potential and not fall behind when they enter preschool and elementary school. As part of an effort to put family's needs first in the provision of person-centered services, it is required that AzEIP services be provided in homes and communities instead of in clinics. As a result, a significant number of AzEIP enrollees in all age groups receive home-based services.

As a team, DES, contracted providers, and families track children's development rating data from their entry to exit of AzEIP. Data reveals that 68% of AzEIP children showed positive social emotional skills, greater than expected when they exited the program in 2012-13; the number was 72% in 2013-14. Nationwide, the percentage of children showing greater than expected growth was 66% in 2012-13 and remained the same in 2013-2014.[ii] Based on the results from eight groups of 15 counties in Arizona, Yavapai county (94%), Mohave & La Paz county block (85%), and Navajo, Apache & Coconino block (72%) were listed as the top 3 county-groups whose AzEIP children showed greater than expected growth in positive social emotional skills.[iii]

Oral health

Research reveal that poor oral health and dental hygiene are prevalent among people with DD. Access to quality dental care is as important as receiving other health care services. Poor oral health is highly associated with decay, periodontal diseases, and losing teeth. Moreover, oral health is linked to other physical health problems including cardiovascular and respiratory diseases; yet it is not a covered service through AHCCCS for adults. As a result, focus group research finds that families in the most need are spending $500 to $1,000 a visit in out of pocket costs to take care of their loved one's teeth. In Arizona, around 45.6% of adults reported having any type of permanent teeth extracted while the number was 44% nationwide.[iv] For children, 34% of Arizona children under the age of three have tooth decay. In addition, more than 50% of children have never visited a dentist until age 3.

Similar to most states, people with disabilities in Arizona are less likely to have adequate dental care than people without disabilities. Survey research from 2015 (Appendix C) finds that 87% report that they have received dental exams in the past two years. Most of those who did not go to the dentist reported that it was not needed, they did not want to go, or they simply could not afford the cost. For others it is related to the accessibility, both physical and social accessibility. Some parents with autism report having a difficult time locating a dentist that can work with their children.

The 2011 ADDPC report “Oral Healthcare for Adults with DD in Arizona” presents the issue. The absence of state funding for preventative care and necessary dental procedures for adults with DD exacerbates health issues that many are currently already facing. Arizona has been building capacity in the form of educational programs dedicated to oral healthcare of individuals with DD (i.e., A.T. Still University and Midwestern University). Despite these programs, there appears to be little if any incentive for these dentists to build a practice around this population. Barriers are based upon financial constraints, including insufficient reimbursement for services; labor-intensive requirements of their offices, and the challenge of treating individuals with special needs.[v]

Mental/Behavioral Health Services for Children and Adults

The Arizona Department of Health Services (ADHS) - Division of Behavioral Health Services (DBHS) contracts with the Regional Behavioral Health Authorities (RBHAs), and Tribal Regional Behavioral Health Authorities (TRBHAs), to administer managed care delivery services in six distinct geographic service areas throughout the State. This regionalized system allows local communities to provide services in a manner appropriate to meet the unique needs of individuals and families. DBHS requires the T/RBHAs to maintain a comprehensive network of behavioral health providers that deliver prevention, intervention, treatment and rehabilitative services to a variety of populations, including: children and adolescents, adults diagnosed with a Serious Mental Illness (SMI), adults diagnosed with General Mental Health Disorders (GMH), and adults diagnosed with Substance Use Disorders (SUD/SA).

According to DBHS data, there were 118,228 members enrolled in the behavioral health system in January 2013. Of this number, 6,790 (5.7%) were also enrolled in DDD - 3,078 were 17 and under, 30% were Hispanic, 46.8% had an intellectual disability, and 36.3% had a diagnosis of autism. Out of the 3,712 working age adults in the DDD and DBHS system, at least 73% of them were not working or attending school.

Only a fraction of Arizonans are receiving mental health services from which they could benefit. Since 2008 there has been a 42% decline in state funding per capita for mental health services in Arizona. Reportedly, more people are in crisis as a result. Crisis centers have become revolving doors for ongoing treatment. In 2016, the Division of Behavioral Health Services will transition from its present organizational home in ADHS to come under AHCCCS.

Mental Health America released its 2016 report on the state of mental health care and ranked Arizona #50 out of 51 for providing access to care among the high prevalence of adults and youth with mental health issues who live in the state. Arizona is also ranked one of the bottom five states in highest prevalence among youth with mental health issues and lowest rates of access to care. Accordingly, there are significant issues facing individuals with DD in the current behavioral health system. Focus groups participants consistently reported numerous barriers within the mental health system.

Access to quality care is a significant problem. Families and individuals have stated that primary care and behavioral health systems aren't coordinated. Some doctors will only treat physical issues before addressing behavioral health issues. In addition, some psychotropic medications are no longer covered under AHCCCS and do not have generics. Individuals who have been on the same medication for years are finding themselves scrambling for replacement medications that don't have side effects. In some cases, there are no replacements. There is also significant turnover of psychiatrists in the behavioral health system; often, individuals are seen by nurse practitioners. Clinics are inconsistent in the quality of care given, and often, they are disorganized. Patients report no return calls or follow-up calls.

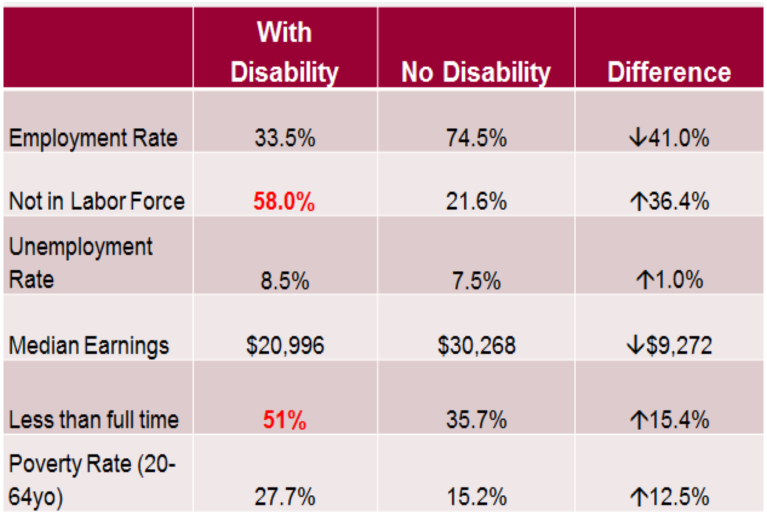
As a result, crisis response is critical for some families. There is a gap in services for people in distress who do not need to be hospitalized, but there is little availability for emergency psychiatrist appointments. Families often have to call crisis response and have an individual hospitalized to get help. In fact, many case managers are not trained beyond crisis intervention. In some cases, families won't call crisis response out of fear that the police will hurt their children. In one instance a family member suffered contusions from his child but did not call for help. Families are not trained in how to effectively interact with their family member and overwhelmingly expressed the need for more support.

There is a significant difference between the services that those with AHCCCS are able to receive and those without AHCCCS. AHCCCS has low copays for clinic visits, but the cost is high for some who are privately insured. Like other states, peer support becomes an inherent part of the behavioral health model, partially due to the shortage of mental health professionals and other systemic issues that are occurring nationwide. Individuals learn about recovery and how to advocate for themselves from others who have successfully recovered from a crisis. Peer support specialists are trained and certified and paid to facilitate support groups, teach classes, and mentor others in their recovery.

Recognizing the lack of community supports that exist, a class action suit—Arnold v. Sarn—was filed in 1981 against the State of Arizona alleging that ADHS and Maricopa County did not provide a comprehensive community mental health system as required by statute. In 1986, the trial court entered judgment holding that ADHS and Maricopa County violated its statutory duty; the Supreme Court affirmed this decision in 1989.

In January 2014, officials at ADHS, Maricopa County, and office of the Governor reached an agreement with Plaintiffs whereby they agreed to provide certain community services and terminate the litigation. The agreement includes an increase of services in four areas: Assertive Community Treatment, Supported Employment, Supportive Housing and Peer and Family Services. The agreement also provides for the use of several tools by the parties to evaluate services provided in Maricopa County, including a quality service review, network capacity analysis and SAMHSA fidelity tools. ADHS has until the end of fiscal year 2016 to see these increases in services are met.

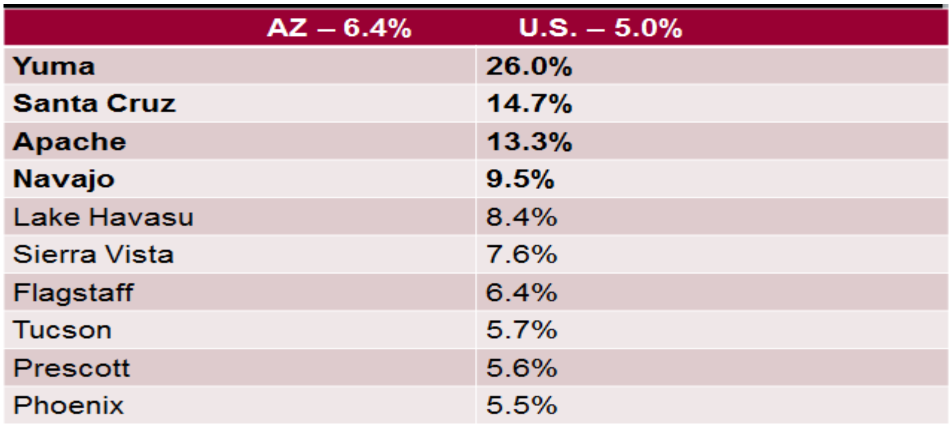
EMPLOYMENT



	With Disability	No Disability	Difference
Employment Rate	33.5%	74.5%	↓41.0%
Not in Labor Force	58.0%	21.6%	↑36.4%
Unemployment Rate	8.5%	7.5%	↑1.0%
Median Earnings	$20,996	$30,268	↓$9,272
Less than full time	51%	35.7%	↑15.4%
Poverty Rate (20-64yo)	27.7%	15.2%	↑12.5%

Arizona's employment gap between people with and without disabilities remains excessive. According to the U.S. Census, only one in three (33.5%) people with disabilities (PWD) and one in four (23.4%) people with cognitive disabilities between the ages of 18-64 are employed, significantly lower than the three out of four (74.5%) people without disabilities who are employed (American Community Survey, 2009-2013). PWDs are not only unemployed, they are not even seeking work - 58.0% of PWDs and 66.8% of people with cognitive disabilities are simply not in the labor force. Of those who are working, many are underemployed. Over half of PWDs (51%) were working fewer than 35 hours a week with median earnings of $20,996 - significantly less than the $30,268 for people without disabilities. 2014 NCI consumer survey data also show that only 10% of Arizona DDD participants have a paid job in the community. Arizona ranks lowest in this measure among the 28 participating states.[vi]

While Arizona's economy has mostly recovered since the great recession with an unemployment rate of 6.1% in October 2015 (still higher than the 5.0% national rate), rural counties continue to face high unemployment. Santa Cruz (13.7%) and Apache (12.7%) Counties have the highest rates in the state; and the City of Yuma has experienced the highest rate in the country (23.2%). Metro areas fare better. Maricopa County has the lowest unemployment rate in the state (5.2%) followed by Yavapai (5.4%) and Pima (5.5%) Counties.[vii] Unfortunately, Arizona's labor underutilization rate, which includes those who have given up looking for work and those who are forced to take part-time work, is surpassed by only Nevada.[viii]

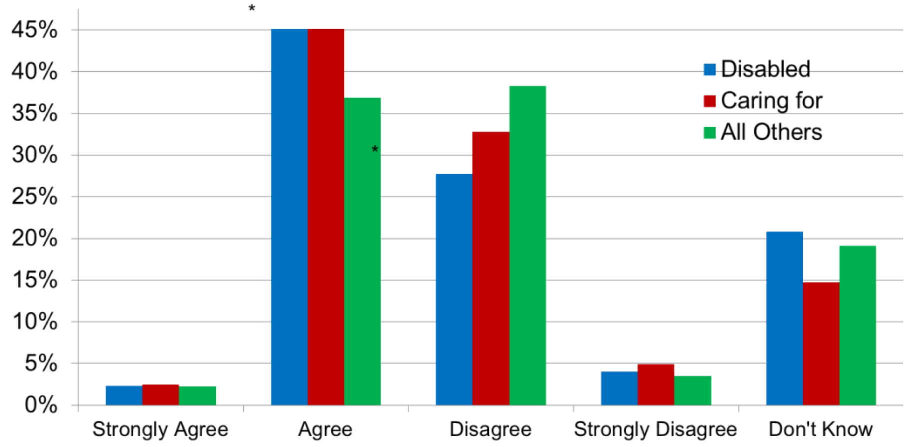


AZ – 6.4%	U.S. – 5.0%
Yuma	**26.0%**
Santa Cruz	**14.7%**
Apache	**13.3%**
Navajo	**9.5%**
Lake Havasu	8.4%
Sierra Vista	7.6%
Flagstaff	6.4%
Tucson	5.7%
Prescott	5.6%
Phoenix	5.5%

Societal Barriers

NCI data show that only 10% of individuals in the DDD system would like a job in the community.[ix] However, focus group research from 2013 and survey research from 2014 and 2015 uncover why these individuals are so apprehensive. Many people with DD would like to work - some would like to start their own businesses. Like nearly everyone, most desire a paycheck and being engaged in something they enjoy; but there are caveats. Some only want part-time work so it does not infringe on their Social Security and AHCCCS (e.g. health insurance) support, and some are afraid to get off of Social Security fully, because they worry they won't be able to reestablish their eligibility should they be terminated. The confusion surrounding Social Security eligibility and work incentive programs begins in high school and remains through adulthood.

In addition, study participants with disabilities cite barriers to employment, including discrimination by employers, a lack of individualized, supported employment options, a lack of transportation, and fear or anxiety of failure. In addition, providers and family members have low expectations for these individuals, and families fear workplace bullying. Among providers, 86% believe families overprotect them, and 57% believe the formal system does not do a good job promoting their independence (Appendix D). This supports research conducted in 2014 with high school youth and parents. Parents tend to have lower expectations for their children regardless of the severity of disability. Further, reliance on formal systems tends to lower their aspirations. A poll of 898 Arizona voters conducted in 2015 was not encouraging. The majority of Arizona voters is comfortable with hiring people with disabilities (80%), would have a more favorable opinion of an employer who recruited them (75%), and would prefer to give their business to companies who hire them (78%). On the other hand, many do not believe, or do not know, if workers with disabilities could perform at the same level as workers without disabilities When Arizonans were asked if they agreed with the statement "workers with disabilities perform at the same level as their counterparts:" 42% think they can perform at the same level, 40% think they cannot, and 18% simply don't know. Only 47% of individuals with disabilities think they can perform at the same level and 21% don't know if they can (Appendix E).



In light of this context, what are Arizona state services doing to overcome lower expectations among adults with DD themselves, Arizona citizens in general, and families to enhance employment opportunities among people with disabilities? Following are the most significant programs utilized by individuals with DD and their families.

Work Assistance Programs

Many individuals pay privately for assistance in job preparation and placement because of the limited options available through the state. Individuals, families, and providers all report that it is an “all or nothing system.” Those who need “slight” supports are not eligible to receive them under current DDD or Rehabilitation Services Administration – Vocational Rehabilitation programs (RSA-VR) eligibility criteria, and the state’s funding and supply of providers do not support individualized employment options. DDD’s provider database includes approximately 143 Day Treatment & Training (DTA) statewide providers – only 14 of these provide a Spanish language option, none offer American Sign Language (ASL). DTA programs range significantly in their pre-employment training offerings, and some are not accepting new clients. Predictably, service shortages are magnified in rural areas. For example, there are no pre-employment training DTAs accepting new clients in Anthem or Nogales.

Many of the job training programs in the state occur through group-supported (GSE) and center-based employment (CBE), where people with disabilities work together in the community or in a facility to train with tasks, such as clerical work, janitorial work, landscaping, or assembly work. There are approximately 47 GSE providers across the state, but only 17 are accepting new clients; 13 of them provide a Spanish language option. There are 22 providers that are currently offering openings in CBE.

Further investigation of the DDD provider database finds there are only about 18 individual supported employment (ISE) providers in Arizona offering individual supports to obtain and retain individualized, competitive-paying jobs in the community. The 2013 provider survey and 2015 focus group data find that many providers have stopped offering ISE because the funding does not support the costs and because employment supports are funded for such a short time. Consequently, only a small percentage of individuals could benefit. Individuals and providers state they had been hired competitively through ISE, only to be terminated soon after their supports were removed. One provider agency stated that with the current supports allowed by DDD, only 10% of her individuals could benefit.

As a result, operating DTAs, CBEs, and GSE is thought by providers to be more efficient in training individuals for employment. In 2013, out of 33,272 individual who received services, 7,471 were in day and employment services.[x] Of this number, 21% were in integrated employment options (e.g. GSE and ISE). In September 2014, 66.8% of DDD Employment/Day Program participants were in DTAs, 19.5% were in GSE, 11.5% were in CBE, 1.7% had an Employment Support Aide, and 0.4% were in ISE.[xi] With the exception of GSE all these services have trended downwards in utilization since 2011.

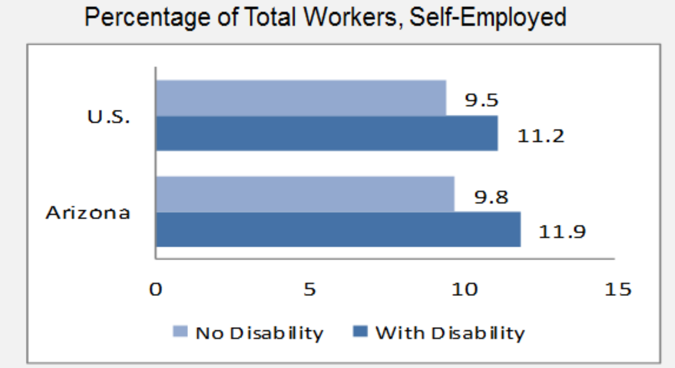
Many GSE sites pay below minimum wage. Arizona allows organizations to pay a work “trainee” less than the minimum wage, but the trainee cannot receive more than 7,560 hours classified in this status unless they move to another training program.[xii] However, organizations are continuing to pay individuals less than the minimum wage indefinitely or move them into day training. DDD reports that from 2009 to 2014 there has been an unprecedented increase (391%) in utilization of “Day Training-Intensive.”[xiii] Regardless, the Industrial Commission of Arizona (ICA) reports no complaints. Individuals and families are not asking for the minimum wage. A 2015 consumer with disabilities survey (Appendix C) indicates that only 18.9% of individuals with DD thought that workers with disabilities should be paid at least the minimum wage; 48.5% didn’t know what it was or how they felt about it and 29.5% didn’t care if they got paid the minimum wage or not - they just wanted to be paid something. Only 3.1% were against paying at least the minimum wage.

DDD has a best practice partnership in which the City of Peoria hires seven individuals with mild to moderate ID in a GSE arrangement to perform janitorial and landscaping work, paying more than the minimum wage. Peoria is one of the first cities in Arizona to create an employment program like this, a branch of the city's Adaptive Recreation Program, but it could serve as a model for others to emulate.

RSA-VR also offers programs to prepare individuals for employment paying at least the minimum wage. Due to state funding shortages where the full federal match of almost 1:4 cannot be received, it continues to operate under an order of selection - meaning that those with the most significant disabilities are served first and those that are considered to have less significant disabilities would have to be referred elsewhere. RSA-VR employment outcomes have been improving since FFY 2011. In 2014, VR served 24,385 clients, and posted a rehabilitation rate of 51% (56.2% for those with ID).[xiv] 1,338 clients that year were closed with successful employment outcomes. However, RSA-VR continues to struggle in obtaining successful employment services for individuals with autism. Their counselors would benefit from autism training and how to accommodate employment for them to succeed.[xv]

Self-Employment: An Underutilized option

Arizonans with disabilities, compared with those without disabilities, are more likely to choose self-employment as an option: 11.9% of workers with disabilities are self-employed compared to 9.8% of workers with no disability. Interestingly, one out of four of these self-employed workers with disabilities have cognitive disabilities.[xvi] In Arizona, RSA-VR consumers who are self-employed work, on average, 35 hours a week earning approximately $17 per



Source: American Community Survey, Public Use Microdata Sample (PUMS), 2009-2013 Arizona Persons File hour compared to those who work for a business without supports for an average of 31 hours per week for $11 per hour.[xvii] These findings of higher wages among the self-employed are replicated across RSA-VR programs nationwide.[xviii]

RSA-VR offers vocational counseling, training, assessments, job placement, and some assistance with self-employment. The agency can provide up to $18,000 in financial assistance for business start-ups and, through the use of contractors, offer assistance with pre-planning and business plan development. Additionally, S.E.E.D. loans operated through the Arizona Technology Assistance Program (AzTAP) are low-interest loans for up to $20,000 for equipment needed to start a business or telework. Funds from the S.E.E.D. program and RSA-VR can be combined to support entrepreneurial activities. Both funding options require strong business plans and committee review for approval.

The Arizona Commerce Authority (ACA) offers a customized small business checklist that simplifies the process of starting a business. In addition, small business development centers (SBDCs) funded by the Small Business Administration (SBA) offer classes with scholarships, incentive programs; and mentors who provide technical assistance and networking to those seeking self-employment.

Despite these available resources and incentives, utilization rates among people with disabilities – especially intellectual disabilities - across all agencies, are low. Between 2012 and 2014 Arizona’s SBDCs report that out of the 3,536 individuals and businesses they assisted, only 61 were minority-owned with a disability. In 2013 and 2014, 13 RSA-VR clients started their own businesses, down from 19 in 2009.[xix] <u>And, over the years, S.E.E.D. reports that only seven entrepreneurs with disabilities have benefitted from the program</u>. Among those who have succeeded in self-employment, none had an intellectual disability.

The number of individuals who take advantage of work incentive benefits remains small, possibly indicating that many are unaware of or do not understand the resources available. In addition, RSA-VR counselors may not steer individuals towards self-employment due to the complexity of starting a business, unless the individual specifically requests it. Those who do request it are referred to contracted providers who, with the consumer, determine self-employment readiness using start-up assessments. Most are deemed “not ready.”

Best Practices

Self-employment can combat barriers to employment facing PWDs, such as lack of transportation and employment opportunities, by giving individuals the opportunities and flexibility to create their own enterprise. There are strategies that Arizona can use to build self-employment. The establishment of an advisory group with measurable goals will help build or strengthen formal cooperation, collaboration, and awareness between agencies and organizations that play a key role in self-employment. These organizations could include RSA-VR, AzTAP, SBDCs, SBA, Social Security, Medicaid, incubators, foundations, universities, and non-profits. Providing RSA-VR counselors and high school transition staff with an education in self-employment and strengthening linkages to external resources that promote self-employment as a career goal for individuals with disabilities has the potential to boost self-employment outcomes. And lastly, understanding the individual and how he or she operates in his or her own environment with the support of others through a customized process called “discovery” can create a better employment fit for the individual with significant disabilities. It can open up previously unseen individual strengths and opportunities for self-employment, while promoting more champions in the process.

Additionally, there are some positive trends that can advance Arizona’s overall employment outcomes among individuals with DD. The recently passed Workforce Innovation and Opportunity Act (WIOA) increases individuals with disabilities’ access to high-quality workforce services to prepare them for integrated, competitive employment. Under WIOA, youth with disabilities are to receive extensive pre-employment transition services before they are deemed “unemployable.” Partnerships between VR agencies and schools are necessary to meeting the goals of WIOA. One such partnership exists through the Transition School to Work (TSW) program, jointly funded by RSA-VR and partnering school districts. TSW assists students with the most significant disabilities in 22 school districts throughout Arizona by providing job training and locating jobs in the community. In addition, the program facilitates referrals to post-secondary employment and education sites to help ensure a seamless transition beyond high school. The goal is to continue to expand the program and meet WIOA goals.

The Arizona Department of Education (ADE) has made shifts in focus with the Secondary Transition Mentoring Project (STMP), which formerly focused solely on building capacity for individualized education plans (IEP) transition planning teams within districts. Changed a little over two years ago, these capacity building groups and trainings now focus on the transition goals to employment or post-secondary options of all students. But, it is not clear how schools are integrating these types of plans within the school day and in curriculum.

Project Search (http://www.projectsearch.us/) prepares transition-aged youth with intellectual disabilities for competitive employment. The program provides real-life work experience combined with training in employability and independent living skills to help youth with significant disabilities make successful transitions from school to productive adult life. The Project SEARCH model involves an extensive period of training and career exploration, innovative adaptations, long-term job coaching, and continuous feedback from teachers, job coaches, and employers. As a result, at the completion of the training program, the goal is for students with disabilities to be employed in non-traditional, complex, and rewarding jobs. Approximately 90% of the 2014-2015 cohort of Project Search students achieved competitive employment and/or enrolled in postsecondary education.

Arizona is also one of only a handful of states to offer AZ DB101 (https://az.db101.org/). The on-line tool introduces individuals, family members, and agency and support staff to work incentive programs that help individuals with disabilities keep and earn more assets for their business without losing all of their benefits. It also calculates how self-employment, or any other job, may affect health insurance and social security benefits so that individuals are fully aware of their options. It should be noted that some assistance with the site may be required for some users due to the complexity of the information. It is not accessible to all workers with disabilities and many still do not know about this resource.

New federal regulations are requiring states to prioritize integrated services for everyone who has a disability. In response, Arizona is striving towards becoming an Employment First state. The vision of Employment First is that employment in the general workforce is the first and preferred outcome in the provision of publicly funded services for all working age citizens with disabilities, regardless of level of disability. It also advocates using typical or customized employment techniques to secure membership in the workforce where:

- employees with disabilities are included on the payroll of a competitive business or industry or are self-employed business owners;
- the assigned work tasks offer at least minimum or prevailing wages and benefits;
- and where typical opportunities exist for integration and interactions with co-workers without disabilities, customers, and/or the general public.[xx]

States that abide by these tenets post high employment rates for PWDs (e.g., WA - 87%; OK - 62%, 2013). It is important to note that APSE states that “Inclusion or exclusion of the specific term 'Employment First' does not determine whether a public system or agency has adopted Employment First principles. Such a determination can only be made in examining whether the underlying policies, procedures and infrastructure are designed for and ultimately result in increased integrated employment in the general workforce for citizens with disabilities” (http://apse.org/employment-first/statement/). There are several measurable outcomes including:

- Measurable increases in employment of citizens with disabilities within the general workforce, earning minimum wage or higher, with benefits
- Greater opportunities for citizens with disabilities to pursue self-employment and the development of microenterprises.
- Employers universally valuing individuals with disabilities as an integral part of their workforce, and including people with disabilities within general recruitment and hiring efforts as standard practice.
- Individuals with disabilities achieve increasing incomes, financial assets, and economic wealth.
- Funding sufficient so that quality services and supports are available as needed for long-term employment success.

INFORMAL AND FORMAL SERVICES AND SUPPORTS

According to the latest U.S. Census, Arizona has one of the highest poverty rates in the country. In 2014 an estimated 21.2 percent of all Arizonans were at or below the federal poverty line, ranking third worst, ahead of only Louisiana and Mississippi. Nationally, the poverty rate was 14.8 percent. Perhaps more worrisome, Arizona's poverty rate increased in 2014 while the rest of the nation stayed flat. In 2014 the share of state residents with half or less the income of the defined poverty line was also high in Arizona, 9.2 percent. That's about one in every 11 state residents. The national average was 6.6 percent, one of every 15 state residents. Arizona ranked fourth among states on this measure of extreme poverty. Among working-age adults, those between 18 and 64, Arizona was fourth-worst. Among seniors, those 65 and older, the state was fifth. For children 17 and younger, Arizona came in fifth. Despite the high number of Arizonans living in poverty, the safety net provided by the state of Arizona continues to be reduced.

Basic Assistance

In Arizona, many people with DD receive Supplemental Security Income (SSI). SSI provides cash benefits to enrollees. In Arizona, 1.5% of the total population was SSI beneficiaries with disabilities in 2014, lower than the nationwide average of 2.3%. Among total Arizona SSI beneficiaries (119,309), 87% (103,554) had a disability.[xxi] For those who are eligible for SSI as disabled or age 65+ but are not receiving a SSI cash payment, they can be eligible for SSI-Medical Assistance Only (SSI-MAO), which gives them medical assistance benefits.

There are additional benefits as well, but those are shrinking. Arizona has recently become the only state to cut its Temporary Assistance to Needy Families (TANF) program, an emergency cash program for families with children, to a one year lifetime limit. Only 14,004 families were served in 2014 with an average monthly payment of $204, down from 45,000 in 2005. At least 8.7% of these families have a member with a significant disability or care for someone with a disability. Arizona's recent budget also cut $4 million from the Child Care Subsidy Program that helps support the cost of child care, making it even more difficult for parents to find and maintain work. As of June 2014, 6,207 children are on the waitlist. Continued cutbacks in Child Care subsidies have resulted in almost half the number of families being served in 2014 as had been served in 2005. And, for those families who do receive assistance, the subsidy is below the provider rate. Thus, providers are allowed to charge families for the difference. The average co-pay for a parent with one child who is within 150% of the federal poverty line was $152 in 2013. [xxii]

In addition, the number of Arizonans who are food insecure has risen. While the monthly caseload decreased slightly over the previous year to a total of 454,123 households in June 2014 (over 1 million people); the monthly caseload was 45 percent higher (140,997) than the FY 2009 average monthly caseload. In fact, the state has topped 1 million individuals being served in 66 of the past 69 months. In August 2015, the average monthly benefit amount was $121. A wait list is in effect for this program.[xxiii] Individuals with disabilities are more likely to benefit from nutrition assistance programs, and they are automatically eligible if they qualify for SSI. For example, in 2013 18.8% of Arizonans without disabilities were receiving food stamps, below the 22.6% of people with disabilities who receive these benefits.[xxiv]

Short-Term Crisis Services provide help to households experiencing an emergent need that cannot be met with their own income and resources. To qualify for services, households must have income less than 125 percent of the federal poverty level or 150 percent of the federal poverty level if there is an elderly or disabled household member. Help includes emergency shelter, case management, eviction prevention or move-in assistance, utility deposits or payments, rent payments, and other special services appropriate for securing and maintaining employment. In 2014, 10,812 received emergency shelter services, 39,797 received utility assistance, 1,932 benefitted from eviction prevention, yet only seven special needs households received assistance.[xxv] It is unclear whether people with disabilities and their families even know this program exists.

DDD Home and Community-Based Services (HCBS)

Arizona has one of the most cost effective Medicaid programs in the country, due primarily to a high percentage of people living with their families. In 2013, Arizona's HCBS program spent over $707 million, or $21,376 per person, which is 60% less than the national average per person cost ($47,786). Arizona has consistently ranked #1 by UCP for its provision of Medicaid services to keep people with DD living in their communities. The DDD caseload continues to rise. In 2014, 33,933 individuals with DD received HCBS through DDD - the majority of services were provided in the home: 87.8% live in their family's home, 7.7% reside in group homes, 3.9% live in a child/adult developmental home, and 0.5% live at Coolidge, the only large state institution in Arizona.[xxvi]

Arizona supported 19,002 families through HCBS in 2013, a larger caseload than in most other states. There are no wait lists for most HCBS services, although there were 413 individuals waiting for residential services in 2013.[xxvii] For ALTCS-eligible individuals with DD, HCBS can pay for case management, attendant care, homemaker, respite care, habilitation, therapy services, residential, and employment services. The most frequently utilized service in Arizona is attendant care services. Arizona is one of the few states where primary family members are allowed to be hired in this capacity.

While there is not much opportunity for self-direction in HCBS services, "Agency with Choice" does give members at least one self-direction opportunity. "Agency with Choice" offers ALTCS members, or the member's Individual representative, the opportunity to play a more active role in directing their own attendant care. The member enters into partnership with the provider agency, the provider serves as the legal employer of record, and the member acts as the day-to-day managing employer of the direct care worker. This gives individuals the ability to advocate for themselves and have more control over their environment.

The Direct Care Workforce

The need for trained direct care workers (DCW) will continue to rise with the number of individuals with DD living longer. Individuals with DD often see professional staff as friends. When staff turnover every six months to two years, it becomes difficult for the individual who has to say good bye to someone they considered a “friend” and to re-teach another worker. This can be especially hard among those who thrive on routine, but the turnover of these individuals and others is systemic.

Why are they leaving? Often, individuals job hop. They stay in the same profession but change organizations. Those who remain with the same organization for years cite a more supportive leadership team and a family environment. In fact, what is available to DCWs can vary significantly from one organization to the next. Some organizations offer very little training beyond what is required for licensing. DCW focus group members requested training in disability-specific areas, such as autism, and to provide more opportunities to advance their education and confidence with some individuals. It was discovered that often job coaches did not have training. An individual stated it wasn’t necessary since her job was “commonsense.”

On the other hand, 2015 provider survey data (Appendix D) indicate that 74% had received person-centered care training, 88% are satisfied with their jobs, and 83% weren’t likely to leave within one year. It is no surprise then that individuals have positive views of people with disabilities. The overwhelming majority believe in their ability to date or marry, and live and work independently with support. Yet, the minority, 47%, think that individuals with disabilities are capable of representing themselves as advocates on issues critical to their quality of life; 28% neither agreed or disagreed, 22% disagreed, and 2% didn’t know. It is important to note that only 30% of the sample is DCWs – the rest are in administration or are executives.

Besides a lack of training and knowledge of self-determination practice, focus group and survey data also show that there are no career paths overall and a lack of benefits. Those individuals who have been working with disabilities for less than eight years and those who have been working for 25 years or more are basically paid the same – the median hourly pay is approximately $12.50 for both groups.

Proven strategies to increase retention involve peer mentoring, offering career ladders, giving incentives or bonuses (like a day off of work), and offering a supportive environment that gives them access to hands-on training and educational opportunities for personal growth.[xxviii] Some organizations are already doing these things, but it is not part of the culture. Work needs to be done to support Arizona DCWs.

Aging Services

Arizonans with DD are living longer, yet the majority of these aging individuals are not enrolled in DDD services. In 2014, census numbers show there are approximately 1.1 million Arizonans who are 60+, comprising 21.6% of the population. That number is expected to double by 2030. Some of these 60+ individuals and those who have disabilities qualify for services through the AAAs, including home delivered meals, congregate meal programs, adult day care, housekeeping, personal assistance services, and respite care. However, these programs are at capacity, serving those with the most critical needs first (e.g. poverty, frailty). Arizona's local aging agencies have seen their federal and state funding reduced by 19 percent since 2010, and the statewide waiting list for services has climbed to 2,345. That doesn't include the unknown number of people who didn't bother to sign up after they learned they would have a year's wait. In Maricopa County, home to Phoenix and the state's most populous county with 3.8 million people, the waiting list has grown by more than 800 percent in three years.[xxix]

Currently, 5% of DDD clients are 55 and over, and that percentage is expected to grow.[xxx] In 2013, 600 clients 50+ were served by only two DDD Premier Units dedicated to aging adults with DD. Now the Premier department has been disbanded and other support coordinators have been cross-trained in aging to address increasingly complex health situations among older adults with DD. For example, those with Down syndrome are likely to develop Alzheimer's disease as they advance beyond the age of 40, increasing the number of incidents of Alzheimer's and related dementias reported, and requiring more restrictive services and support. Some DDD support coordinators have been trained by Division of Aging and Adult Services (DAAS) staff on Alzheimer's and related dementias to ensure consumers are receiving the services they need to maintain safety.

According to DDD, Arizona's aging caregiving population is directly impacting the provision of services. In the majority of cases, the adult with DD has always lived at home with his or her parents. When health issues arise with the primary caregiver(s), there is often no other family or friend able to provide care. For those with access to DDD services, the division has to identify emergency placement for this member who has never been away from home. Once the member is placed, he/she becomes depressed and either isolates or lashes out because of this life altering event. As Arizona's DD population continues to grow and as caregivers age, this problem will continue to grow.

Independent Living

Independent living skills such as doing the laundry, cleaning, washing dishes, and taking out the trash are requisite skills to function in the "real world" and have a direct connection to post-school education, employment and success after high school. Yet, many students with disabilities do not learn them, making it even more difficult for them to function independently. Fifty-seven percent of the students in a 2014 youth transition study, regardless of disability, can prepare their own breakfast and lunch, but only half clean their own rooms and one in three do their own laundry. There are also gender and disability differences in these household roles. Females are more involved in household tasks than males, while few students with autism complete any household tasks other than preparing their own breakfast or lunch. In addition, two out of three cannot comfortably navigate outside of their homes on their own, and 56% need at least "a little help" looking up numbers and using the telephone. Disability experts and family members confirm that, overall, students with disabilities struggle with independent living skills that impacts their ability to manage on their own.

Financial literacy is also critical to independent living. Unfortunately, many struggle with these skills. Only 39% of families in the 2014 transition study give their children with disabilities checking accounts or debit cards, and expect them to manage their own budgets. Only 29% of youth can go to the store and buy a few things by themselves, and one in three cannot count change. In a 2015 survey of adults with DD, 64% have a bank account with their names on it, but focus group findings reveal that those with guardians and fiduciaries still control how the money is spent. Some individuals had no idea what the balance was of their accounts.

DDD funded providers and five Centers for Independent Living (CILs) across the state teach independent living skills. While the majority of consumers served do not have DD, there is a trend towards increasing programs and services for this population. For example, ABILITY 360 offers an independent living program for people with DD who don't qualify for DDD services; however, few have enrolled. The program teaches how to manage transportation, manage a budget, and move into an apartment. Also, interview data with providers find there are very few "real world scenarios" set up in a home environment that teach individuals how to live independently. The few programs that do offer this outside school are private pay.

Informal/Peer Support Programs

Eighty percent of caregiving is provided by families, which helps support individuals with disabilities to live in the community. In Arizona, there are 855,000 caregivers providing over $9 billion of care to those with a disability, representing about 14% of the general population[xxxi] - 30% of these 855,000 caregivers are ages 56 and older, according to a 2015 Arizona poll (Appendix E). This work is appreciated by Arizonans. The same poll shows that 79% of Arizonans think that family members who help care for someone with a significant disability should receive financial assistance from the federal government.

Arizona's DDD program directly supports families in two ways. It allows primary family members to serve as paid personal assistants. It also provides families with 600 respite hours per year. In addition, the Family Caregiver Support program (FCSP), through DES, provides case management, counseling services and support groups, caregiver training, respite, and home modifications/supplemental provisions through AAAs. <u>The respite program is always overspent.</u> In FY 2014, the FCSP served 21,000 caregivers with support services, including respite care, support groups, stress management training, and other supplemental services that complement the care of the caregiver. The FCSP Partners in Service database was created for family caregivers, individuals living with a disability, and older adults to access supportive services at no charge. These agencies offer trained caring volunteer services free-of-charge for individuals, family caregivers and adults living with disabilities to help them to continue living in their own homes.

In spite of all these available services, families report often being overwhelmed by information and confusion about what to do. They feel lost inside a very complex system. A 2014 parent survey finds that over half receive some type of informal support from friends and neighbors; they are just not getting help often enough - only 31% of parents receive help <u>at least</u> 2 to 3 times per month. The most frequent requests for informal help are recreational and social opportunities, information and advice, and help with transportation (38%). In fact, those parents who have informal help with transportation are about 10 times more likely to go to school events than those parents who have no informal transportation assistance.

Peer support is critical to helping individuals and families feel supported. Peer mentors provide positive role modeling, exhibit strong coping and problem-solving skills, and share the benefit of their knowledge about community resources. The five centers for independent living offer peer support, as does Raising Special Kids (RSK) and Pilot Parents as well as some provider groups. It is important to note that peer-support services in DDD are not woven into the care system, like the delivery of mental health services. In mental health terms, peer support services are designed to provide greater structure and intensity of services than is available through community-based recovery groups. Peer support in behavioral health refers to an individual who is, or has been, a recipient of behavioral health services and who currently provides behavioral health services to individuals enrolled in the public behavioral health system; fully one-third (34.5%) of members with SMI statewide utilized services fit into this sub-category.[xxxii]

Cultural Implications

2015 focus groups with Latino families demonstrated that they “take care of their own,” and typically do not avail themselves of formal residential services. Often these families have a difficult time accessing services based on language barriers. Some complain of translators not translating accurately or having to translate through their children. Undocumented immigrants are ineligible for programs or medical care through AHCCCS; they oftentimes have no idea how to help their family member with disabilities. Some of these families have even quit their jobs to care for loved ones. These families are adversely impacted by poverty (25% of Latino households) and have a difficult time, or are afraid, to advocate for themselves to receive needed assistance.

Similarly, the majority of Arizona’s Hopi and Navajo communities report a dearth of formal disability services while they continue to face high poverty rates, 33.3%. They are unaware of home modification funding to receive such basic necessities as indoor plumbing. They are also often victims of predatory loans to acquire such services. A 2011 report by NADLC found that tribal members with disabilities continue to face stigma due to their disabilities. They regularly request assistance in accessing disability services programs, such as Social Security, health care, special education, housing, and employment. There are extensive problems among children with disabilities in state and Bureau of Indian Affairs (BIA) - funded public schools; some schools provide no transition planning for secondary education students. Often, individuals faced transportation barriers to and from, or physical barriers at the offices where they are trying to gain access to services.[xxxiii]

Faith-Based Initiatives

The Governor’s Office of Faith-Based and Community Initiatives advances informal initiatives to address community problems. In one such initiative, people meet regularly to discuss the quality of life for residents within their communities. Approximately 40 of these Community Network Teams in rural/urban areas across the state identify gaps in local human services and work to focus all available resources on eliminating those gaps by connecting faith-based and community organizations in targeted areas. Ending hunger, poverty and violence, or improving transportation, health care, child safety or career training are just a few of the issues the groups work to resolve collaboratively.[xxxiv]

Best Practices

The goal of the National Community of Practice, funded by the Administration on Intellectual and Developmental Disabilities (AIDD), is to support family caregivers of individuals with I/DD.[xxxv] Because of the role families continue to play in the lives of their family members with DD, the belief is that future policies and practices must reflect the family’s role as an integral part of the support system. Supporting the family is actualized as a set of strategies targeting the family unit but ultimately benefiting the individual with I/DD. Supporting families requires a comprehensive and coordinated infrastructure that includes the following strategies:

- Providing education and training on how to access and develop options, opportunities and best practices within and outside of disability services
- Establishing connections to other families and to self-advocates
- Creating collaborative processes to plan, explore, problem-solve and support a vision for the future for their family member with a disability and entire family system, starting early and continuing across the lifespan
- Build mechanisms to assist in navigating and accessing services and supports within and outside of disability service systems
- Lean how to recognize mechanisms to address issues related to poverty
- Leaning to local funding for goods and services specific to the support and/or caregiving role for the person with I/DD across the lifespan (e. g., respite, home modifications, cash assistance, assistive technology)
- Planning for crisis prevention/intervention for families and other caregivers
- Training to enhance the family’s ability to advocate for services and policies
- Establishing a system for accountability and quality assurance through data collection, evaluation and feedback loop components

There are also peer support strategies that assist helping individuals to meet their personal goals. Utilizing a micro-board strategy can better support people with DD. A micro-board is a small group of committed family and friends who join together with an individual with a disability to create a non-profit organization. Individuals with disabilities and their families typically form micro-boards to serve as natural circles of support for individuals with disabilities, regardless of age. Micro-boards that serve as natural circles of support help identify opportunities for community inclusion and membership, generate resources outside government programs, and establish a formal commitment between the individual and the micro-board's volunteers. When the individual who is forming a micro-board receives services and supports through a government program like a Medicaid Home and Community Based Waiver, the micro-board may choose to become the provider of those services and supports.[xxxvi]

INTERAGENCY INITIATIVES

Arizona's network of community-based services and supports for people with developmental disabilities and their families, called the system of care, provides a wealth of resources assuming the family/individual knows how to locate them. For example, DDD is entitlement-based, meaning that there are no waitlists for services. Further, there are parent training and information centers that help parents learn about the resources available. And many providers have stepped up to fill in gaps in services and have valuable resources to share with individuals and families. But despite all of these available assets, the lack of coordination between agencies, individuals and families poses tremendous barriers to community living.

There is not a single phone number to call or a website to access all these services; multiple steps are required. This creates significant barriers to families and individuals whose options and life choices are dictated by the information they receive. Some agencies may give help to them, some may not. Some are so overwhelmed by the system's complexity they may not access the services that could help them, thus narrowing their choices. For instance, in the case of special education, although it is important to have agencies represented at the student's IEP to ensure a comprehensive plan for the student, families often don't know who to invite. And, some schools don't encourage invitations to outside parties. Most agencies report that communication between agencies and with schools is a significant problem due to staff turnover and large caseloads.

There is also confusion among agencies involved in interagency agreements over their respective roles when a child is dually diagnosed. Specifically, is a child's behavioral health diagnosis related to a developmental disability or is it a separate emotional disability? The answer to this critical question draws on different funding, programs, and services. In addition, multiple programs include care coordination or case management, resulting in unnecessary complexity for families. Families report that sometimes they have to coordinate the care coordinators across these systems.

To address some of these issues, some federally-assisted and state-funded services and programs have chosen to collaborate to tackle specific issues and challenges. Some of these collaborations are below:

- The Arizona Community of Practice on Transition consists of agencies involved in Arizona's system of care, including ADE/Exceptional Student Services (ESS), RSA/VR, Tribal 121 programs, DDD, DBHS, Office of Children with Special Health Care Needs (OCSHCN), RSK, ADDPC, and a youth advocate. Its mission is to break down silos and improve the life-long outcomes for youth with disabilities transitioning into adulthood. They have monthly meetings to inform and educate the public and one another on what each agency does; they address unmet needs through collaboration; evaluate the transition process and system; and remove barriers and recommend systemic improvements. Key issue areas include: meaningful youth involvement; increasing post-secondary education options/success; improving employment outcomes; outreach to child welfare/healthcare issues, juvenile justice, and mental health systems; addressing transportation barriers; and procedure and policy review to update/align organizations when possible There is recognition among this group, however, that meeting with no action will bring about only minimal change.

- Arizona was one of six states to receive the Achieving Success by Promoting Readiness for Education and Employment (ASPIRE) grant to promote interagency collaboration. It is a grant that is led and housed by ADE’s ESS and administered over a five-year period (2015-2019) by the Governor’s Office for Children, Youth and Families to parents and children living in poverty. The goal is to determine the efficacy of the program and its impact on post-school outcomes among 1,000 14-16 year old youth whose families are on SSI. Some of the interventions include parent and youth training on advocacy, community resources, and educational and employment opportunities. The program also offers paid employment for the student while he or she is still in high school, self-determination training for the student and family, financial management education and training for families, and case management support to guide them through the maze of resources and public benefits. The case manager will also facilitate all of these interventions, as well as interact with school personnel, vocational rehabilitation counselors, and all other providers of services. It can serve as an aspirational model for Arizona’s current transition system.

- Employment First is a coalition that was recently created to advance integrated employment for all people with disabilities. It has representation from many different stakeholders in the community. The group is co-chaired by ADDPC and DDD. Other members include AHCCCS, advocates, educators, family members, University Centers for Excellence in Developmental Disabilities (UCEDDs), and provider groups. Its strategic plan is comprehensive and uses a multi-pronged strategy to increase employment outcomes.

- In 2012, the Sonoran UCEDD and ADDPC partnered with DDD to launch a "Picture of Life", a statewide project to improve outcomes for foster youth with DD in the DDD system. The goal of the project is to prepare youth with DD who are about to exit foster care to exercise choice, promote the use of informal and community supports and to make knowledgeable decisions on community living and work. In doing so, the project intends to improve transition outcomes for these youth.

- Arizona’s First Things First was a recipient of the Early Childhood Comprehensive Systems grant. The purpose of this grant is to improve the healthy physical, social, and emotional development of children during infancy and early childhood; to eliminate disparities; and to increase access to needed early childhood services. By engaging in systems development and integration activities and utilizing collective impact approaches, the goals is to improve the quality and availability of early childhood services at both the state and local levels. Arizona has focused on coordinating the expansion of developmental screening activities in early care and education settings statewide to achieve measureable improvements in the rate at which children with developmental concerns or delays are identified and in the rate at which they are connected to services and support that address their concerns or delays. Representatives from school districts, DES, DBHS, providers, ADE, tribal liaisons, AHCCCS, ADHS, higher education, health care facilities, and family members are working towards creating a shared data and referral system.

- The Division of Behavioral Health Services has developed a "systems of care" approach to planning and service delivery which engages families as well as the child welfare, developmental disability and juvenile justice systems. While families continue to receive services from independent agencies, planning and coordination are intended to ensure that each family has one integrated service plan meeting their goals. However, there still remains a lack of integration between acute care and behavioral health services resulting in a lack of emphasis on the physical health concerns of those who suffer from serious mental health conditions.

In areas of employment, beyond Employment First, the coordination of the private sector and disability organizations has not been diffuse. The Workforce Arizona Council was created to provide guidance to the Governor and the Arizona State Legislature regarding workforce development issues. Appointed by the Governor, this diverse group includes people from a variety of backgrounds, including public and private sector, city and state government, large and small business, industry, youth groups and higher education. ADE, DDD, RSA-VR, and providers are notably absent from this list. In addition, the mission of the Arizona Governors State Rehabilitation Council is to advise, evaluate and partner with the public vocational rehabilitation program in support of improving access to employment and promoting a diverse workforce statewide. Members on this Council include providers, ADE, DDD, Arizona Center for Disability Law (ACDL), ADDPC, school district, higher education, and ADHS. However, large and small business and industry, and individuals/family members are missing from Council membership.

AZ Links, Arizona's ADRC employs a no wrong door approach to provide information, referral and access to services through the members of its AZ Links Consortium. Key partners include DES, DAAS, DDD, AAA, and AHCCCS. The central website, www.AZLINKS.gov, serves as a virtual resource center where individuals can access information through a self-help web portal and find community AZ Links partners for counseling and assistance on long-term support options. Arizona currently has six regional partnerships, covering all 15 counties (excluding tribal areas). Unfortunately, with no money to make significant changes, DD and mental health continue to be left out of the dialogue. The federal government is opening up new funding and tweaking existing funding to force agencies to demonstrate that they are working on partnerships with Medicaid agencies.

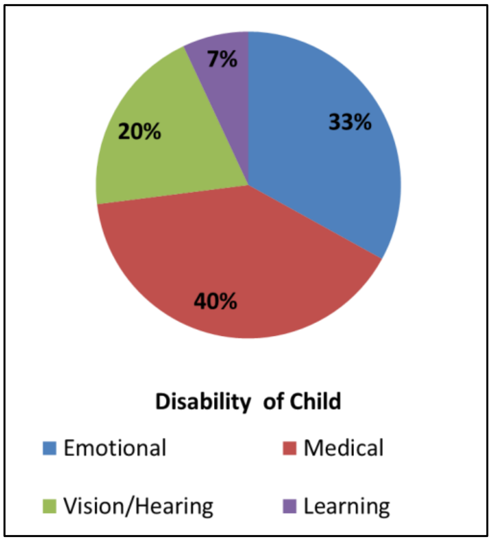
The Governor's Advisory Council on Aging (GACA) is a statewide body of fifteen members appointed by the Governor to serve three-year terms. The Council's purpose, by statute, is to “advise the Governor, Legislature and all State Departments which the Council deems necessary on all matters and issues relating to aging, including the administration of the State Plan on Aging.” The GACA mission is to enhance the quality of life for older Arizonans.
The Council advises policymakers and state agencies, and works with local communities, private enterprises and older adults across Arizona to accomplish its mission. Current issues include affordable and accessible transit options, Alzheimer's disease and related disorders, state and federal legislation impacting older and vulnerable adults, and support for mature workers age 50+. The Governor's Advisory Council on Aging has been instrumental in providing training and awareness programs concerning vital aging issues. Currently, there is no presence of DD issues among this group.

QUALITY ASSURANCE

There is significant evidence of discrimination towards people with disabilities in Arizona. The Division of Civil Rights Section ("DCRS") of the Attorney General's (AG's) office enforces the Arizona Civil Rights Act ("ACRA"). ACRA prohibits discrimination in employment, housing, public accommodations and voting. The DCRS investigates, mediates, and litigates complaints alleging violations of ACRA and seeks to reduce discriminatory conduct through education, outreach, conflict resolution services and mediation training programs. In FY 2015, the DCRS investigated 1,412 discrimination charges that potentially violated ACRA. The highest number reported, 235 (16.6%), were disability-related and intersected issues related to residential abuse, special education, employment, and housing.[xxxvii] This pattern of discrimination impacts diverse members of the community. Following are groups that merit special attention.

Division of Child Safety (DCS)

Over the past twenty years, studies have found that children and youth with disabilities experience a higher rate of maltreatment than children and youth without disabilities and are disproportionately represented in the child welfare system.[xxxviii] In 2013, 4,001 (30%) of children in Arizona's DCS system had a disability. Of these, 40% had a medical condition, 33% had behavioral issues, 20% had a vision or hearing impairment, and 7% had a learning disability. Children with ID or physical disabilities only represented 20 total cases. [xxxix]



Arizona is currently facing a crisis in its child welfare system that disparately impacts youth with specific disabilities. After 6,500 Child Protective Services (CPS) cases were found to never have been investigated, in 2014 CPS was replaced with the new Division of Child Safety (DCS). To promote better practices, an audit of DCS was conducted by Chapin Hill, University of Chicago and the report was released in July 2015.[xl] The following are the most noteworthy findings:

- *Child Abuse trends*: While national trends show a decrease in abuse and neglect reports, Arizona's trends reveal a sharp increase in the number of neglect victims since the economic downturn beginning in 2008.
- *Group home abuse reports*: In 2013 there was an increase in reports about group homes and residential facilities which led to an increase in the number of victims in foster care.
- *Out-of-home care*: Substantiated cases of neglect led Arizona to place more of these children in out-of-home care than almost every other state, and require it to spend a greater percentage of its overall budget on financing foster home and group home care.

The cost associated with these placements in 2014 was about 60% greater than the total child protection budget just 10 years earlier. As a result, the state has less flexibility to invest in other parts of the system.

- *Length of time in foster care:* In general, after children are removed from their families, DCS' goal is either reunification or adoption. But, the rate of reunification is lower in Arizona than it is in comparable states, meaning kids spend more time in foster care. However, they are more likely to be adopted than in other states. The majority, 52%, were in out-of-home placements between 31 days and 12 months, while 41.6% were in placements for over 13 months.

Since the reorganization, continued high caseloads are affecting DCS workers' abilities to serve each child effectively:[xli]

- 2,269 children in foster care did not receive a required monthly visit from DCS in March, 2015.
- 1,091 parents with a case plan to reunify with their children did not receive a required monthly visit by DCS in March, 2015
- 616 foster homes did not receive a required quarterly visit from their licensing agency between October, 2014 and March, 2015.

In June 2015, there were 18,059 children in state care - 7,558 of whom went into unlicensed kinship care. The rest went to foster care, group homes, institutions, and shelters. Minority groups are overrepresented in out-of-home placements: 36.4% are Latinos, 36.1% Caucasian, 13.6% African American, and 8.3% Native American. The average number of placements for these children is two.[xlii] But, some children are so impacted by the severity of the abuse they suffered that they become unable to form meaningful relationships or to respond to services, e.g., they have emotional disabilities. These children tend to go through multiple placements with numerous individuals and agencies. One child had been placed 42 times - in fact, of the 751 children who aged out of the system in 2013, over half had at least four different placements, and 35% were in more than five placements.[xliii]

Children with disabilities are 1.7 times more likely to be abused or neglected than children without disabilities. These numbers may be much higher, as many cases of abuse and neglect are never reported to the authorities.[xliv] The recently released SB 1375 report and findings from previous studies indicate that youth with disabilities have a higher average number of out-of-home placements and are less likely to have a concurrent plan for their permanency outcomes than their non-disabled peers. They make up the majority of older youth in care, and make up a substantial proportion of all children and youth in the child welfare system.[xlv] Increasing the support available to foster parents, group homes, and biological families of children with disabilities is a critical need that could be addressed through more inclusive research practices and policy-making. And given the high prevalence of children and youth with disabilities in the child welfare system, child welfare workers and managers should receive mandatory training and support in order to increase their knowledge and skills about disabilities, disability services, and resources in their communities for people with disabilities.[xlvi]

In addition, every year in Arizona, more than 700 teenagers “age-out” of the foster care system, meaning they have reached their 18th birthday without finding a permanent family. Fewer than 3% of them will graduate from college. Without a family to turn to for support, many of them will face high rates of poverty, unemployment, incarceration and homelessness.[xlvii] In January of 2014, 213 youth aged 24 and under were reported to be living on the streets, and another 504 were living in emergency shelters or transitional housing throughout the state.[xlviii] While there are resources that target this group, such as the Youth Opportunity Initiative that works on coordinating systems, and the previously mentioned Picture of Life program, there is little to no awareness of disability services and other available resources among many of these youth who are not enrolled in any state disability services.

For infants and toddlers new to the DCS system, other issues arise. Rapid development during the first years of life makes very young children extremely vulnerable to the negative and long-lasting impacts of maltreatment. Early identification of developmental delays, followed by appropriate, timely support services can help reduce or alleviate maltreatment’s impact. In recognition of the vulnerability of babies in the child welfare system and the importance of detecting developmental problems early, the Child Abuse Prevention and Treatment Act (CAPTA) requires that states have procedures for screening and, if necessary, referring young children to the early intervention evaluation and services mandated by Part C of the federal Individuals with Disabilities Education Act (IDEA). In Arizona, developmental and mental health screenings for all maltreated infants and toddlers are not required.[xlix] Work needs to be done to ensure that all maltreated children receive mental health services and regular medical care, including the full schedule of immunizations, regular dental exams, and screening for vision and hearing problems and developmental delays, to help maltreated infants and toddlers achieve their full potential.

Adult Protective Services (APS)

In 2013, the national rate of violent crime against persons with disabilities (36 per 1,000) was more than twice the age-adjusted rate for persons without disabilities (14 per 1,000). Persons with cognitive disabilities experienced the highest rate of violent crime (67 per 1,000) among all disability types measured, a level similar to that of previous years. Serious violent crime—rape or sexual assault, robbery and aggravated assault—accounted for a greater percentage of all violent crime against persons with disabilities (39%) than persons without disabilities (29%). Nearly a quarter (24%) of violent crime victims with disabilities believed they were targeted due to their disability.[l] Despite data to the contrary, in Arizona in 2015, only 10% of people with disabilities self-reported that they had been a victim of crime. Focus group data, however, reveal that those who navigate their communities by themselves are at higher risk.

There were 11,599 reports of vulnerable adult mistreatment investigated in FY 2014. This represents an all-time high for the program and a 79% increase since SFY 2010. Family members make up 31% of the alleged perpetrators. Neglect by self (35%) and abuse, neglect, and/or exploitation by family members (31%) continue to be the leading causes for protective services investigations. More than a quarter of APS cases (3,084 or26.6%, are adults between the ages of 18-59; the highest rate since 2007. In 2014, Coconino (35%) and Graham (33%) counties had higher rates of APS cases for adults ages 18-59 than other counties - a trend that has continued since the earliest available report in 2011.[li] Statewide, ADHS data show that there have been no enforcement actions related to the quality and safety of the 998 adult DDD group home providers in the last three years; however, ACDL reports that they receive a number of abuse and neglect calls related to group home residents. That is corroborated by the AG's office.

From SFY 2012 to SFY 2013, the number of reports of vulnerable adult abuse, neglect, or financial exploitation to APS increased by 27%. More recently, the growth in APS reports has slowed; for SFY 2014 the number of reports increased by 4% above SFY 2013. However, the previous and continued growth in the number of reports has made it difficult for APS to manage the increased investigative workload within caseload and timeliness standards. Specifically, in July 2014, the statewide average caseload was 149. The National Adult Protective Services Association found that, in 2012, the national average was 41 cases per investigator, with a median of 31 cases per investigator.[lii] In SFY 2015 APS was appropriated 31 additional staff to reduce the number of cases to 109 per investigator in SFY 2015. For SFY 2016, DES has requested an additional 28 FTE. The addition of these staff will reduce caseloads to an average of 64 per investigator, still well above the national average.[liii]

FCSP is coordinating with APS on the preventative side, so that caregivers at-risk can be identified for assistance and support. DAAS also has an agreement with DDD that outlines the roles and responsibilities of each division as they pertain to incidents of mistreatment of vulnerable adults receiving DDD services or eligible for DDD services. The agreement also outlines the process for information sharing. Joint investigations are conducted when necessary.

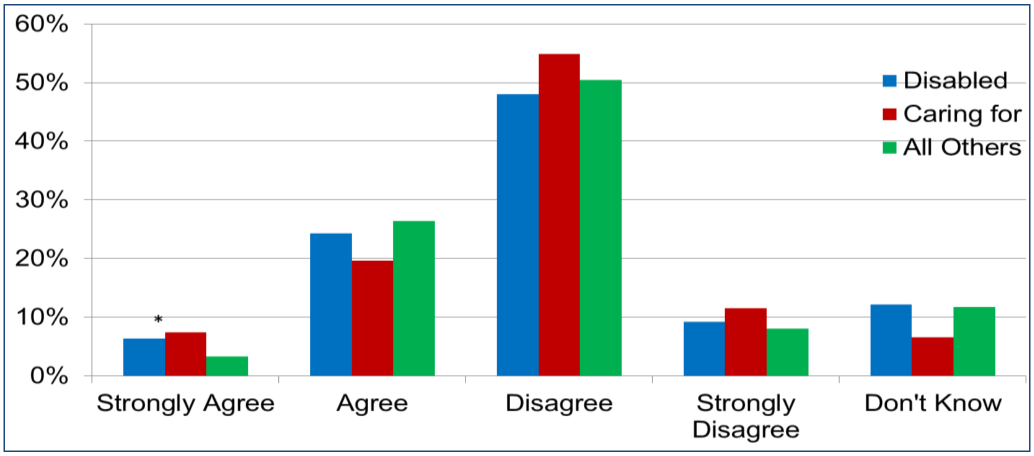
Fair Housing

Disability complaints make up the largest number of complaints submitted to the U.S. Department of Housing and Urban Development (HUD) nationally and statewide, as well as to the Arizona AG's office. They make up 66% of the fair housing cases reported in Arizona since 2009.[liv] In FY 2015, as a preventative measure, the ACRAB published a letter encouraging home builders and home buyers to consider single family residences that contain characteristics that make the home accessible to people of differing levels of physical ability. This "inclusive housing design" was recommended by the Board because houses with these features remain accessible or are inexpensively transformed in cases of injury or illness.[lv] HUD also recently awarded the Arizona Fair Housing Center and the Southwest Fair Housing Council approximately $1.2 million to fight housing discrimination through enforcement, information, education, and research.[lvi]

Education

Focus groups and survey data show that there are significant issues concerning special education in Arizona public schools. The state continues to struggle with special education complaints related to schools not following the IEP and not providing the supports necessary. The AG's office, RSK, and ACDL report a significant amount of time spent on special education issues. With the teacher shortage magnified in special education, there is confusion among many parents and students surrounding IDEA, the IEP, the transition process, and the outside resources that are available. In addition, the shortage of quality occupational, physical, speech, and autism trained therapists (i.e., OTs, PTs, STs) across the state compounds the problems experienced in education and will continue to do so unless systemic changes are made.

A recent poll finds that most Arizonans (60%) disagree with the statement that children with disabilities should be educated in the same classroom as other kids their age. There was little difference in response between caregivers and students with disabilities.



Focus group findings highlight why there is disagreement. Families report that their student is placed in a mainstream classroom with little support. While other children are reading or learning math, their child is given busy work that does not advance them academically, such as putting together puzzles. A few parents stated that they had to pay for a tutor when the student was finished with school to learn to read and write. It is no surprise then that parents of children with disabilities are the largest group of Empowerment Scholarship Account (ESA) holders that enable them to leave the public school system. ESAs allow parents to use public funds to pay for a tutor, home schooling, or other private school option for their child.

Transportation

In 2012, the Arizona Department of Transportation (ADOT), as required by Title II of the ADA, conducted a comprehensive statewide survey to evaluate current accessibility along existing public rights-of-way. The field survey included sidewalks, curb ramps, and pedestrian crossings (e.g., median treatments, over/underpasses, signals, handrails). It found levels of non-compliance as follows: 17% of sidewalks, 81% of curb ramps, 73% of traffic islands, and 5% of handrails.[lvii] ADOT's public comment and this study's 2013 and 2015 focus group results corroborated the lack of accessible sidewalks and curb cuts that allow people with disabilities to freely access their communities, especially in rural areas. Focus group participants reported that in many cases there are just dirt roads and no sidewalks at all.

The majority of NCI members (68%) normally get rides from family members to go places. In the 2015 consumer survey, individuals used para-transit or public transportation more often (36%). The transportation mode a person uses is dependent on where they live and with whom they live. Areas with no service require familial or staff support. Research indicates that low-income and African American persons with disabilities are less likely to get rides from household members; public transit has a more substantial role to play in their mobility than it does in the mobility of others with disabilities.[lviii] The availability of affordable transportation is a top concern for both individuals and families. NCI data from 2014 show that 64% of individuals always have a way to get places when they want to go somewhere; but one in three don't. While still positive when compared to other states, these percentages make Arizona the worst performing state in reliability of transportation of the 28 states, according to adults with DD.

Health Care

There are several barriers to access to health care as reported by ACDL and focus group findings. Many individuals with DD are being denied coverage for medically necessary items, treatments, durable medical equipment, or needed supports. Families who aren't fluent in English state they have a very difficult time communicating with their doctor and other medical professionals and often feel that they are rushed by the medical professional. Some families are not provided adequate therapy services or supports under AHCCCS. Even when they are prescribed them, there is such a shortage of STs, OTs and PTs across the state that some individuals have reported waiting as long as one year to start services. The supply has not kept up with the demand. DDD has also recognized the issue and has increased rates for all therapy services, as well as adopted incentive rates for the most underserved parts of the state – Pima and Santa Cruz counties. Those changes won't go into effect until 2016.[lix] ACDL has also prioritized health care access issues to constituents in its five year plan.

Given the rising number of individuals diagnosed with autism, Arizona's complex health care system, and a lack of knowledge of autism among professionals, the Governor's Office established the statewide Autism Spectrum Disorder (ASD) Advisory Committee. ASD consults with a broad range of stakeholders to provide recommendations to strengthen services for treatment. The work groups are also addressing systemic challenges that can positively impact all individuals with disabilities. They are charged with building network capacity, reducing system complexity, early intervention, and evidence-based treatment.

Criminal Justice

The prevalence of disabilities is particularly high in the juvenile justice system, mirroring national trends. In 2014, there were only 347 new juveniles committed, lower than previous years. Of this number, 111 (31.9%) had a SMI, and 73 (21%) were in special education. In October 2015, Arizona's adult state correction inmate counts show that 11,482 (26.8%) of 42,900 inmates require on-going mental health treatment, 75% require substance abuse treatment, and 148 are enrolled in special education. Latinos and African Americans are disproportionately represented in rates of incarceration: 40% Latinos, 40% Caucasian, and 13.5% African American.

The U.S. Bureau of Justice Statistics recently released a report that finds that disabilities are overrepresented in the jail and prison system.[lx] An estimated 32% of state and federal prisoners and 40% of local jail inmates reported having at least one disability in the 2011–12 National Inmate Survey. The disability rate among prisoners was nearly three times the rate of the general population, while the rate among jail inmates was more than four times that of the general population. A cognitive disability, defined as serious difficulty concentrating, remembering, or making decisions, was the most common disability reported by prisoners (19%) and jail inmates (31%). It is the one type of disability that did not vary in prevalence between 18-24 year olds to those 50 and over; but this type of disability is significantly over-represented when compared to the U.S. population.

While the overall number of those with ID/DD is unknown in Arizona, these national statistics are compelling. The 2015 consumer with disabilities survey finds that 6% had been arrested before. Too many are in the corrections systems with no recognition of their need for accommodations. ARC's National Center on Criminal Justice and Disability finds that their disability identification is often ignored at time of arrest, which has led to misunderstandings between the officers and suspects, forced confessions, inappropriate sentencing, and no awareness of rights.[lxi] There are recent incidents of this happening in Arizona (e.g. Jessica Burlew). There is little being done in this area to advocate for individuals with DD. Further, focus group participants state that there is a lack of mental health and other medical services for inmates. A settlement agreement between the ADC and the ACLU in 2014 regarding the prison's healthcare system will hopefully improve these outcomes.

Labor

The AG office affirms that the key to preventing EEOC charges and lawsuits against Arizona is to train state employees, especially supervisors, on various employment laws ranging from discrimination statutes to wage and hour to medical leave and disability law. Information on how to provide reasonable accommodations under the Americans with Disabilities Act (ADA) was frequently requested by state managers and supervisors. ACDL, Untapped Arizona, and the newly formed Employment First Coalition also are conducting outreach and training with potential employers to educate them and improve the employment rate among people with disabilities.

In states such as Vermont and Oregon, the payment of the sub-minimum wage to large groups of people catalyzed those states to move beyond CBE to more integrated settings. New Hampshire became the first state to officially ban the sub-minimum wage this year. In Arizona, while employers are not allowed to pay workers with disabilities less than the minimum wage, this continues to occur. It is unclear whether the affected individuals know their rights or who to call, but it is more likely that the individuals don't view it as a major concern, as survey data demonstrates (Appendix C). ICA stated that they would investigate any complaints they receive regarding this issue, but they haven't received any.

Restraints/Seclusion

Office of Civil Rights data from 2012 found that of Arizona students physically restrained at school, 77% have an IEP. In addition, 13% of students with IEPs had been suspended; for students without disabilities, it was only 6%.[lxii] Arizona Task Force on Best Practices in Special Education and Behavior Management put out a guidance document that categorizes and compares current best practices in the use of seclusion and restraint.[lxiii] Arizona Revised Statutes § 15-843 state that restraint and seclusion can only be used in situations in which students exhibit behavior that presents an imminent danger of bodily harm to the pupil or others. In addition, school staff must notify parents within 24 hours of the use of restraint and seclusion; however, no school is required to report these incidents to ADE.

Physical aggression at school is more frequent among students with disabilities. Students with disabilities are bullied frequently, with 18% of the 2014 youth transition study reporting being bullied at least weekly. Being attacked or involved in fights at school was found to also be predictive of being suspended or expelled. This is a significant problem among students with disabilities, with 25% of students in the family sample having been suspended. Those with emotional disabilities are ten times more likely to be suspended than others with disabilities**.** This negatively impacts their expectations to graduate high school or college and, for some, it is the beginning of the pipeline into the juvenile justice system.

ADDPC has helped to advance the Positive Behavior Intervention and Supports (PBIS) movement in Arizona, where 30-40 districts are said to participate (http://pbisaz.org/). PBIS is a school-wide set of processes that facilitate development of a positive school climate through a broad range of systematic and individualized data driven strategies for achieving important social and learning outcomes while preventing problem behavior among all students. PBIS applies a three-tiered system of support, and a problem-solving process to enhance the capacity of schools to effectively educate all students. Tier 1 focuses on setting and teaching behavioral expectations in all areas of the school including the hallway, bus, cafeteria and classroom. Tier 2 and Tier 3 allow educators to focus more closely on the needs of groups or individual students. Core components of PBIS include creating a system for acknowledging positive behaviors, another system for handling behavior errors, training for staff and students on behavior expectations and making data driven decisions. PBIS results in reduced office referrals and truancy, and increases in attendance rates, school safety, and positive student-teacher relationships. The next goal is to teach parents PBIS to promote safety and support in the home.

SELF-ADVOCACY/LEADERSHIP TRAINING

What is self-determination and self-advocacy?

Self-determination consists of seven components:[lxiv]

- Self-awareness - the ability to identify and understand one's needs, interests, strengths, limitations and values.
- Self-advocacy - refers to the ability to express one's needs, wants and rights in an assertive manner.
- Self-efficacy - self-confidence - the belief that one will attain a goal.
- Decision-making - complex skill of setting goals, planning actions, identifying information to make decisions, and choosing the best option to reach one's goals.
- Independent performance - the ability to start and complete tasks through self-management strategies.
- Self-evaluation - the ability to self-assess performance and determine when a goal or task has been satisfactorily completed.
- Adjustment - the process of revising one's goals and plans to improve performance or success.

The national self-advocacy organization, Self-Advocates Becoming Empowered (SABE), defines self-advocacy as the following:

> *[It] is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in.*

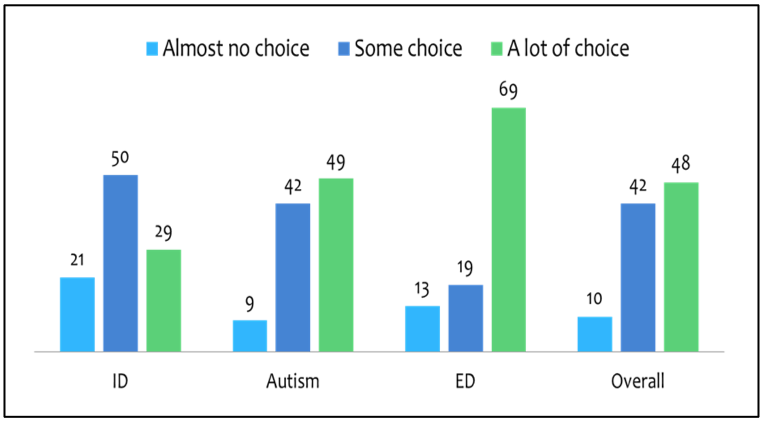
Simply put, self-determination means knowing and doing what is best for oneself, and self-advocacy means sharing this information and supporting each other collectively in fighting discrimination and other barriers.

The Status of Self-Determination and Self-Advocacy

Data from the 2015 adults with DD survey (Appendix C) and adolescents with DD indicate that few have opportunities to self-advocate and that the incidence of self-determination is low for adolescents. For instance, data from ADDPC's Graduation Cliff report indicated that learning how to self-advocate impacted adolescents' perception of outcomes. Less than half of the sample of adolescents indicated they had choice over important aspects of their educational life, such as what classes to take, what school activities they participate in, and what IEP goals they would target.

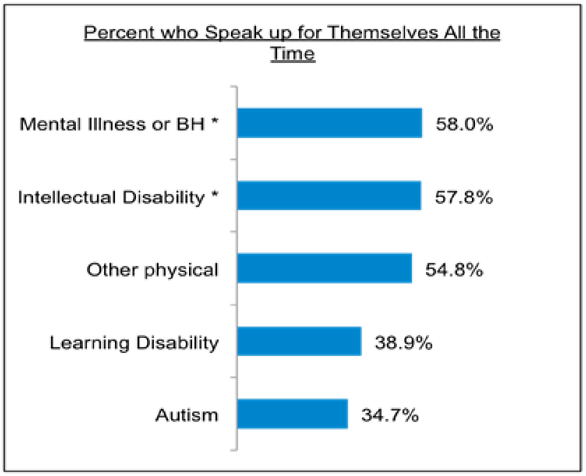
Students with more intensive support needs indicated less control and decision making in the IEP process. A large majority of adolescents indicated that adults are helping them with their decisions, but only half indicated that adults listen to them, leaving the adolescents to feel disempowered.

Choice over IEP

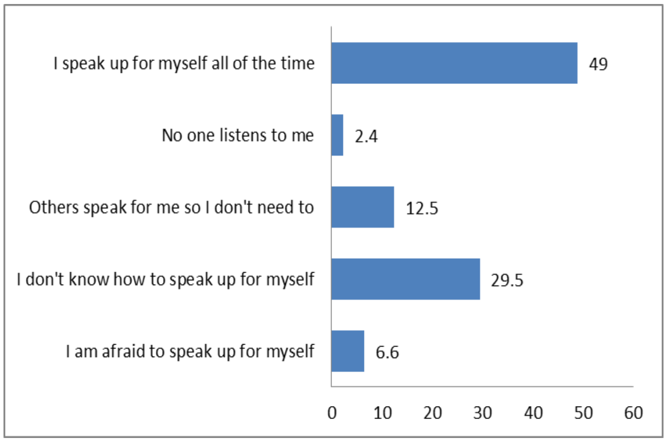


Having the opportunities to engage with peers without disabilities also was important for gaining employment. For instance, the research indicated that “Having contact with peers” (at least a little bit and frequently) was associated with being three times more likely to have paid work. Additionally, “Being involved with groups that were mostly students without disabilities” was associated with their being seven times more likely to have paid work. However, only half of the respondents indicated they were in extracurricular activities. This means the opportunities where self-advocates would engage in activities to make social connections to learn about work opportunities or practice self-advocacy were far less than needed to build those skills. And, the isolation these individuals experience is very real for some.

Being able to speak up for oneself has important implications for adult consumers in Arizona, yet Arizona falters in this area. In the 2015 survey of adults with DD (Appendix C), only 49% of respondents state that they speak up for themselves all of the time – those with autism and learning disabilities were less likely to do so. Over 40% didn’t know how to speak up for themselves or were afraid to.



Percent who agree (%)



Among those who speak up for themselves, there are real implications. While they are more likely to worry about things, such as having enough money and their health, they are also active. They are more likely to work and get a paycheck, exercise, volunteer in the community, and play sports. They are also more likely to be happy with the services they are receiving, have a bank account, and be aware of the minimum wage.

Ten self-advocacy groups across the country and in Arizona were interviewed to determine how they measured success, goal development, and barriers to self-advocacy. It was clear that self-advocacy went beyond advocating on policy issues. Members also used these groups to socialize and help each other with day to day problems. Supporting self-advocates to participate in both regional and national self-advocacy activities was a priority among the groups. Doing so helps these members realize they are part of a larger movement and motivates them into action. Repeated interactions and connections with other self-advocates at the regional and national level provide them with relationships to support advocacy work within the state and to obtain new information to share with self-advocates in Arizona.

However, they indicated that limited support for travel reduces how much Arizona will be represented at the national level. The individuals also indicated the need to create a state conference and technical assistance center to promote, train, and sustain self- determination and self-advocacy for individuals with developmental disabilities. One of the other self-advocacy organizations hosts a self-advocacy conference but can only support 89 self-advocates' attendance. With transportation always a barrier, the conference in Payson is difficult for many to participate. They also indicated the need for funding for lodging and transportation as well as involvement in research and development. Using self-advocates as part of the process for research, program development and implementation was also reiterated in teacher education.

Another barrier for these groups is recruitment and recognition by the community that self-advocacy is important. Since many members do not have access to the internet, self-advocacy group rely on organizations to help recruit, but many have stated that organizations often don't see self-advocacy as a priority. In a 2015 service providers survey, 74% of respondents had received person-centered care training, but only 47% think that individuals with disabilities are capable of representing themselves as advocates on issues critical to their quality of life (Appendix D). Of the sample, 30% are direct care workers, the rest are administrators or executives. The same lack of priority of teaching self-advocacy was noted in Arizona schools. High turnover and job hopping makes it difficult to sustain teachers and a direct care workforce to support self-advocacy and self-determination skills and activities.

In addition, communicating with members between meetings is difficult. Some rely on face to face communication or email. Rarely is social media used. As a result, many of these groups are small and flounder with small budgets, few who can take leadership roles, and a very small base of members. Some groups have used technology to mitigate the transportation barriers, but the organizer had to teach the members how to use it as part of the group's activities. All parties expressed the need to expand opportunities for self-determination and for self-advocacy train-the-trainer types of programs so that these groups are self-sustaining.

Regional summits regarding the self-advocacy movement for people with IDD were held in Spring 2011 and Spring 2012 with the goal of determining the condition of self-advocacy groups across national, state, and local levels; and to plan for action steps to take to strengthen the advocacy movement at both the state and national level. The summits were a collaborative effort among national self-advocacy groups and their allies. State themes around self-advocacy included self-advocacy training for people and their families, including the use of peer mentoring; youth advocacy training, leadership development, and chapters; family support; speaking up for oneself regarding guardian issues; and voting training.

Major themes concerning self-advocacy included access (technology and transportation); education (improving inclusive education, disability history); employment; growing self-advocacy (leadership development, peer mentoring); inclusion (in boards and commissions; self-advocates working in DD organizations); organizational development; policy; projects; and other activities such as informing the public through radio shows and self-advocacy in governments. Data from the summit indicates that Arizona is doing some of this work, such as improving organizational development by utilizing technology and growing individual self-advocacy by conducting voter training.

Best Practices

Several states have made progress in building self-advocacy training and leadership skills of self-advocates including Minnesota, Massachusetts, and Maine. The national summits on self-advocacy identified six areas of growth in the future of self-advocacy: training and leadership development (training, mentoring, and leadership opportunities); infrastructure to support self-advocacy (local and regional, statewide, funding); cross disability coalitions, partnerships, and allies (this was reiterated with interagency coalitions); public education (public attitudes and knowledge about self-advocacy, employers), community services, and supports. Some suggestions included self-advocacy training centers as the “fourth leg of the DD act” or initiatives to collaborate to build self-advocacy. Self-advocates could serve as partners to inform state plans and policies, and self-advocate members of DD councils and other commissions at the local level can help drive state and local policy for individuals with DD.

There are several existing resources and activities available to self-advocates:

- ACDL has comprehensive guides on the rights of self-advocates on a wide range of topics, including understanding legal rights under the ADA. These guides are useful for self-advocates.

- People First of Arizona is collaborating with the Southwest Institute for Families and Children through a funded project (Administration on Intellectual and Developmental Disabilities) that aims to help individuals with IDD to advocate across Colorado, Arizona, Texas, and New Mexico. The group has two goals: (a) to have Arizonans with DD to know their rights and (b) to have Arizonans with DD to have informed voting decisions. One of the first activities the group has engaged in is a webinar titled “50 statements on legislative actions.” The webinar shared 50 statements on the purpose of legislative advocacy and provided participants with instructions on how to share stories with legislators to change laws that affect individuals with developmental disabilities (e.g., email, phone call, in-person meetings). The group intends to provide additional support via video blogs. Expanding this program is important, and perhaps linking these opportunities and supports across disability sectors may expand the understanding of people with disabilities.

- This is My Life program is a self-advocacy training program that provides individuals with disabilities training to speak up and advocate for themselves. There are only two trainers in this program but the organization and self-advocates indicated they would like to train more individuals to train other people with DD to build self-advocacy and self-determination skills. There may be a way for ADE to partner with this group to provide technical assistance to schools for implementing self-determination and self-advocacy training and in improving employment for individuals with developmental disabilities.

- ADDPC, DDD, and Pilot Parents of Southern Arizona are collaborating to provide Partners in Policymaking. Partners in Policymaking is an innovative leadership training program that teaches people to be community leaders, and to influence systems and policy change at the local, state and national levels. The program is designed for individuals who have a disability and for parents raising children with a disability. Partners provides the most current information and education about disability policy, the legislative process, and local, state and national issues that affect individuals with disabilities. Partners’ participants are people who are ready to work for long term systems change and for change in public policy. The overall goal of the program is to foster a partnership between people who need and use services for disabilities, and those who determine public policy. Partners’ graduates gain the abilities to teach policymakers a new way of thinking about people with disabilities.

- The Arizona Statewide Independent Living Council (AZSILC) and VR coordinate the Arizona Youth Leadership Forum (YLF). YLF is an innovative, intensive five-day training program for high school sophomores, juniors, and seniors who have disabilities. The program includes structured small and large group activities, field trips, a dance, a formal banquet, and a tour of the state capitol. It provides educational programs on topics such as: positive self-concept, options after high school, the history of disability as a culture, and leadership responsibilities. Staff and presenters who engage with the student delegates include disability community leaders, legislators, and numerous role models who have disabilities. Student delegates are assisted in developing a Personal Leadership Plan which includes specific action items that they complete when they return to their communities. Following completion of YLF, student delegates serve as a youth voice to inform the Arizona State Plan for Independent Living (SPIL), and are assigned a mentor for on-going support for one year.

EDUCATION

Education in Arizona

The state of Arizona has a difficult history related to education funding, teacher shortages, and its relationship to high-quality standards. Recent reports on per student education spending in Arizona indicate that the state spends only $7,147 per student, with the national average being $11,674 in 2013. Further, during the Great Recession the Arizona legislature was not able provide inflation-based funding to Arizona school districts, causing most Arizona districts to experience extreme budget shortages.[lxv] As a result, many teaching positions are left unfilled, particularly those in special education.[lxvi] This is not just an Arizona problem. National research[lxvii] indicates that special education positions are the most difficult to fill everywhere. The shortage is exacerbated among teachers of students with the most significant support needs, whose enrollments in Arizona public schools continue to climb every year.

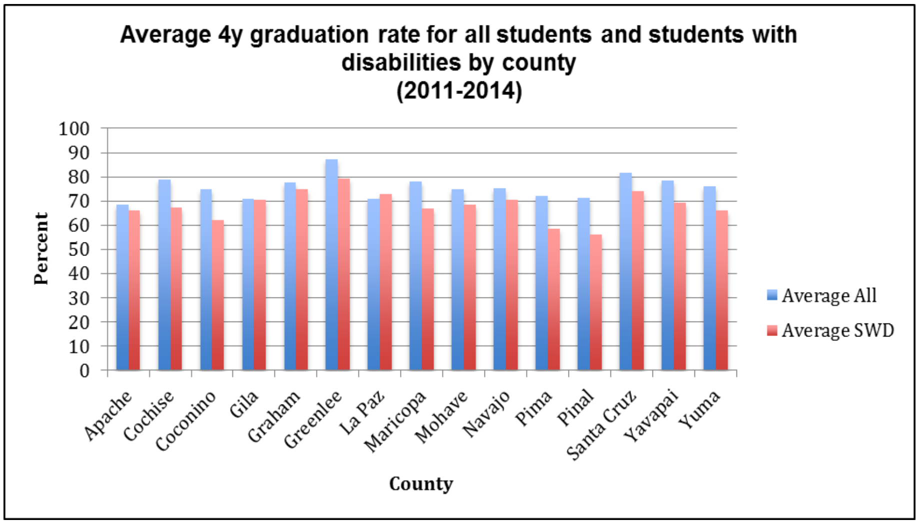
The percentage of public school districts with at least one position open is slowly decreasing from 2000 levels (NCES report); however, special education positions, along with math and science teaching positions in middle and high schools continue to be those positions hardest to fill. For instance, in the latest figures available, as of the 2011-12 school year, 17% of public middle schools and 28% of public high schools report shortages in hard-to-fill teaching positions (i.e., special education, math, science). “After mathematics, special education had the next highest level of staffing difficulties” (NCES report, p.6) with almost 8% of districts reporting difficulty filling special education positions – this is down from 20% in 1999-2000 and may be related to the personnel preparation investment grants from the Individuals with Disabilities Education Act (IDEA). The schools with the most difficult-to-fill positions were schools that had more than 1,000 students and minority enrollment of 50% or more.[lxviii]

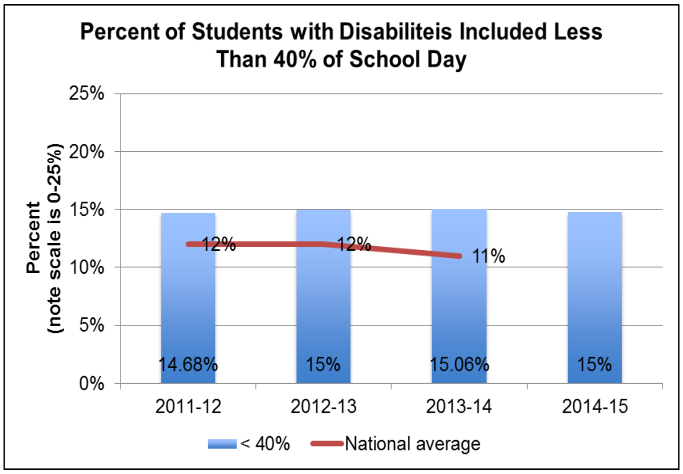
Arizona is also faced with a high teacher-student ratio. In the 2013-14 school year, the national average teacher-student ratio is 16.07 and in Arizona it is 22.80. Urban, high-minority high schools typically are understaffed and face large classrooms as a result, sometimes as high as 30 students in elementary school classrooms to mid-30s for middle school and high school classrooms. A recent literature review indicated that class size is one of the single most important policies that can impact student achievement and students with disabilities.[lxix]

Due in large part to low teacher salaries, high case loads, and lack of support, there is a severe teacher shortage resulting in a higher incidence of inexperienced teachers in general education and, particularly in special education. As a result, students with disabilities experience difficulty in getting access to a free and appropriate public education (FAPE). Focus groups and survey responses find that students are not getting the supports they need to learn academically. Reportedly, the parents have to spend resources to teach them to read and write outside of the classroom, due to the expectation by some teachers that their student can’t learn.

The proficiency rate for both math and reading for students with disabilities continues to be low, 27.8% and 41% respectively for the 2013-14 school year (this includes data on alternate assessment achievement). ADE has addressed this concern in their state performance plan for FY 2012-13, highlighting the need for math and reading training of school teams using research-based interventions, resources, and coaching. This deficiency has impacted graduation rates.

Not unexpectedly, the rate among students finishing high school with their cohort in four years continues to be lower for students with disabilities (SWD). In fact, over the last four years, students with disabilities have consistently graduated in 4 years on average 7% lower than the overall average 4 year graduation rate. The four counties with the lowest four year graduation rate in the last four years are Coconino, Maricopa, Pima, and Pinal.[lxx]If students do not graduate within four years, they are put into the 5 year graduation cohort. Like the 4 year graduate rate, the 5-year graduation rate for students with disabilities is substantially lower than all other students – 75%. Yet, students with disabilities in smaller communities continue to have higher graduation rates than their peers in larger communities, presumably due to lower class sizes.





While improving, Arizona consistently reports more students than the national average participating in the general education environment less than 40% of the school day, but alternatively Arizona has fewer students with disabilities in separate schools or homebound than the national average. Access to the general education environment is a key indicator of positive long-term outcomes. Opportunities in inclusive environments allow students with disabilities to access academic content and build social interaction and communication skills with peers without disabilities. Students without disabilities learn to interact with students with disabilities and differentiate academic content so students with disabilities can participate. Learning this type of skill in school can be beneficial to students without disabilities who may need to engage in similar activities in increasingly diverse work environments.

Access to Post-Secondary Education

Arizona post-school outcomes for the 2011-2012 graduating cohort find that 33.3% of youth with disabilities remain unengaged in work or education after graduation. More specifically, youth with ID have the lowest rates of education, work, or preparation for work after high school of all disability groups.[lxxi] Yet, post-secondary education programs are important because recent research suggests participants have greater opportunities for individual, competitive employment paying at or above minimum wage, obtain career development activities, and/or successfully transfer to other colleges. Continued funding for supporting participation of individuals with IDD within post-secondary education is important. These opportunities not only have a real impact on competitive employment and greater economic self-sufficiency, focus group findings point to increases in self-determination and self-advocacy, integration within the community and the workforce, and job satisfaction.[lxxii]

The West, and particularly the southwest, has very limited options for college opportunities for students with ID/DD.[lxxiii] In response, the University of Arizona started a Think College program called Project Focus. Think College is a national initiative for improving access to college for students with ID. University of Arizona received DOE funding to support Project Focus. The program partners with RSA-VR to give students with ID the opportunity to attend college. The partnership covers tuition reimbursement, fees, and books for students who qualify. However, funding has not been renewed and applications for new participants are on hold.

Sustaining such programs has been difficult nationally. The 2014 annual report from Think College indicates that a majority of funding for these programs comes from private pay with a combination of RSA-VR, institutes of higher education, and local education agency (LEA) funding. Additional suggestions for maintaining funding include expanding use of Medicaid eligible funds to support participation and individualized supports. With private pay being the largest proportion of sustainability for post-secondary education programs, the opportunities for individuals from socio-economically diverse backgrounds is limited. An interagency task-force examining the development and sustainability of funding for these programs is needed.

Representatives from two of the state’s Institutes of Higher Education indicated a need to expand programs for students with ID in transition, but they are unable to obtain enough students to fill courses in this area. One expert indicated:

> “We need better employment outcomes but we need better options for that. And along with that in education. The higher ed piece. We need to do better transition planning, meaningful transition planning in our IEP meetings. Period. Even local staff would say they need more help and training on how to do this.”

It comes down to teacher training.

Teacher Training

ADE was recently awarded a state professional development grant from DOE to improve personnel training of teachers of students with disabilities. For transition, the issues that come up consistently are transportation and getting students with more intensive support needs meaningful opportunities to participate, engage, and become employed in the community. Having these conversations needs to start earlier. Building capacity and sustainability in these practices has been an issue and is of primary focus for ADE. But, as several experts, self-advocates, and the consumer and adolescent data suggest, the focus on employment and employment options for individuals with disabilities is a paradigmatic shift for Arizona. There's a real barrier among teachers and transition teams who are focused on changing the person rather than examining how the context can be modified to support the person. One expert stated the unspoken model adopted by most is to teach youth "*to appear not too disabled. It's not changing the context. It's trying to do something to the person.*"

One expert suggested the need for a job development specialist - a self-advocate - who could work with employers to find opportunities for employment, provide training and technical assistance to employers, so that jobs could be cultivated that appeal to individual interests. The job development specialists would be a group of staff who can broker those relationships with the business community and connect individuals with disabilities to jobs that match their interests. The idea of working collaboratively across sectors to build and expand relationships to support individuals with developmental disabilities was a theme across the transition process.

All data collected for this study indicated the importance of children and adolescents with disabilities learning self-determination skills in order to self-advocate. Representatives from institutes of higher education, DOE, self-advocates, and adult service providers indicated the need to embed self-determination and self-advocacy training within the school system and IEP practice, but indicate there is a lack of effort to do so in the schools. Some suggested ways to do this is to expand opportunities to teach transition planning, self-determination, and self-advocacy. For example, these practices could be taught when developing Education and Career Action Plans (ECAPs) that are required among all high school students. They can embed these practices within teacher preparation and professional development programs as a collaborative effort with self-advocacy organizations within the state.

An effective way to develop transition plans that are individualized and specific to the support needs of the individual with developmental disability is to implement person-centered planning. However, our provider surveys indicated that those who receive person-centered planning training are in DD provider agencies and those who have received the training are in administrator types of positions. So, similar to what was expressed by experts in teacher preparation and transition, training on evidence-based methods is being provided. However, there seems to be a lack of implementation and utilization by individuals working with adults and children with developmental disabilities in developing their IEPs or individual services plans (ISPs).

In this context the need for high-quality and accessible training is even more relevant to improving services among all agencies for transition-age adolescents with disabilities. Given the state’s budget difficulties, this obstacle may be difficult to overcome; but there are potential solutions. Online training and support through webinars and online coaching can facilitate training for all stakeholders, including agency staff, support staff, and parents, in which transportation and location poses a barrier. Virtual training and support has been used in other fields with substantial benefits, such as tele-health and education.

HOUSING

Like youth without disabilities, the majority of youth with DD would like to live away from home to have their independence and pursue their own goals. But, the choice to live on one's own is not an option for many individuals with DD in Arizona. Some of these individuals rely solely on SSI and live below the federal poverty line. If these individuals want to live on their own and away from their families (87.8% of DDD members remain with their families), their living options are limited by what is available through DDD. Only one out of five adults with DD participates in residential options outside of the home, while the rest tend to access in-home services. The 2014 DDD annual report shows that of the 12.2% who live away from their parents, 7.7% live in group homes and 3.3% live in adult developmental homes. Individually designed living arrangements (IDLAs) pay for the supports to allow individuals to live on their own, but according to the 2014 report, people living in their own homes or apartments make up less than 1% of members served. Residential services for ID/DD in Arizona are one of the lowest utilized in the country with only 68 per 100,000 individuals accessing services. The national utilization rate was more than twice that, with 148 per 100,000 individuals accessing residential services.[lxxiv]

It is evident that having individuals live with their families saves DDD and the state money. For example, group homes are the largest expenditure among DDD services by far - with the Division paying approximately $231 per day per resident, regardless of the individual needing 24 hour supports or not. Adult developmental homes (foster homes) cost DDD $100 per day. IDLAs are $217 per day, and personal attendants are $14.50/hour. It's not surprising then that Arizona is one of a handful of states that serves the highest number of people with ID/DD through HCBS at the lowest per capita rate in the country ($21,376 in 2013). It serves the highest proportion of individuals with ID/DD living with their families, and the lowest number of individuals in their own home with supports. By comparison, in 2013, Arizona's rate of individuals with ID/DD living in their own homes with supports is substantially lower (1.4%) when compared to states like Washington (31.5%).[lxxv] This remains a serious concern for aging parents who worry about what will happen to their loved ones when they are no longer around.

And for the majority of individuals not eligible for DDD services, some have no families and require affordable housing, but the short supply of affordable housing leads to homelessness among some of these individuals. There were 29,170 adults and children who experienced homelessness in 2014. At any point in time, 2,500 are unsheltered. Fifty-six percent of the single adult population on the streets is living with a physical or mental disability and often with both. In Maricopa County, 4,300 are families with children - 41% of whom have physical or mental disabilities.

As of October 2015, there is a lack of supply of affordable housing that could last multiple years, even though Arizona's overall housing market has improved since 2008. Any housing under $200K is heavily supply constrained, and supply has gone down 38% since last year. Rents are also going up even faster.[lxxvi] For FY 2016, the proposed fair market rates for a one bedroom unit in Arizona ranges between $516 and $898 ($691 and $1,121 for two-bedroom units), with Flagstaff holding the highest fair market prices in the state. For someone only making $733/per month on SSI, this is simply unaffordable.

Further, a majority of affordable, accessible public housing is age-restricted and not available to those under the age of 62. And while HUD requires that those receiving HUD moneys make 5% percent of public housing units accessible to those with mobility impairments and 2% of the units accessible to those with visual/hearing impairments, this doesn't necessarily mean that all people with disabilities have access to them. The 2013 HUD Resident Characteristics Report shows that Arizona's public housing was 94% occupied, and 18% of these residents have disabilities. Residents had to wait an average of 28 months to move into a unit and paid $276 per month on rent. Unfortunately, out of 16,145 HUD-subsidized units across the state, only 468 (3%) are designated for non-elderly people with disabilities and built with accessible features.

Federal funding of Housing Choice vouchers are the most popular option of all HUD housing programs accessed by people with DD. These vouchers can be given to the tenant or they may be project-based and tied to specific housing units. The tenant-based vouchers are flexible and may be used to rent townhomes, apartments, and single-family homes in the private market. A housing subsidy is paid directly to the landlord by the public housing authority and the resident is responsible for the difference between the subsidy and the rent, which cannot be more than 30 percent of the tenant's adjusted monthly incomes. There are currently 575 vouchers allocated to non-elderly people with disabilities across Arizona.[lxxvii] The wait lists in many areas across the state is three to five years, if not closed altogether. Once an individual obtains a voucher, the difficulty becomes finding landlords that will accept the voucher and locating units that are accessible.

There are some positive trends on the horizon. This year, Arizona received $2,950,000 to provide permanent affordable rental housing and needed support services to 54 households. The ADOH will identify four or five apartment complexes, and DDD will help locate individuals and coordinate supports. No more than 25% of the total available units in any given complex may be used for this program to reduce the chances of segregation. In addition, in its 2016 Qualified Allocation Plan, the Arizona Department of Housing (ADOH) has included a priority in its scoring process for awarding funding for the development of low income housing projects, which set aside at least 25% of its units for special populations, including individuals with DD.

Adult developmental homes are the priority in the years ahead, as demonstrated in a 98% increase in utilization between 2009 and 2014. But there are other options in supported housing that have not been considered to expand individual choice and independence. Supported Living offers independent living in apartments or homes with some supports from the community to maintain the person's independence. To counteract the high turnover of caregiver staff in HCBS, increasingly newly developed buildings and duplexes that house people with ID/DD are allowing families (or caregivers and their families) of people with ID/DD to live on site. The examples below show two ways of providing housing supports to people with DD:

- Options in Community Living is a private, non-profit organization in Madison, Wisconsin, which provides residential support services to individuals who have developmental disabilities — 90 percent of whom have an intellectual disability. It assists individuals in finding and keeping a home of their own in the community. The home may be in an apartment, a townhouse, a condo or a single family house. Most are renters through the Section 8 Housing Choice voucher program. The Options program has benefited from strong county support, including a commitment to self-directed services and the county exceeding the required match on Medicaid waiver funds available for services that promote dispersed, integrated housing. The organization also benefits from Wisconsin's relatively minimal requirements for service providers to qualify for funds from Medicaid waivers. The organization's director explains that this flexibility allows them to support people as active leaders in their own process, instead of having to follow conventional models that are focused on delivering services to passive clients.

- Located in Cupertino, California, the Cupertino Duplexes offers four duplexes for twelve individuals with developmental disabilities and four families responsible for their care. This development is a collaborative effort between the developer, owner/advocate, the provider, and the construction management agent. This project's funding source is the State of California Department of Developmental Services.

Shared Living Arrangements/House Shares give people with ID/DD the opportunity to choose their own roommates and live in their own houses/apartments together. Supports from the state are through personal attendant support. Onandaga Community Living in Syracuse, N.Y. utilizes housemates in its house shares. Housemates are typical members of the community who enter into a life-sharing situation with a person with a disability. Housemates not only share the home, it is their home as well. They live there as friends and companions to the person with a disability. The housemate is able to attend school or maintain his or her full time position elsewhere, and support is backed up with agency staff, reviewing each housemate's personal work and social schedule to ensure that there is proper support at all times for the person with a disability. There is a one-year commitment and a three-month notice of intention to move. The housemate typically lives in the home rent free and free from the costs of utilities, but shares in the food expenses and pays for the extra phone line and/or long distance calling, if needed.

Despite all of these options, there is still a limited supply of affordable housing available in Arizona. In response, specialized housing has popped up to meet demand. For example, with the rise in autism, proponents argue that the development of autism-specific housing with attention placed on the sensory environment in design and specialized training in its personal attendant support will be more successful at reducing behavioral problems and promoting independence of its residents. Proponents also state that specialized housing offers more opportunities for peer support, in which those with similar disabilities can learn from each other, build friendships and increase socialization. This more efficient delivery of services also reduces the risk of gaps in critical services, or personal attendants' no shows, with a stable group of residents to serve.

There is a push for more integrated, affordable options. Integrated housing is typical housing that is scattered throughout the community among residents without disabilities. While specialized housing often delivers a bundle of services to a group of residents, integrated housing links individuals with disabilities ranging from moderate to severe to services that he or she needs to live in the community, i.e. personal attendants, transportation, and employment. Federal actions and initiatives stemming from the Olmstead Decision have targeted this individualized, person-centered approach as its focus is integration over segregation and individual choice over compliance with rules and procedures. Proponents of integrated housing believe that inclusion of people with disabilities in the community among their non-disabled counterparts will improve outcomes in employment, community participation, empowerment, health, relationships, and overall life satisfaction. The stigma that people with disabilities have to be segregated to live in the community also fades with increased integration.

Most opponents also see the benefits of integrated housing, but they do not believe that this is an option appropriate for all people with disabilities. There is a very limited supply of integrated, accessible housing available, and community services support is not adequate to maintain the independence of a person with a significant disability, which is why many remain at home with loved ones.

Many Arizona housing departments and city officials are willing to work with the DD community to increase the supply of supportive housing, but many remain unaware of the great need and barriers facing this population. In addition, relationships need to be built with developers to start increasing the supply of accessible, affordable housing stock.

TRANSPORTATION

A 2015 survey of adults with DD (Appendix C) show that para-transit services and rides with family members are the prevalent forms of transportation used. While most stated they were satisfied with transportation and could get to where they wanted to go most of the time, a few were dissatisfied with the long wait times and a lack of availability at times when it is needed.

Transportation barriers are more predominant in rural communities. Some rural areas do not have transportation at all. One individual stated:

> "We feel like we can't live life the way other people can and it hard on us having to deal with not be able to go out and do stuff when we want to...we all want to feel independent and to be able to live without help."

Many are unable to access needed services due to a lack of transportation, which exacerbates isolation and dependence, and negatively impacts an individual's quality of life. In the city of Nogales, for example, out of four accessible vans, only one is in use due to funding constraints.

Arizona is only one of four states that does not fund its public transit programs. There is heavy reliance on federal 5310 (e.g., for seniors and people with disabilities) and 5311 (e.g., rural transit) funds to transport individuals with disabilities in their communities. There is a drawback to these programs, however. Agencies with these funds often receive transportation requests from the general public, but many agencies only accept agency clients, shutting out non-clients. Further, many of these agencies provide transportation only to and from agency activities. There have also been problems with needed accessible vehicles standing idle, vehicles operating only during the work hours on weekdays, and a lack of coordination between agencies sharing service areas, leading to gaps in service.

With funding levels on the decline, transportation coordination is critical to meeting demands of the growing number of older adults and people with disabilities who don't drive. The federal transit law requires that projects selected for funding under the Section 5310 program be derived from a locally developed, coordinated human services transportation plan. The coordination plan brings together non-profit agencies, citizens, municipalities, and faith-based communities to identify the transportation needs and gaps of individuals with disabilities and older adults; develop an inventory of available services to identify gaps and avoid duplication of services; provide strategies for meeting needs and overcoming these gaps; and prioritize transportation services for funding and implementation.

There are nine transportation planning regions in Arizona – six operated by Councils of Governments (COGs), and three operated by Metropolitan Planning Organizations (MPOs) in Flagstaff, Yuma County, and Central Yavapai County. Each area is responsible for developing a coordinated transportation plan. Human services coordinated transportation plan committee meetings encourage public comment. The voices of people with DD should be heard at these meetings so their needs are better understood and 5310 funds are leveraged in meaningful ways. Rural communities are in desperate need for transportation. These areas' towns, churches, community centers, or other organizations should be approached with the needs facing the disability community. Many don't know this is a problem unless they are educated.

ADOT is also encouraging agencies to pool their resources to more effectively coordinate transportation programs, but many regions have run into insurance barriers with this type of resource sharing. For example, changing the type of passengers served when another organization uses the vehicle may constitute a material change in the primary insured's contract, which is not allowable by some insurance companies. Another complaint is that if a van is shared between two organizations with their own drivers, the owner of the van would serve as the primary insured entity and could encounter higher liability and costs.
Some providers have overcome these barriers.

- Foothills Caring Corporation in Maricopa County shares its vans with eight other non-profit organizations, including a city library and a local group that serves people with developmental disabilities, and they are planning to add other organizations. Drivers from these organizations become Foothills volunteers – all from the same organization. These drivers receive stringent safety, volunteer, and customer service trainings. Foothills negotiated with their insurance company by arguing that all clients transported are part of their mission to serve those who are shut in. They have never had an issue with insurance coverage.

- In Pima County, Community Food Bank contracts with Marana Health Center to transport food bank clientele. The Community Food Bank uses its 5310 funds to pay Marana an hourly rate, which compensates for Marana's higher insurance premiums and driver time, and allows Marana to serve more people with a van that would have been idle. Its insurance company viewed food bank and health center clientele as the same population served, thus it was not perceived as a material change in the contract.

When companies share vehicles with separate drivers, strategies to reduce liability include creating an "additional insured" addendum on the insurance policy. The vehicle owner and borrower would enter into a lease agreement for some nominal consideration (e.g., $1) for the "lease" of the vehicle, and through a formal memorandum of understanding specifies the insurance coverage of the borrowed vehicle(s). The borrower then adds borrowed vehicles as "non-owned" vehicles to its policy. Both agencies would then name each other as "additional insureds" on their respective policies and provide certificates of insurance to each other. In addition, the vehicle owner should request assurance from the borrower to demonstrate that the borrower's driver selection, training, safety and supervision programs meet the vehicle owner's standards, or else mandate that they complete the vehicle owner's driver training. Thus, when an agency loans a vehicle to the secondary operator, and there is an accident, the vehicle owner's insurance will pay the claim first, and then seek reimbursement from the secondary operator's insurer.

RECREATION

With much focus given to housing, employment, and health issues, fewer resources are dedicated to issues related to recreation/leisure for individuals with disabilities. However, participation in recreation options is an important part of life. Over the last five years, there has been a decline in Arizonans with DD availing themselves of recreational and social opportunities, such as vacations, going out to eat, and shopping (when comparing previous 2010 survey data). NCI 2014 data show that compared to other states, DDD members ranked lowest on the Community Inclusion Scale, which includes attributes such as frequency of shopping, going out to eat, entertainment, going to religious services, exercise, running errands, and an annual vacation. It is no surprise then that only 62% of them said they had friends outside of family and staff, again one of the lowest rates in the nation.

Individuals and families state that if there weren't providers and summer camps, there would be nothing for these individuals outside of Special Olympics. And for adults with DD who are aging, there is not much at all. Focus group participants report that the disability-specific community activities in which their child engages is just as important to the families. Parents bond with other parents of children with disabilities, thus these activities give a space for both individuals with DD and their families to socialize. When the adult with DD ages and cannot participate in activities as frequently, this impacts the parent's ability to participate as well – at a time when emotional support is needed the most.

All parents and individuals with DD expressed a need to get together and fellowship. The majority said that there is a lack of recreation and socialization with their peers once they graduate school. And focus group data confirms that as adults with DD age, health barriers may get in the way of activities they used to enjoy doing. When parents become the only person important to their child's world, they worry about his/her future. However, those individuals who were highly involved in their self-advocacy groups tended to be busier with volunteerism, work, and socializing with friends. They stated in these groups they did "fun things," and they helped each other with problems.

There are accessible spaces where individuals with DD could spend leisure time throughout the state. Arizona has one of the accessible sports/fitness facilities in the country with an indoor track, swimming pool, climbing wall, basketball courts, and exercise equipment. There are also miles of accessible hiking trails throughout the state, as well as accessible sports stadiums. Accessible art programs are also a popular activity among those who have them in their areas. The barriers to accessing any of these activities, however, are primarily transportation or lack of needed supports to take them.

ANALYSIS OF STATE ISSUES AND CHALLENGES

CRITERIA FOR ELIGIBILITY FOR SERVICES

Generic Services The primary cash assistance program used by individuals with DD is SSI. SSI eligibility is for people who are: disabled, blind, or over age 65, have resources below $2,000 ($3,000 for an eligible couple), are unable to work very much because of disability, have limited income, and are US citizens (or meet certain requirements for noncitizens). If a person is able to get SSI, they are automatically eligible for AHCCCS medical insurance and nutrition assistance (if needed). There are some gaps in AHCCCS, with adults 18+ not eligible for dental services, eye exams, or nail care under AHCCCS. And some supplies, such as incontinence supplies and durable medical equipment, have been systematically turned away when they shouldn't have been denied.

If the person has a mild to moderate disability but is deemed able to do "substantial gainful activity" in employment by the Social Security Administration, they won't qualify for SSI or for AHCCCS. There is a disincentive set up in our current system for individuals to say they want to work or locate a job. This limits opportunities for everyone in the DD system - many of whom are on SSI. Schools start helping individuals get on SSI before students even graduate, although employment is the primary option for the student.

While the state offers a Disability 101 website that explains benefits and guides individuals through the disability benefits process, much of this information is not at the reading level of individuals with DD. Further, for those individuals with DD who don't qualify for ALTCS, coordinating health care and other options becomes extremely complicated without some assistance. Many non-U.S. citizens are aware of the benefits that are available to them, but they cite a disparity in access to physical, speech and occupational therapists that are not covered through emergency-only AHCCCS care for their child with DD, considered "undocumented" and not eligible.

Waiver Services Although there are no wait lists for most of DDD services, the eligibility criteria to receive supportive services is fairly strict. To qualify for these services, the individual has to be eligible for ALTCS. The criteria for eligibility is that if the person does not receive HCBS services, they are at risk of moving into an institution. They are also required to have a diagnosis of ID, epilepsy, autism, or cerebral palsy; the diagnosis is expected to last a lifetime; onset has to occur at age 18 or before; and the individual has limitations in at least three of the following areas:

- ability to care for oneself;
- ability to comprehend or communicate;
- ability to learn;
- ability to move;
- ability to makes independent choices;
- ability to live independently; or
- ability to financially provide for him/herself.

This definition is more stringent than the definition in the federal DD Act, which allows other diagnoses, and a manifestation before the age of 22; however, it's looser than some other states that just serve intellectual disabilities. Many individuals do not qualify for DDD services or may only receive case management assistance only if they are not ALTCS-eligible. Out of approximately 120,000 Arizonans with DD, only 33,272 individuals are receiving DDD services in 2014. The majority are paying privately or are foregoing assistance altogether.

The majority of ALTCS services in the DDD system are provided through the 1115 waiver that provides home and community-based services, which includes habilitation, employment, therapy services, and attendant care. While these are the services that help individuals to live independently, this is where a significant number of people with DD are excluded from services, or have to advocate to obtain sufficient services in this areas. Individuals with autism, intellectual disabilities, cerebral palsy, and epilepsy are eligible to apply. In addition to resource limits, ALTCS services are administered under the condition that the individual would be at risk for institutionalization if HCBS services were not administered. Many individuals and families state that they are not considered "disabled enough" to receive services, but they are too disabled to not have some assistance. Families state that the State-Only or Targeted Support Coordinator services provide minimal, if any, assistance. Yet this group makes up 21% of DDD's current caseload (7,029 people).

Early Intervention Services AZEIP is another area where children with DD slip between the cracks, but for different reasons. Therapy services recommended under AZEIP in many cases cannot be obtained in a timely manner, due to the lack of therapists in the state. The eligibility criteria state that the child must be between birth to 36 months of age and has not reached 50 percent of the developmental milestones expected at his/her chronological age, in one or more of the following domains: physical, cognitive, language/communication, social or emotional; or adaptive (self-help). Those that are at-risk of developmental delays are not covered under AZEIP services, thus these children may not ever be able to get these services. In addition, some medical providers still do not refer families to AzEIP services even when there child has a delay.

Special Education Services The 2014 Child Find data indicate there are 131,541 students with IEPs in Arizona public education agencies (public and charter schools). Nearly 36% of those students are included in the general education classroom less than 80% of the school day. This indicates that the opportunities for interacting and being educated in environments with peers without disabilities are not available to a substantial proportion of students with disabilities. A child is eligible for special education services if they have an identified disability (e.g., intellectual disability, hearing impairment including deafness, speech or language impairment, visual impairment including blindness, serious emotional disturbance, an orthopedic impairment, autism, traumatic brain injury, another health impairment, a specific learning disability, deaf-blindness, or multiple disabilities). This disability also has to impact their ability to access general education. If deemed eligible under IDEA, the student will receive special education and related services in order for the student to receive FAPE in the least restrictive environment. Assessments need to be conducted by a qualified professional, and the assessment should be completed in the child's native language, and completed within 60 days of the identification meeting.

While the eligibility requirements do not prevent children from receiving services, the implementation of IDEA in Arizona schools has encountered significant barriers. With the shortage of special education and general education teachers, therapists, lack of supports in the mainstream classroom, which is often overcrowded, parents of children with IEPs often request to go back to segregated environments or leave the public school system altogether. In fact, the 2015 Arizona poll finds that when asked if children with intellectual disabilities should be educated in the same classrooms as other kids their age, 60% didn't think so. With budget reductions, schools just do not have the resources to support inclusion in general education classrooms successfully.

Employment Services There are several significant barriers to individuals with DD obtaining employment services. RSA-VR programs are under an order of selection, meaning that the shortage of state funding only allows them to serve those individuals that are considered to be in the most significant need (priority one consumers). Priority one requires that the individual with a disability be considered the most significantly disabled. They have to have an impairment that seriously limits three or more functional areas, and must be expected to require multiple services for at least six months or more. Those who do not fall in these categories must be provided with information and referral services. DDD employment services are only provided to ALTCS-eligible members; and there are very few who are enrolled in employment for a number of reasons, including lack of willingness to work and a lack of employment options. Additionally, there are many who need a little support, specifically, individuals with autism, but are unable to meet the eligibility requirements for state agency assistance and have a difficult time finding and retaining a job.

Long-term Services and Supports Eligibility for long-term services can be obtained through ALTCS. DDD delivers these services through HCBS waivers to the majority of individuals who live with their families. Families and providers frequently report that the time allotted for attendants, employment supports, or even therapies are too short, unrealistic, and not person-centered. In addition, providers constantly turn over due to low pay or because they find something better. Training among providers is inconsistent, although many would like more hands-on training to help them better meet individual needs.

The 2015 provider survey and focus groups uncover a common theme. There is a cookie cutter approach to determining how many hours a person needed to achieve his/her goals that has resulted in many individuals being excluded from socializing with others. Only 33% of NCI participants said they had the supports needed to see their friends and family. Those who aren't eligible for ALTCS are also those individuals who only need some support to be successful. They often remain living in homes with their families in the absence of other options.

ANALYSIS OF BARRIERS TO FULL PARTICIPATION OF UN-SERVED AND UNDERSERVED GROUPS OF INDIVIDUALS WITH DD AND THEIR FAMILIES

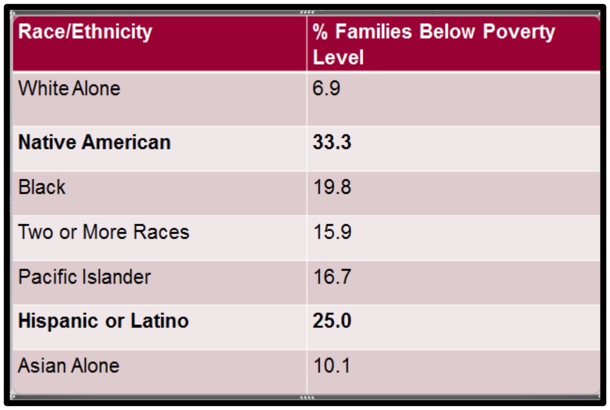
****Rural Communities*

The highest proportion of individuals with DD lives in rural areas of the state. Individuals located in rural areas have significantly more barriers to community inclusion than their urban counterparts. In these areas access to healthcare is a serious problem. These are medically underserved areas of the state where therapists, specialists, and primary doctors are difficult to access. Families have to travel to the nearest metropolitan area, often hours away, to receive services; families with no access to transportation often forego these services altogether. There is little to no transportation in these communities. Many individuals walk or bike where they need to go, unless sidewalks or roads are inaccessible, which disparately impacts rural communities. There are limited options in housing, employment, and social activities. Some of these rural communities have a high number of non-English speaking residents, which presents more barriers to access. There is also a shortage of resources and providers to these communities, leaving some of these community members to feel forgotten.

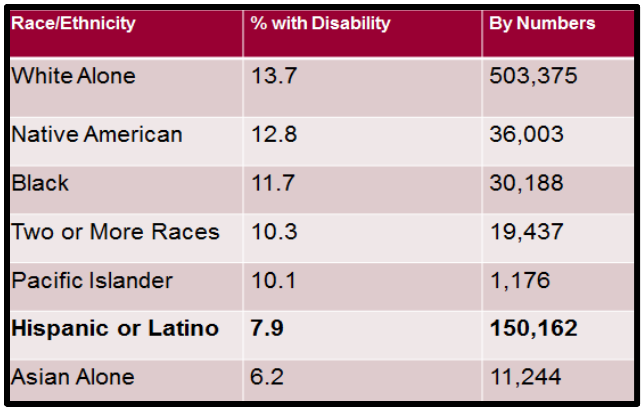
The strength of these communities is the strong bond that neighbors have towards each other. In a 2014 transition study, youth with disabilities who lived in rural communities were nearly twice as likely to have paid work if they lived in a small town or rural area. Community members who knew them helped them to find spaces to work and/or be self-employed that are often hard to locate in urban spaces. In addition, students with disabilities in smaller communities continue to have higher graduation rates than their peers in larger communities, presumably due to lower class sizes.

****Culturally Diverse Communities*

The highest rates of poverty in the state are among Latino (25%) and Native American households (19.8%). The numbers of these race/ethnic groups with disabilities make up a sizable portion of Arizona’s population. There are over 216,000 ethnically diverse individuals with disabilities: 150,162 Latinos, 36,003 Native Americans, and 30,188 African Americans. The needs among these communities are great and diverse.



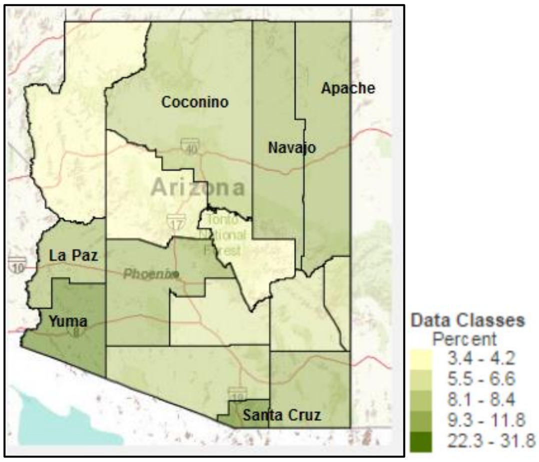
Race/Ethnicity	% Families Below Poverty Level
White Alone	6.9
Native American	**33.3**
Black	19.8
Two or More Races	15.9
Pacific Islander	16.7
Hispanic or Latino	**25.0**
Asian Alone	10.1

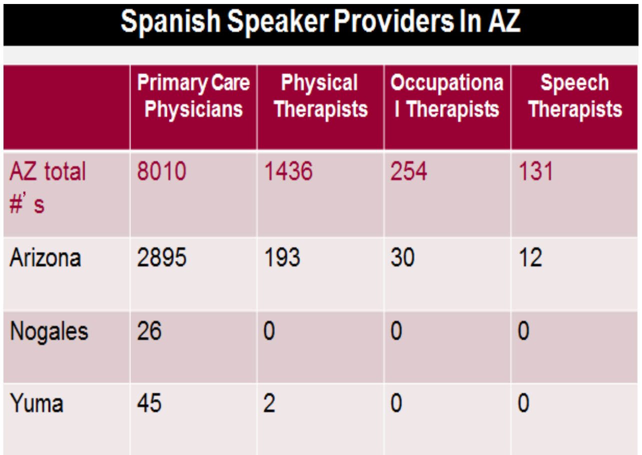


Race/Ethnicity	% with Disability	By Numbers
White Alone	13.7	503,375
Native American	12.8	36,003
Black	11.7	30,188
Two or More Races	10.3	19,437
Pacific Islander	10.1	1,176
Hispanic or Latino	**7.9**	**150,162**
Asian Alone	6.2	11,244

In focus groups, Latino families stated that the communities where they lived were unsafe and inaccessible to wheelchairs, citing a lack of sidewalks as a common problem. Families do not always speak English (9.5% don't speak English well) and even when they do, they are not proficient; thus, it complicates the communication process with school officials, doctors and other authorities. The following table shows the number of providers that take AHCCCS and have Spanish speaking ability. The lack of proficient translators makes things even more difficult for these families. They state that the translators are not always communicating what they say.

Percent Does Not Speak English Very Well





Spanish Speaker Providers In AZ

	Primary Care Physicians	Physical Therapists	Occupationa l Therapists	Speech Therapists
AZ total #' s	8010	1436	254	131
Arizona	2895	193	30	12
Nogales	26	0	0	0
Yuma	45	2	0	0

These families also often feel a sense of not being welcome in public places, even at hospitals. They feel discriminated against by medical professionals, and believe that school officials, police and other authorities take advantage of them because they can't speak English. Those who are undocumented are afraid to advocate or speak up for themselves. In effect, there is a lack of resources and lack of awareness in these communities that affects families' goals of independence for and social inclusion of their children. Yet, they feel powerless to improve the situation for their children in their current communities.

The Native American populations face similar experiences. They show significant health disparities due to high poverty rates, low education attainment, culturally impotent health providers, language barriers, and an overall lack of services. In 2013, American Indians ranked worse than the statewide average on 49 out of 69 indicators. Specifically, they ranked poorly on measures of maternal lifestyle and health, as well as utilization of prenatal care. In addition, they have an median age of death from all causes of 60, 17 years younger than the state median of 77.[lxxviii]

Additional secondary research from NADLC yields data specific to the Navajo and Hopi tribes. The majority of Arizona's Hopi and Navajo communities report a dearth in formal disability services, stigma by their leadership, and a lack of awareness of the needs of people with DD. Although this group has the highest prevalence of DD among all ethnic groups, some members say that tribal leaders choose to "hide it away." Thus, services to help people become more connected to their communities are sorely lacking due to a lack of education.[lxxix]

While African American groups were not interviewed in the context of this analysis, their high representation in foster care, incarceration, and disability numbers, and a lack of this State's attention to disability issues among this group, warrants special attention.

******Those with DD Not Eligible for State DDD or RSA-VR Services***

The State's eligibility criteria for both VR and DDD services are more stringent than the federal definition of DD in the DD Act. For that reason, there were repeated comments from focus group participants that Arizona maintains an "all or nothing" system. Many individuals with DD who could use the help just cannot benefit from state services. An individual stated, "You have to be significantly disabled or you receive no services." This same phrase was repeated in the auspices of behavioral health. Most individuals and families said they could use a little help finding and keeping a job, but most felt that they were on their own and unsupported. Expanding the DD definition to include individuals not served by these agencies may include more individuals who acquired lifelong behavioral health issues before the age of 22, or someone who has high-functioning autism but cannot find a job, or a homeless individual with SMI who also was enrolled in special education in school, but never identifies himself as having a "developmental disability." The complaint by families is that the state focuses on the categories - not individual needs. For that reason, this underserved population are those individuals who do not fit in a category, still meet the broader federal definition of DD, yet still need services.

******Transitioning Populations***

Through the review and analysis, several themes arose that were consistent - and they had to do with life transitions. It is important to note that transition-aged youth are not reported here due to the fact that recent federal legislation requires state agencies to prioritize and serve this group. It is unclear at the time of this writing how they will do so, but addressing post-school outcomes of transition-aged youth remains a pressing issue. The following populations have also been identified as having a significant need but not being significantly served by existing programs.

Older Adults with DD and Aging Caregivers

Older adults with I/DD and their caregivers face unique challenges and complexities. Not only must they plan for a future in which aging parents may no longer be able to care for their aging child with I/DD, but the stresses on family members caring for aging loved ones with I/DD have been shown to be especially acute. By their mid-60s, parents of adults with I/DD, compared to parents of adults without a disability, reported lower marital stability, reduced leisure time, higher limitations in parental activities of daily living, poorer mental health, and lower health related quality of life.[lxxx]

There is a great need to assess and meet the needs of aging caregivers for people with I/DD. Failure to receive needed services, including respite, training, and other caregiver-targeted supports, contributes to early or unnecessary out-of-home placements for people with I/DD. For example, there is a recognized need to train caregivers how to recognize and respond to age-related changes in health, adaptability, and cognition. This includes how to physically adapt the home, how to tailor social and recreational opportunities to changing needs/abilities, and how to provide health and behavioral support in safe and appropriate ways. For families dealing with dementia, caregiver training and support are especially critical to keeping older adults at home with a higher quality of life. Several training programs and curricula have been developed for both formal caregivers and family members of people aging with I/DD, including some that are specific to dementia.[lxxxi]

In addition, planning is a key to improved supports for both individuals and caregivers. Especially for the many families who have not been connected to state or local service systems, there is a need for help with future planning related to housing, finances, personal assistance, and quality of life, among other issues. Future planning for individuals and family members has "significantly contributed to families completing a letter of intent, developing a special needs trust (a trust which protects government and disability benefits), and taking action on residential planning" (Heller, et. al., 2004, p.2).[lxxxii] It has also been shown to produce other benefits such as decreased caregiver burden, increased choice-making of individuals with disabilities and increased discussion of plans with individuals with disabilities. However, state agencies and federal programs are not consistently able to prioritize future planning when they allocate funds and resources and develop programs.

Most family members of aging adults with DD stated that they had not yet discussed what they were going to do about the future, and that their support coordinator had not brought it up. Some families wanted to “try out” a residential option to see how his/her loved one did, but they stated that the DDD support coordinator stated that this wasn’t an option. Some family members have children with Down syndrome that aren’t eligible for DDD services. These families have no idea what to do. Some worry that their trustees who are their age will also pass away, and their loved ones will wind up “warehoused.” There was just no certainty among these family members that their loved ones would be okay, especially if their child relied on only them their whole lives. These issues of uncertainty will grow as Arizonans age.

Foster Care

Arizona has a crisis on its hands with the 18,000+ children in out-of-home foster care. Many of these kids have a mental health issue or other disability and face tremendous barriers between their own disabilities, dealing with abuse/neglect, and changing school systems. A parent fighting to get his foster child on an IEP stated that the principal said, “I don’t want to waste resources on a child who might not be here next month.” Once foster children turn 18 their foster parents no longer receive subsidies. Some foster parents keep them, but others can’t afford to. Children also lose their AHCCCS, and don’t know how to advocate for themselves in the adult system. Some end up on the street or in Corrections with no awareness of their rights. While there are current resources targeted to help this population, they are primarily children that are already enrolled in the DDD system.

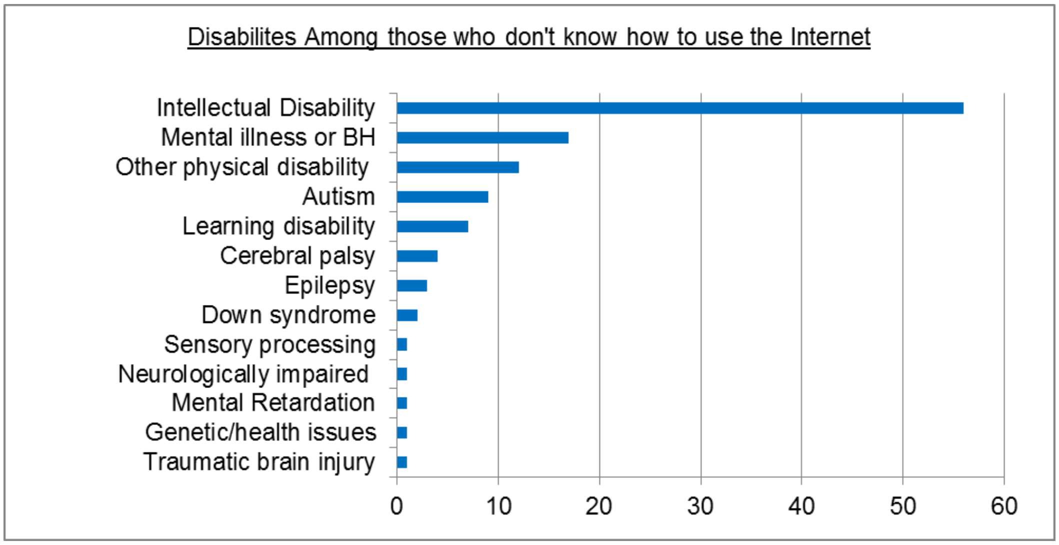
Former Prisoner/Felons with DD

Former prisoners and felons of state prisons face enormous barriers accessing employment, housing, or any others services to assimilate back into society. These barriers are magnified when the individual has a DD. Currently, there are no services targeted to released prisoners with DD who are overrepresented in the corrections system.

THE AVAILABILITY OF ASSISTIVE TECHNOLOGY

In our adolescent study, 4 out 5 students indicated they used technology and social media. This is promising, particularly for adolescents, as technology is the primary means of communication and social interaction used by teens But we know that there is a significant technological divide for adults with intellectual disability. So, getting students connected, digitally, is a key to obtaining social support and being included in activities, both formal activities sponsored by schools and informal activities created by students.

The same promising results were not seen in our consumer survey (Appendix C). Overall, over 31% of respondents don't know how to use the internet. This 31% represents 109 disabilities (respondents were able to list more than one disability). The vast majority of those who don't know how to use the internet are between the ages of 22 and 59 (72%) with older respondents more likely than younger respondents to not know how to use the internet. Interestingly, we found that 35.7% of Pima County respondents do not know how to use the internet; this was a significant finding. Further investigation on why this is the case is needed.



It appears that 66% of the respondents in this survey fall into the "no technology" category meaning that they do not have access to any technology including a cell phone. Among these, 47.6% of them go to a day program for people with DD. Conversely, among those who attend a day program, 78% of them do not use the internet or a cell phone. Barriers to technology include skill level of the individuals with a DD, the inaccessibility of technology, lack of training on integrating technology across life domains, technology affordability and broadband access, and the lack of skill and access that caregivers or assistants supporting individuals with DD have.

Further investigation of this phenomenon is warranted, particularly considering the connected nature and need of technology in supporting the lives of individuals with DD. There is a relationship between self-advocacy skills and use of technology. Those who speak up for themselves all of the time are significantly more likely to use technology than all other respondents. Those who don't know how to speak up for themselves are significantly more likely to not use technology than all other respondents.

In interviews with experts in assistive technology (AT) for the state, experts indicated that access of smaller, more rural communities to the internet impacts technology's ability to be an integral part of the lives of individuals with DD. Those working in AT for the schools indicated a need for general understanding that technology is really integrated and critical to the lives of all students. They also expressed concern with the lack of teacher knowledge on what assistive technology is and how it can be integrated within all aspects of lives for students with disabilities. One expert indicated, "There needs to be a political will to integrate technology training in teacher training and professional development. Districts have to want AT consideration." A self-advocate with an intellectual disability reiterated this point when he stated: "People with DD do not have access to technology. We do not have choice when to use the computer." The 2014 NCI consumer with DD survey reports the same findings: 39% of respondents from Arizona and 89% across NCI states reported that they can use the phone and Internet without restrictions. Arizona scored lowest of the 28 participating states.

Best Practices

The American Association of People with Disabilities, in collaboration with the National Council on Independent Living and AT&T, recently released a brochure on "The Internet of Things" explaining how internet-based technologies such as phone-based security systems, smart appliances, and automated routine reminders can be used to support individuals with DD to live independently. The material maps out the many ways cloud-based technology can help support individuals with disabilities to communicate and manage their households with the assistance of technology.

This position statement is in alignment with research on cognitive disabilities and technology from the annual Coleman Institute on Technology and Cognitive Disabilities which for 15 years, has explored the impact that technology has in supporting individuals with I/DD to live independent lives. The *Rights of People with Cognitive Disabilities to Technology and Information Access* declares the imperative right for the 28 million U.S. citizens with cognitive disabilities to have access to technology and technological information. The state legislatures of Colorado and Maine have both adopted these declarations through the collaborative efforts of self-advocates and allies.

The President's Committee for People with Intellectual Disabilities (PCPID) annual report to the President titled "Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities" connects the need for technology access as it relates to employment, education, and independent living options for people with intellectual disabilities. The report focuses on "enhancing the capacity of people with ID to fully participate in their respective communities, in their own health care decisions, in their educational attainment, and in their economic wellbeing. The Committee is convinced that in today's world the full participation of people with ID in their communities is achievable, but requires accessible, affordable and sophisticated technology," as stated by Julie Petty, PCPID's Chairwoman.

Considering the integration of technology within everyday life, the field of DD has moved to adopt a paradigm shift from AT to applied cognitive technologies or information communication technologies (ICTs). This movement utilizes technology to support activities of daily living and social communication and networking. DOE and the Administration on Community Living have indicated funding priorities for research practice partnerships focused on infusing technology in three areas, including education and technology access, improving community living through technology, and improving well-being through technology use. Given the interest of education experts and self-advocates, a collaborative initiative in this area may move the needle on improving inclusion of children and adults with DD.

ANALYSIS OF ADEQUACY OF HEALTH CARE AND OTHER SERVICES INDIVIDUALS WITH DD IN FACILITIES RECEIVE

There has been a freeze on placements at the one state institution in Arizona, the Arizona Training Center (ATC) in Coolidge. In 2013, there were 106 residents still living there. ATC has been inspected annually by ADHS in the last three years. Recent inspection reports show that there are no enforcement issues that seriously impact the quality of life of the residents. However, long term care data indicate that out of 159 nursing homes, 72 (45%) of them have significant quality of life deficiencies for the residents that have resulted in civil penalties. Some of the issues cited are failure to follow physician orders, failure to administer medications according to treatment plan, neglect, pressure sores, failure to follow fall prevention, dehydration of residents, and many others. There is a low number of people in these homes. In 2012, there were 12,424 residents in nursing homes; however, 20.4% of them were under the age of 65. This percentage of younger residents living in nursing homes is well above the national average of 15%. Arizona has the highest percentage of residents living in nursing homes with mild or no cognitive impairment (48.1%) - 63.7% of the residents have limitations in four or five activities of daily living.[lxxxiii]

ANALYSIS OF HOME AND COMMUNITY-BASED WAIVER SERVICES

As Arizona’s older adult population and number of people with disabilities increases, the delivery of HCBS is essential to ensure that people are fully included in their communities. Final CMS rules mandate that individuals receive services in the most integrated setting and have full access to the benefits of community living. Person-centered planning is required in defining service plans that honors individual preferences and choices. The rule is clear that person-centered planning needs to be timely, the individual is informed of all options, that they receive choices, and it reflects cultural considerations. CMS also urges states to allow individuals to self-direct some or all of their services operated through the HCBS waiver. Self-direction gives individuals the control to plan and purchase their own services. CMS also encourages an independent advocate to assist the individual with access and oversight of their waiver services, including self-direction.

There are mixed reviews on Arizona’s delivery of HCBS waivers. While it remains a high performing state in supporting individuals in family homes, self-direction is not a key component of the HCBS system, and few individuals report self-directing their own supports. However, recently, DDD has given individuals the opportunity to hire their own attendants through the Agency of Choice initiative. Still, some individuals and families complain of few options and that the spectrum of services available does not meet individual choice, specifically in residential and employment options and the type of supports received. While Arizona rates high on the level of choice they feel they have over their days and satisfaction with their support coordinator, there are not many choices. This survey finds that 60% of providers felt that the formal system did not do a good job maximizing client independence. NCI data show that Arizonans feel that they have the highest level of control over everyday decisions, but they still remain excluded from community activities. They rated the lowest in the country in community inclusion, ability to date, having the supports to see friends, and having friends outside of family.

HCBS services should be re-examined to look at how individuals are currently living their lives. They are reporting low involvement in self-advocacy, low participation in community activities, low employment, and few friends. The purpose of the HCBS waivers is to promote community inclusion, but on many outcome measures, they are failing. There is essentially a conflict with limited system options driving individual choice and exclusion from community activities. While HCBS has promoted inclusion in place by supporting individuals from living with their families, they are still excluded from community spaces.

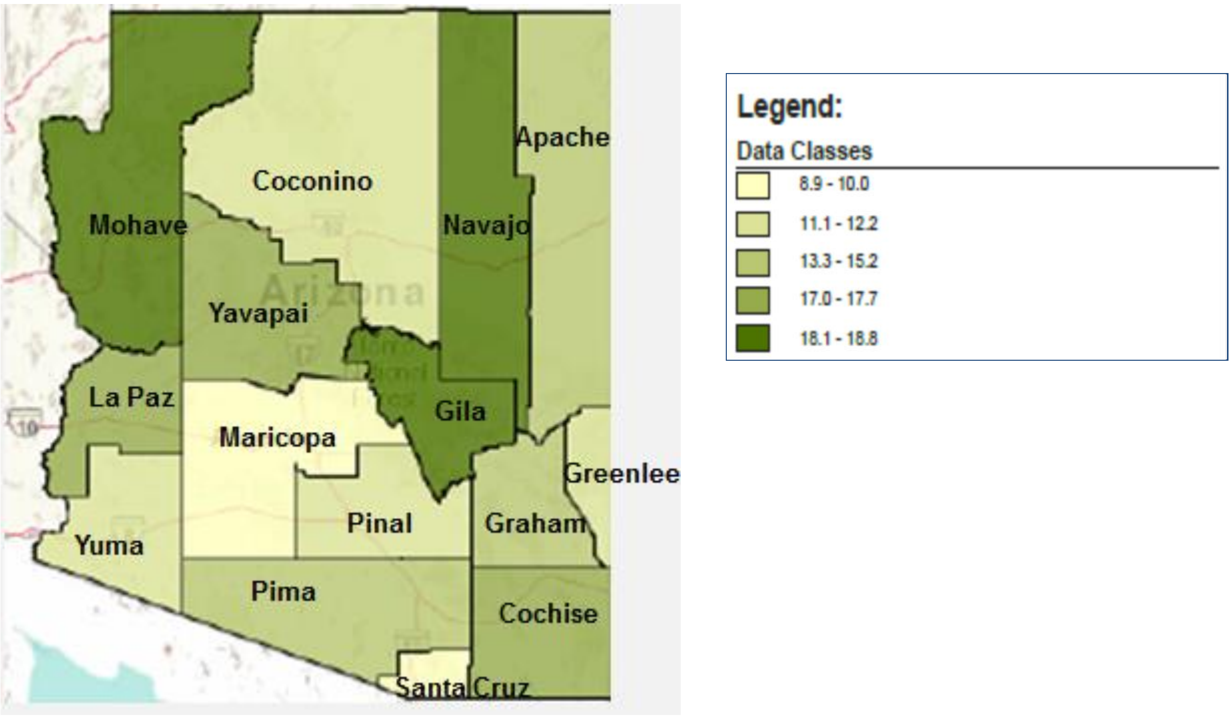
APPENDICES

APPENDIX A: ACRONYMS

AAA – Area Agency on Aging
ABA – Applied Behavior Analysis
ACA – Arizona Commerce Authority
ACDL – Arizona Center for Disability Law
ACRAB – Arizona Civil Rights Advisory Board
ADA – Americans with Disabilities Act
ADE – Arizona Department of Education
ADDPC – Arizona Developmental Disabilities Planning Council
ADHS – Arizona Department of Health Services
ADOH – Arizona Department of Housing
ADOT – Arizona Department of Transportation
AG – Attorney General’s office
AHCCCS – Arizona Health Care Cost Containment System
APS - Adult Protective Services
APSE – Association of People Supporting Employment First
ASD – Autism Spectrum Disorder
ASL – American Sign Language
AT – Assistive TechnologyAZDB101 – Arizona Disability Benefits 101
AZSILC – Arizona State Independent Living Council
AzTAP – Arizona Technology Assistance Program
BIA – Bureau of Indian Affairs
BLS – Bureau of Labor Statistics
CBE – Center-based employment
CMS – Centers for Medicare & Medicaid Services
DAAS – Division of Aging & Adult Services
DBHS – Division of Behavioral Health Services
DCRS – Division of Civil Rights Section
DCS – Department of Child Safety
DCW – Direct Care Worker
DD – Developmental Disability
DDD – Division of Developmental Disabilities
DES – Department of Economic Security
DOE – U.S. Department of Education
DOJ – Department of Justice
DOL – Department of Labor
DTA – Day treatment & training providers
EEOC – Equal Employment Opportunity Commission
ESA – Empowerment Scholarship Account
ESS – Exceptional Student Services
FAPE – Free and Appropriate Public Education
FCSP – Family Caregiver Support Program
GMH – General Mental Health
GSE – Group-supported employment
HCBS – Home and community-based services
HUD – U.S. Department of Housing & Urban Development
ICA – Industrial Commission of Arizona
I/DD – Intellectual and Developmental Disabilities
IDEA – Individuals with Disabilities Education Act
IDLA – Individually Designed Living Arrangements
IEP - Individualized Education Plan
ISE – Individual supported employment
LEA – Local Education Agency
NADLC – Native American Disability Law Center
NCI – National Core Indicators
OCSHCN – Office of Children with Special Health Care Needs
OT – Occupational therapy
PT – Physical therapy
PWD – People with disabilities
RBHA – Regional Behavioral Health Authority
RSA-VR – Rehabilitation Services Administration - Vocational Rehabilitation program
RSK – Raising Special Kids
SBA – Small Business Administration
SBDC – Small Business Development Center
S.E.E.D – Self-Employment for Entrepreneurs with Disabilities
SMI – Serious Mental Illness
SNAP – Supplemental Nutritional Assistance Program
SSI – Supplemental Security Income
ST – Speech Therapy
TANF – Temporary Assistance for Needy Families
TSW – Transition School to Work
UCEDD - University Centers for Excellence in Developmental Disabilities
UCP – United Cerebral Palsy

APPENDIX B: STATE INFORMATION & DISABILITY CHARACTERISTICS

Source: U.S. Census Bureau, 2009-2013, 5-Year American Community Survey
Disability Prevalence by County



Racial and Ethnic Diversity of the State Population

Race/Ethnicity	Percentage
White Alone	79.2%
Black or African American Alone	4.2%
American Indian or Alaska Native Alone	4.4%
Asian Alone	2.8%
Native Hawaiian and Other Pacific Islander Alone	0.2%

Some other race alone	8.7%
Two or more races	6.2%
Hispanic or Latino (of any race)	29.9%

Poverty Rate

Percentage Whose Income is Below the Poverty Level within the last 12 months	**Percentage**
Families	13.0%
All individuals	17.9%
Under 18	25.5%

Percentage of all Disabilities by Age

People in the State with a disability	**Percentage**
Population 5 to 17 years	7.1%
Population 18 to 64 years	50.4%
Population 65 years and over	42.0%

Prevalence of DD: People with disabilities make up the second largest minority group in Arizona (12.2%) behind Latinos (30.2%). With a 1.8% prevalence rate of DD for the overall population, (as suggested by the Administration on Developmental Disabilities), there are estimated to be approximately 116,635 individuals with DD in Arizona – only 33,272 of them are DDD members. A 2015 Arizona poll finds that at least 30% of Arizonans either care for (14%) or have a disability (16%).

Residential Settings

Year	Total Served	A. Number Served in Setting of <6 (per 100,000)	B. Number Served in Setting of >7 (per 100,000)	C. Number Served in Family Setting (per 100,000)	D. Number Served in Home of Their Own (per 100,000)
2014*	33,933	No data	No data	No data	No Data
2013	33,171	2,882	106	29,987	456
2012	32,681	2,870	108	29,264	439

*Percentages listed in FY 2014 annual report don’t correspond with actual numbers.

Race and Hispanic or Latino Origin of people with a disability	**Percentage**
White Alone	13.7%
Black or African American Alone	11.7%
American Indian or Alaska Native Alone	12.8%
Asian Alone	6.2%
Native Hawaiian and Other Pacific Islander Alone	10.1%
Some other race alone	8.7%
Two or more races	10.3%
Hispanic or Latino (of any race)	7.9%

Employment Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Employed	33.5%	74.5%
Not in Labor Force	58.0%	21.6%

Educational Attainment Population Age 25 and Over	Percentage with a disability	Percentage without a disability
Less than high school graduate	21.3	12.7
High school graduate, GED, or alternative	29.0	23.5
Some college or associate’s degree	33.3	34.5
Bachelor’s degree or higher	16.3	29.3

Earnings in Past 12 months Population Age 16 and Over with Earnings	Percentage with a disability	Percentage without a disability
$1 to $4,999 or loss	18.2	10.5
$5,000 to $14,999	22.4	16.6
$15,000 to $24,999	15.6	15.6
$25,000 to $34,999	12.6	14.2

Poverty Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Below 100 percent of the poverty level	20.4	14.8
100 to 149 percent of the poverty level	13.4	9.3
At or above 150 percent of the poverty level	66.2	75.8

APPENDIX C: CONSUMER SURVEY AND ANALYSIS (2015)

ADDPC Consumer Survey -Frequencies

Did you get your disability before the age of 22 AND is it permanent?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	212	65.0	84.1	84.1
	No	10	3.1	4.0	88.1
	I don't know	30	9.2	11.9	100.0
	Total	252	77.3	100.0	
Missing	System	74	22.7		
Total		326	100.0		

Please choose the answer that best describes you as the person who is completing this survey:

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I am a person with a disability.	37	11.3	15.5	15.5
	I am a family member filling this survey out for my loved one with a disability. He or she is not with me. I am serving	56	17.2	23.4	38.9
	I am none of the above. (Choosing this will end the survey.)	4	1.2	1.7	40.6
	I am a service provider or caregiver of a person with disability, and I am helping him/her fill this survey out. He/she	142	43.6	59.4	100.0
	Total	239	73.3	100.0	
Missing	System	87	26.7		
Total		326	100.0		

How old are you (the person with the disability)?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 - 3 years old	2	.6	.9	.9
	4 - 21 years old	43	13.2	18.6	19.5
	22 - 59 years old	163	50.0	70.6	90.0
	60 years and older	23	7.1	10.0	100.0
	Total	231	70.9	100.0	
Missing	System	95	29.1		
Total		326	100.0		

Have you ever been restrained or secluded (separated) in a room by yourself at school?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	29	8.9	70.7	70.7
	Yes	12	3.7	29.3	100.0
	Total	41	12.6	100.0	
Missing	System	285	87.4		
Total		326	100.0		

What county do you live in?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Cochise	5	1.5	2.2	2.2
	Coconino	1	.3	.4	2.6
	Maricopa	65	19.9	28.5	31.1
	Mohave	8	2.5	3.5	34.6
	Pima	143	43.9	62.7	97.4
	Pinal	2	.6	.9	98.2
	Yavapai	3	.9	1.3	99.6
	Yuma	1	.3	.4	100.0
	Total	228	69.9	100.0	
Missing	System	98	30.1		
Total		326	100.0		

Are you?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	144	44.2	62.1	62.1
	Female	88	27.0	37.9	100.0
	Total	232	71.2	100.0	
Missing	System	94	28.8		
Total		326	100.0		

What type of disability do you have? (Please check all that apply.)

		Frequency	**Percent**		
	Intellectual Disability	147	45.1		
	Mental illness or behavioral health	50	15.3		
	Autism	49	15.0		
	Learning disability	36	11.0		
	Other physical disability (i.e. hearing, vision, etc...)	31	9.5		
	Epilepsy	20	6.1		
	Other (please specify)	20	6.1		
	Cerebral palsy	17	5.2		
	Down syndrome	13	4.0		
	Traumatic brain injury	10	3.1		
	I don't know	4	1.2		

What type of disability do you have? OTHER - listed:

		Frequency	Percent
Valid			
	Asperger's Syndrome	1	.3
	Club feet	1	.3
	Complex Trauma/PTSD	1	.3
	Fragile X Syndrome	1	.3
	genetic/health issues	1	.3
	inborn error of metabolism	1	.3
	Massive Stroke	1	.3
	Mental Retardation	1	.3
	Microcephalic. ADHD	1	.3

	Mitochondrial Disorder/rare genetic disorder	1	.3
	MS	1	.3
	neurologically impaired - 42, functions at 3-1/2 years of age	1	.3
	Non Epileptic Seizures	1	.3
	PTSD	1	.3
	sensory processing	1	.3
	Speech	1	.3
	Speech Apraxia, feeding disability	1	.3
	Tourette Syndrome	1	.3
	Type 1 Diabetes (autism interfers with diabetic care)	1	.3
	vocal cord damage	1	.3
	Total "Other"	**20**	

How do you define your racial/ethnic identity? (Please choose all that apply)					
		Frequency	Percent		
	American Indian or Alaska Native	11	3.4		
	Asian	4	1.2		
	Black or African American	3	.9		
	Hispanic or Latino	53	16.3		
	White	161	49.4		
	Other (please specify)	3	.9		
	Other listed:				
	African	1	.3		
	greek descendent	1	.3		
	Italian	1	.3		

Where do you currently live?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Foster care or host home	12	3.7	5.2	5.2
	Group Home or Adult Developmental Home	56	17.2	24.1	29.3
	I share a house or apartment	14	4.3	6.0	35.3
	Nursing facility	1	.3	.4	35.8
	In my family's home	122	37.4	52.6	88.4
	My own house or apartment	25	7.7	10.8	99.1
	Other (please specify)	2	.6	.9	100.0
	Total	232	71.2	100.0	
Missing	System	94	28.8		
Total		326	100.0		

What is the highest level of education you completed:					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than high school	158	48.5	70.5	70.5
	GED	2	.6	.9	71.4
	Graduated high school/certificate of completion	45	13.8	20.1	91.5
	Trade/technical school	1	.3	.4	92.0
	Some college	8	2.5	3.6	95.5
	Bachelor's degree	5	1.5	2.2	97.8
	Graduate degree	5	1.5	2.2	100.0
	Total	224	68.7	100.0	
Missing	System	102	31.3		
Total		326	100.0		

Among those who live with a family member helping them, the most common age of the family member is between 45 and 60.

I do the following: (Please check all that apply)					
		Frequency	Percent		
	Go to a day program for people with developmental disabilities	101	31.0		
	Go out to eat	171	52.5		
	Go on vacation	124	38.0		
	Go shopping	151	46.3		
	Go to church/synagogue/temple	78	23.9		
	Volunteer in the community	27	8.3		
	Play sports (including Special Olympics)	50	15.3		
	Work and get a paycheck or I'm self-employed	109	33.4		
	Exercise	74	22.7		
	Go to school	50	15.3		
	Other (please specify)	26	8.0		
	None of the above	2	.6		
	OTHER - Listed:				
		Frequency	Percent		
Valid					
	2 year old	1	.3		
	counseling	1	.3		
	dance	1	.3		
	dances	1	.3		
	go to dances	1	.3		
	go to library and read books	1	.3		
	gymnastics	1	.3		
	hobbies	1	.3		
	In a 24/7 Group Home	1	.3		
	live in a residential group home w/ 24/7 care	1	.3		
	out & about(device users) Arc rec program, cooking group=ABIL	1	.3		
	outings limited, movies, park, walks in neighborhood	1	.3		
	perform on stage	1	.3		

	play music and dance	1	.3		
	Play video games	1	.3		
	REC. PROGRAM	1	.3		
	ride Sun Van	1	.3		
	Special Olympics	1	.3		
	Spend time at home with Mother	1	.3		
	Spend time with my husband and baby.	1	.3		
	take art classes	1	.3		
	therapies PT, OT, ST, music	1	.3		
	Therapy	1	.3		
	Time with Mother	1	.3		
	Video games	1	.3		
	Write and self-publish epic poetry	1	.3		

Agree? "I would like to have a job."

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Agree	98	30.1	70.5	70.5
	Disagree	15	4.6	10.8	81.3
	Don't know	26	8.0	18.7	100.0
	Total	139	42.6	100.0	
Missing	System	187	57.4		
Total		326	100.0		

Please select the answer that best fits your work situation.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I get paid LESS than $8.05 per hour	62	19.0	57.4	57.4
	I get paid $8.05 or MORE per hour	38	11.7	35.2	92.6
	I am self-employed.	1	.3	.9	93.5
	I don't know.	7	2.1	6.5	100.0
	Total	108	33.1	100.0	
Missing	System	218	66.9		
Total		326	100.0		

How many hours per week do you work?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 10 hours per week	10	3.1	9.3	9.3
	11-20 hours per week	14	4.3	13.1	22.4
	21-31 hours per week	15	4.6	14.0	36.4
	32-40 hours per week	63	19.3	58.9	95.3
	More than 40 hours per week	5	1.5	4.7	100.0
	Total	107	32.8	100.0	
Missing	System	219	67.2		
Total		326	100.0		

Do you wish your employer gave you more hours, fewer hours, / or are they about

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	More hours	12	3.7	11.3	11.3
	Fewer hours	10	3.1	9.4	20.8
	Just right	84	25.8	79.2	100.0
	Total	106	32.5	100.0	
Missing	System	220	67.5		
Total		326	100.0		

How did you find out about this job or career choice?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Friend	6	1.8	5.6	5.6
	Family member	2	.6	1.9	7.5
	A service provider, agency, or government worker helped me	88	27.0	82.2	89.7
	I found it myself	8	2.5	7.5	97.2
	Other:	3	.9	2.8	100.0
	Total	107	32.8	100.0	
Missing	System	219	67.2		
Total		326	100.0		

How did you find out about this job or career choice?-TEXT

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		323	99.1	99.1	99.1
	combo - family, friends, research	1	.3	.3	99.4
	Through CPES	1	.3	.3	99.7
	Through work program while in high school	1	.3	.3	100.0
	Total	326	100.0	100.0	

Of the following, which do you use the most to get to your / job? (Please check					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Public bus or para-transit (e.g. Dial A Ride, etc...)	59	18.1	56.2	56.2
	Drive my own car	10	3.1	9.5	65.7
	Family members or friends drive me	9	2.8	8.6	74.3
	My provider drives his/her own personal vehicle	3	.9	2.9	77.1
	I walk or ride a bicycle	4	1.2	3.8	81.0
	Agency provides transportation	11	3.4	10.5	91.4
	Taxi cab (not Dial-A-Ride)	4	1.2	3.8	95.2
	Other: Fill in the blank below.	5	1.5	4.8	100.0
	Total	105	32.2	100.0	
Missing	System	221	67.8		
Total		326	100.0		

Of the following, which do you use the most to get to your / job? OTHER LISTED					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		321	98.5	98.5	98.5
	Group Home Van	1	.3	.3	98.8
	Handi Car	1	.3	.3	99.1
	School bus	1	.3	.3	99.4
	work at day program	2	.6	.6	100.0
	Total	326	100.0	100.0	

Which of the following statements about speaking up for yourself apply to you?			
		Frequency	Percent
	I am afraid to speak up for myself	19	5.8
	I don't know how to speak up for myself	85	26.1
	Others speak for me so I don't need to	36	11.0
	No one listens to me	7	2.1
	I speak up for myself all of the time	141	43.3
	Totals	288	88

Do you own a computer (including Notebook or iPad)?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	117	35.9	48.0	48.0
	Yes	127	39.0	52.0	100.0
	Total	244	74.8	100.0	
Missing	System	82	25.2		
Total		326	100.0		
Do you use the Internet regularly?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes, and I could not live without it!	45	13.8	18.4	18.4
	Yes.	70	21.5	28.6	46.9
	No, but I would really like to. I just don't have internet.	11	3.4	4.5	51.4
	No, I don't know how.	75	23.0	30.6	82.0
	No. Don't care to.	44	13.5	18.0	100.0
	Total	245	75.2	100.0	
Missing	System	81	24.8		
Total		326	100.0		

Do you have a cell phone? (e.g., smartphone, flip phone, etc.)					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes, and I could not live without it!	41	12.6	17.0	17.0
	Yes.	87	26.7	36.1	53.1
	No, but I really need one.	14	4.3	5.8	58.9
	No, I don't know how to use a cell phone.	59	18.1	24.5	83.4
	No. Don't care about having one.	40	12.3	16.6	100.0
	Total	241	73.9	100.0	
Missing	System	85	26.1		
Total		326	100.0		

What problems do you worry about? (Check all that apply)

		Frequency	Percent		
	I don't worry about anything	82	25.2		
	Not having enough money	56	17.2		
	Loneliness	35	10.7		
	Never being able to be independent	35	10.7		
	What happens to me if my family can no longer take care of me	34	10.4		
	My health	33	10.1		
	Not able to get or keep a job	29	8.9		
	Concern about living on my own	27	8.3		
	Family doesn't agree with what I want	26	8.0		
	Other:	23	7.1		
	Finding transportation	20	6.1		
	Losing my public benefits if I work	16	4.9		
	Having no place to live	15	4.6		
	Not having a family of my own	13	4.0		
	OTHER - LISTED:				
	I'm in my own world,don't have those kinds of thoughts I	1	.3		
	bullies	1	.3		
	Discrimination against people with disability	1	.3		
	family interactions	1	.3		
	FAMILY NOT KEEPING IN TOUCH	1	.3		
	I am non verbal, and insufficiently capable to express any worries I may have	1	.3		
	if I'll lose my temper and hurt someone I love	1	.3		
	In the future when family is older it will be harder to get to work	1	.3		
	Issues with my wife/also with a developmental disability	1	.3		
	My daughter	1	.3		
	my mom and dad help me with everything	1	.3		
	n/a too young, only 4yrs old	1	.3		

	Na	1	.3		
	Not able to communicate my worries.	1	.3		
	NOT HAVING ANY FRIENDSHIPS	1	.3		
	Not having internet	1	.3		
	Parent comment - not self aware enough to worry.	1	.3		
	progressive disorder, being able to work less	1	.3		
	Religious beliefs	1	.3		
	she is nonverbal, and lives in the next activity	1	.3		
	who is going to feed me	1	.3		
	worries or has anxiety about unfamiliar people, places, events	1	.3		

If each of the below options were accessible and available with some supports, where would you like to live?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	With my family (e.g., my mom, dad, and/or sister or brother)	107	32.8	46.9	46.9
	In my own house	59	18.1	25.9	72.8
	In a group home (i.e. house with two other people with disabilities and professional staff)	15	4.6	6.6	79.4
	In my own apartment in a building with people with and without disabilities	32	9.8	14.0	93.4
	In my own apartment in a building that houses only people with disabilities	3	.9	1.3	94.7
	With another family in their home	12	3.7	5.3	100.0
	Total	228	69.9	100.0	
Missing	System	98	30.1		
Total		326	100.0		

How often do you eat the following?					
Fresh fruits and veg					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Rarely or never	11	3.4	6.4	6.4
	At least once a week	27	8.3	15.8	22.2
	More than once a week	58	17.8	33.9	56.1
	Daily	75	23.0	43.9	100.0
	Total	171	52.5	100.0	
Missing	System	155	47.5		
Total		326	100.0		
Canned, dried, or frozen fruits and veg					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Rarely or never	23	7.1	13.5	13.5
	At least once a week	30	9.2	17.5	31.0
	More than once a week	81	24.8	47.4	78.4
	Daily	37	11.3	21.6	100.0
	Total	171	52.5	100.0	
Missing	System	155	47.5		
Total		326	100.0		
Fast food					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Rarely or never	55	16.9	32.0	32.0
	At least once a week	86	26.4	50.0	82.0
	More than once a week	27	8.3	15.7	97.7
	Daily	4	1.2	2.3	100.0
	Total	172	52.8	100.0	
Missing	System	154	47.2		

Total		326	100.0		
Candy, cookies, chips					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Rarely or never	59	18.1	34.3	34.3
	At least once a week	51	15.6	29.7	64.0
	More than once a week	35	10.7	20.3	84.3
	Daily	27	8.3	15.7	100.0
	Total	172	52.8	100.0	
Missing	System	154	47.2		
Total		326	100.0		
In the past year, has your family ever had to cut the / size of meals or skip meals?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	220	67.5	92.8	92.8
	Yes	17	5.2	7.2	100.0
	Total	237	72.7	100.0	
Missing	System	89	27.3		
Total		326	100.0		

Have you had a medical check up in the past two years?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	6	1.8	2.5	2.5
	Yes	230	70.6	97.5	100.0
	Total	236	72.4	100.0	
Missing	System	90	27.6		
Total		326	100.0		
If no, why not? -					
	I cannot afford the cost	1			
	I cannot find a doctor who is able to accommodate my disability	1			
	i am very healty and my parents have not taken me in for a health check up i have seen doctors in the last 2 years just not for a check up.	1			
	I don't like to go to doctor	1			
	no one made an appointmeny	1			
	not needed	1			
	Seen doctor but not for check up	1			

Have you had a dental exam in the past year?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	28	8.6	12.3	12.3
	Yes	200	61.3	87.7	100.0
	Total	228	69.9	100.0	
Missing	System	98	30.1		
Total		326	100.0		
If no, why not? -					
	I cannot afford the cost	6			
	I had a problem with transportation that kept me from getting to the dentist's office	2			
	Nearby dentists do not accept my health payment plan	6			
	have had dentures since I was in my 20s and currently is difficult to get to my preferred dentist due to driving distance	1			
	Have not thought about it	1			
	he has dentures. schedule for exam next two weeks. there are no issues.	1			
	I do not like getting my teeth worked on	1			
	Insurance don't cover	1			
	Insurance won't cover	1			
	no teeth	1			
	no time, not needed	1			
	sensory concerns	1			

	Wasn't cooperative and acted out	1			
	Wears dentures	1			

In the last week, how many times have you been unable to go where you wanted to go?						
	Freq.	Percent				
Never	201	86.6%				
1-2 times	22	9.5%				
3-5 times	6	2.6%				
> 5 times	3	1.3%				
Total	232	100%				

In a normal week, what type of transportation do you usually use?					
		Frequency	Percent		Percent "happy" w/ this mode:
	1. Public bus or para-transit (e.g. Dial A Ride, etc...)	116	35.6		56.5%
	3. Family members or friends giving me a ride	79	24.2		78.2%
	6. Agency provides transportation	48	14.7		70.8%
	5. Walking or riding a bicycle	19	5.8		50.0%
	2. Driving my own car	16	4.9		68.8%
	8. Other: Fill in the blank below (if applicable)	13	4.0		66.7%
	4. My personal assistant uses his/her own car	9	2.8		55.6%
	7. Taxi cab (not Dial-A-Ride)	9	2.8		77.8%

Other TEXT:					
adh providers take him	1	.3		**Number of respondents who are UNHAPPY with this mode of transport:**	
Group home staff	1	.3		Family Members	5
Group Home Van	1	.3		Public bus or para-transit	4
Handi Car	1	.3		Personal assistant	2
handicar	1	.3		Walking or riding	2
have a golden travel scooter that I can use but am limited to 8 miles in distance	1	.3		Agency	2
IDLA Staff	1	.3		Driving own car	2
patient is only 4yrs old	1	.3		Other	1
School bus	2	.6		Taxi cab	0
Sun Shuttle	1	.3			
Sun Van	1	.3			

<u>Why are you not happy with this transportation option?</u>	
Public bus or paratransit:	no responses
Driving my own car:	1 respondent = not available where I live
Family members of friends:	1 respondent = long wait times; 1 respondent = unreliable; 4 respondents = not available at times I need it
Personal assistant:	1 respondent = unreliable; 1 respondent = not available at times I need it
Walking or bike:	1 respondent = weather problems; 1 respondent = unreliable; 1 respondent = too slow
Agency transport:	1 respondent = long wait times; 2 respondents = unreliable; 2 respondents = not available at times I need it
Taxi cab:	no responses
Other:	1 respondent = long wait times; 1 respondent = unreliable; 1 respondent = not available at times when I need it

Satisfaction with Services:

Early intervention

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I have not had this service.	60	18.4	66.7	66.7
	Happy	17	5.2	18.9	85.6
	Unhappy	7	2.1	7.8	93.3
	Neither happy nor unhappy	6	1.8	6.7	100.0
	Total	90	27.6	100.0	
Missing	System	236	72.4		
Total		326	100.0		

School-based special education

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I have not had this service.	37	11.3	38.5	38.5
	Happy	26	8.0	27.1	65.6
	Unhappy	14	4.3	14.6	80.2
	Neither happy nor unhappy	19	5.8	19.8	100.0
	Total	96	29.4	100.0	
Missing	System	230	70.6		
Total		326	100.0		

DDD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I have not had this service.	27	8.3	12.6	12.6
	Happy	156	47.9	72.9	85.5
	Unhappy	9	2.8	4.2	89.7
	Neither happy nor unhappy	22	6.7	10.3	100.0
	Total	214	65.6	100.0	

Missing	System	112	34.4		
Total		326	100.0		
Behavioral health services					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I have not had this service.	41	12.6	33.3	33.3
	Happy	63	19.3	51.2	84.6
	Unhappy	4	1.2	3.3	87.8
	Neither happy nor unhappy	15	4.6	12.2	100.0
	Total	123	37.7	100.0	
Missing	System	203	62.3		
Total		326	100.0		
Vocational rehab services					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I have not had this service.	70	21.5	74.5	74.5
	Happy	10	3.1	10.6	85.1
	Unhappy	8	2.5	8.5	93.6
	Neither happy nor unhappy	6	1.8	6.4	100.0
	Total	94	28.8	100.0	
Missing	System	232	71.2		
Total		326	100.0		
Foster care					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I have not had this service.	84	25.8	93.3	93.3
	Happy	2	.6	2.2	95.6
	Unhappy	1	.3	1.1	96.7
	Neither happy nor	3	.9	3.3	100.0

	unhappy				
	Total	90	27.6	100.0	
Missing	System	236	72.4		
Total		326	100.0		

Have you had any type of physical, speech, occupational, applied behavior analysis or sensory therapy in the last five years?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	161	49.4	69.1	69.1
	Yes	72	22.1	30.9	100.0
	Total	233	71.5	100.0	
Missing	System	93	28.5		
Total		326	100.0		
How happy were you with therapy services?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very happy	27	8.3	100.0	100.0
Missing	System	299	91.7		
Total		326	100.0		

Why were you not happy with therapy overall?			
		Frequency	Percent
	I did not like my worker or the worker did not seem trained	2	.6
	I did not get services based on what I needed and wanted	4	1.2
	I had to wait a long time to get services	2	.6
	Once the services started, they were not always delivered when they were supposed to be.	1	.3
	Other: Please explain.	4	1.2
	OTHER TEXT:		
	I get ot and am happy would like to have it more often. I am supposed to get speech but there are not any in my area	1	
	I hate Therapy	1	
	Lack of local services, and the quality of services that are available in our town are substandard and inefficient. Our family has to travel an hour away to get quality OT and Speech.	1	
	Not enough therapists in Bullhead City, AZ	1	

Are you currently waiting for or have you been turned away for any type of services to help you, like employment training, day programs, therapy services, personal attendant services, etc. in the past five years?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	191	58.6	81.6	81.6
	Yes	43	13.2	18.4	100.0
	Total	234	71.8	100.0	
Missing	System	92	28.2		
Total		326	100.0		

What services are you waiting for or have you been turned away / from?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	VR	4	1.2	10.0	10.0
	DDD services	7	2.1	17.5	27.5
	Day program	7	2.1	17.5	45.0
	Therapy services	9	2.8	22.5	67.5
	Other: Fill in the blank.	13	4.0	32.5	100.0
	Total	40	12.3	100.0	
Missing	System	286	87.7		
Total		326	100.0		

What services are you waiting for or have you been turned away / from?-TEXT					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		313	96.0	96.0	96.0
	Attendant care / Music therapy	1	.3	.3	96.3
	Board Certified Behavior Analyst	1	.3	.3	96.6
	day program and work program	1	.3	.3	96.9
	I have ddd but cannot find providers, or qualified providers so I don't get to participate.	1	.3	.3	97.2
	I think it's just awful for HAB-M services to be automatically discontinued at first grade!!! More often than not behaviors get extremely worse/harder as they get older. And insurances are still denying these services as well!!	1	.3	.3	97.5
	job	1	.3	.3	97.9
	Lack of the type of therapy I need in my community.	1	.3	.3	98.2
	Long Term Care	1	.3	.3	98.5
	Music therapy, hyperbaric chamber therapy	1	.3	.3	98.8
	speeh and occupational	1	.3	.3	99.1
	VR and DDD	1	.3	.3	99.4
	VR=meaning? / DDD=meaning? Department of Defense? / Therapy denied.	1	.3	.3	99.7

	When the state became broke the only services that my son was receiving were respite and habilitation, along with funding to allow him to attend the Marc Center program. As a result we now pay privately to the center so that my son continues t	1	.3	.3	100.0
	Total	326	100.0	100.0	

Have you ever called the police as a victim of crime?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	208	63.8	90.0	90.0
	Yes	23	7.1	10.0	100.0
	Total	231	70.9	100.0	
Missing	System	95	29.1		
Total		326	100.0		
Have you ever been arrested?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	219	67.2	94.0	94.0
	Yes	14	4.3	6.0	100.0
	Total	233	71.5	100.0	
Missing	System	93	28.5		
Total		326	100.0		

Please select the answer that best fits your feelings about the minimum wage and workers with disabilities:					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	What is that?	56	17.2	24.7	24.7
	I think that everyone should be paid at least the minimum wage, even if they have a disability.	43	13.2	18.9	43.6
	I don't care if I get paid the minimum wage or not. I just want to be paid for the work I do.	67	20.6	29.5	73.1
	If you make businesses pay workers with disabilities more, then we will lose jobs.	7	2.1	3.1	76.2
	I don't know how I feel about it.	54	16.6	23.8	100.0
	Total	227	69.6	100.0	
Missing	System	99	30.4		
Total		326	100.0		

Do you have a bank account with your name on it?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	65	19.9	36.1	36.1
	Yes	115	35.3	63.9	100.0
	Total	180	55.2	100.0	
Missing	System	146	44.8		
Total		326	100.0		

If you could set up a tax-free savings account (i.e. called the / ABLE account) with your own money that you can continue to add and take money out at any time (tax free) … would you do it?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes.	110	33.7	76.4	76.4
	No, I don't have enough money to put into a savings account.	18	5.5	12.5	88.9
	No.	16	4.9	11.1	100.0
	Total	144	44.2	100.0	
Missing	System	182	55.8		
Total		326	100.0		

Question: Is there a difference in outcomes among those who speak up for themselves? Is there an ethnic / racial difference in this?

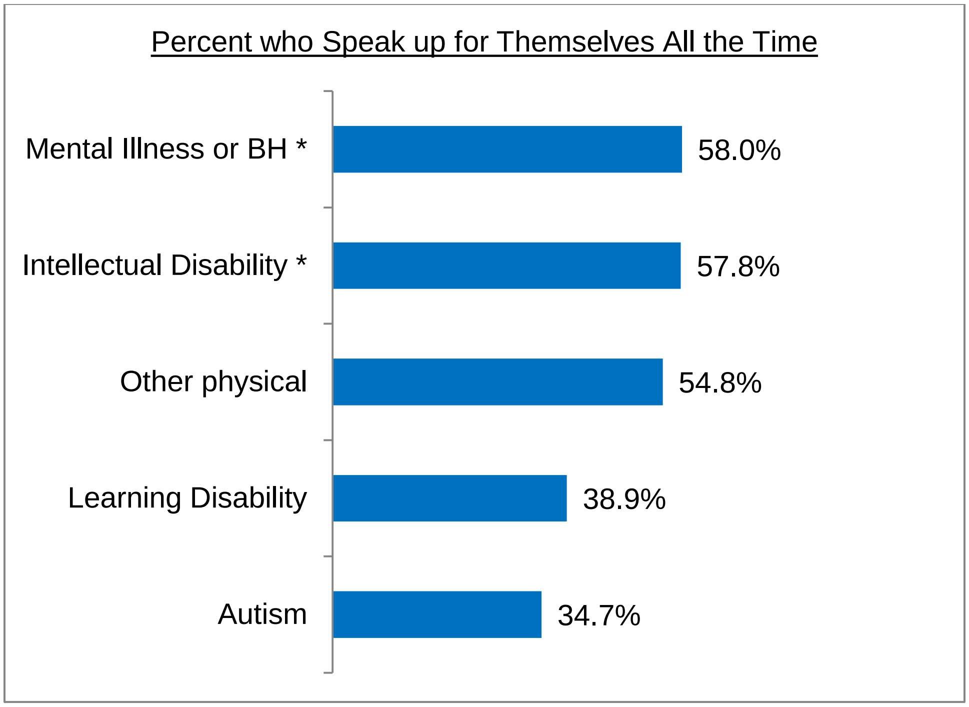
Methods: The survey question, "Which of the following statements about speaking up for yourself apply to you?" was examined for those who responded, "I speak up for myself all the time." Those who speak up for themselves were examined against almost all other survey variables for reportable findings. Ethnic differences were also examined.

Results:

1. There is no statistical difference in the proportion of whites and Latinos who speak up for themselves all the time. Other racial categories could not be examined due to their small representation among the respondents.

   Almost 59% of whites speak up for themselves all of the time, and almost 55% of Latinos speak up for themselves almost all of the time.

2. *Those with mental illness / behavioral health issues and with intellectual disabilities are statistically significantly more likely to speak up for themselves all of the time than those with other disabilities. The percent who speak up for themselves all of the time, by respondents' most common disabilities, is listed in the figure below:



3. Respondents who work and get a paycheck; exercise; volunteer in the community; and play sports are significantly more likely to speak up for themselves than respondents who don't do these activities. Respondents who go to school are significantly less likely to speak up for themselves than respondents who do not go to school.

4. Those who speak up for themselves all the time are significantly more likely to worry about not having enough money than those who don't and significantly more likely to worry about their health than those who don't. Among those who speak up for themselves, there are no significant differences between those who worry about loneliness and those who don't; between those who worry about not being independent and those who don't; and those who worry about what will happen to them if their family can no longer take care of them and those who don't.

5. Those who are happy with services provided by the DDD are significantly more likely to speak up for themselves than those who are unhappy.

6. Those who are not currently waiting or have not been turned away from services are significantly more likely to speak up for themselves than those who are currently waiting or have been turned away from services.

7. Those who have ever called the police as a victim of a crime are significantly more likely to speak up for themselves than those who have not. Similarly, those who have ever been arrested are significantly more likely to speak up for themselves than those who have not.

8. Those with a bank account are significantly more likely to speak up for themselves than those who do not.

9. The older the survey respondent is, the more likely they are to speak up for themselves.

10. Women and men are not more or less likely to speak up for themselves than the opposite gender.

11. Respondents who live in a group home or developmental home are significantly more likely to speak up for themselves than those who live in their family's home.

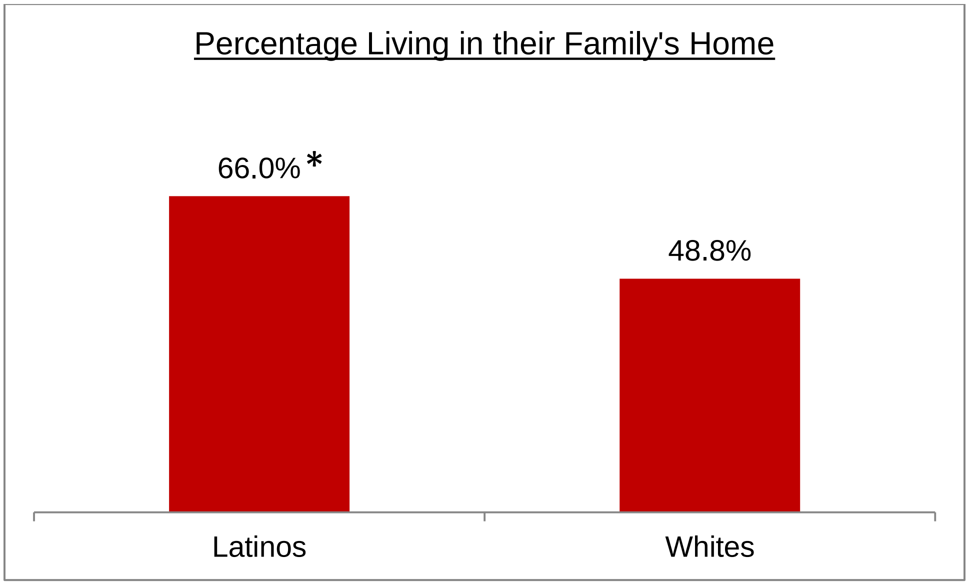
12. Respondents who go to a day program are more likely to speak up for themselves than respondents who don't go to a day program.

Question: Do Latinos live with their families at a higher rate than other groups?

Methods: The survey question, "Where do you currently live?" was examined among whites and Latinos. Other race / ethnic categories did not have enough responses to be included in crosstabulations. Other potential differences between Latinos and whites were examined.

Results:

1. Latinos are statistically significantly more likely to live in their family's homes than whites, as shown in the figure below.



2. Whites are slightly more likely to be waiting for services or to have been turned down for services than Latinos, but the difference is not significant.

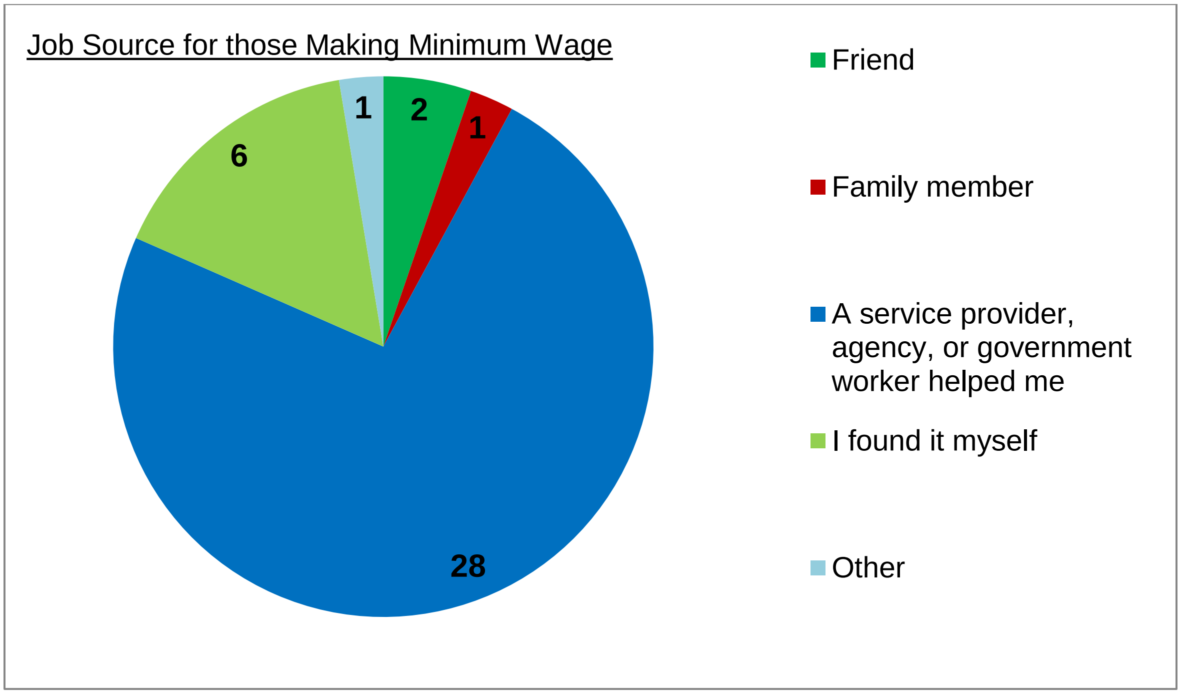
3. Latinos are slightly more likely to have called the police as a victim of a crime than whites, but whites are slightly more likely to have been arrested than Latinos. These differences are not significant.

Question: For those who have jobs that make a minimum wage or more, how many of those were found through providers vs. on their own or through family or friends?

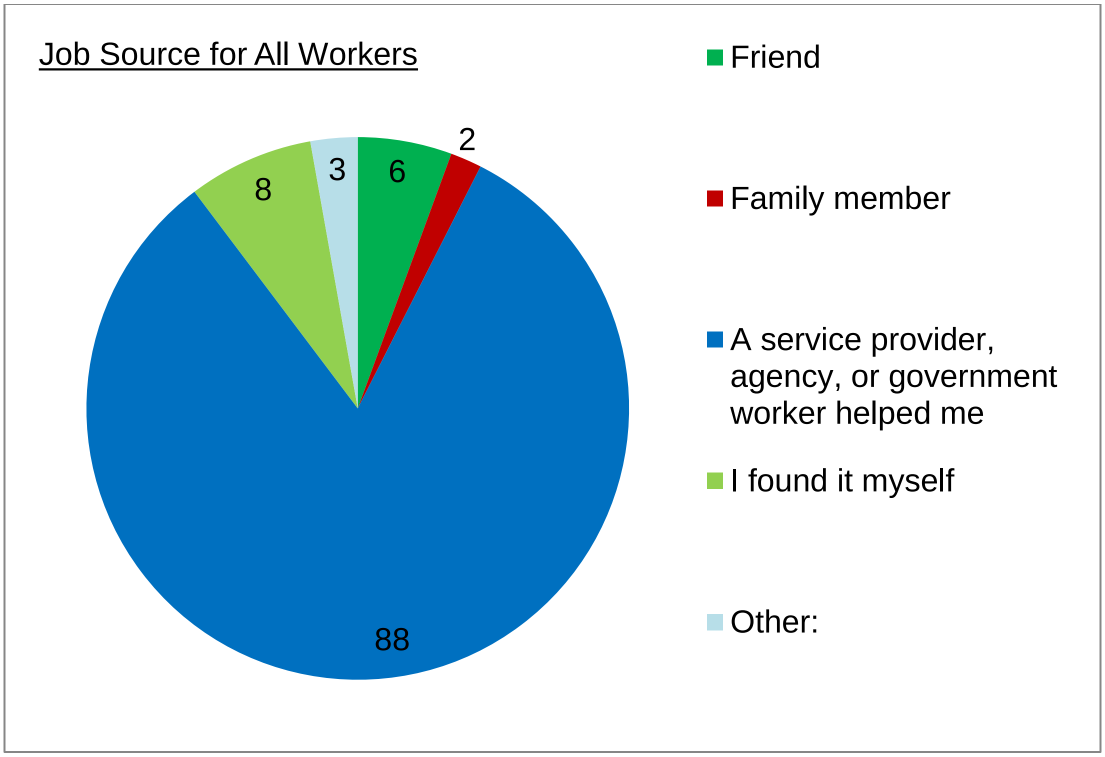
Methods: The survey question, “How did you find out about this job or career choice?” was examined among those who make a minimum wage or more and among all respondents with a job.

Results:

1. Thirty-eight survey respondents make minimum wage or more. The job source for these 38 is detailed in the figure below.



2. *One hundred and nine survey respondents work and get a paycheck or are self-employed. The job source for these 109 is detailed in the figure below.

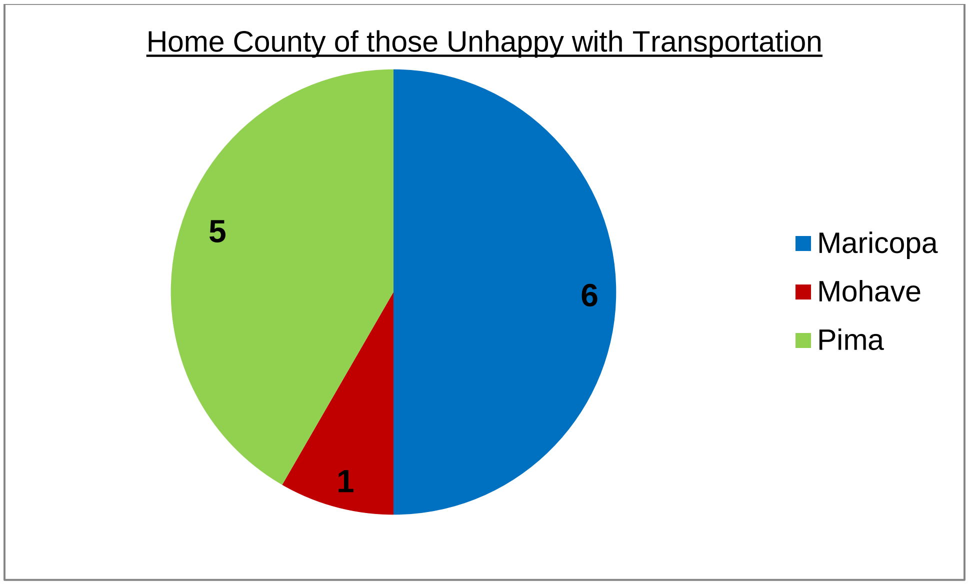

Job Source for All Workers
6
2
88
8
3
🟩 Friend
🟥 Family member
🟦 A service provider, agency, or government worker helped me
🟩 I found it myself
🟦 Other:

Question: For those who report dissatisfaction with transportation, is there a correlation between rural vs. urban?

Methods: The survey question, “What county do you live in?” was examined among those who were not happy with any transportation means (“How happy are you with the ability of your transportation to get you where you want to go when you want to be there?”).

Results:

1. Only 13 respondents were unhappy with any of their transportation means. Their home counties are shown in the figure below (one respondent did not reply where he/she lives). Among those who are unhappy with their transportation, 50% of them live outside of Maricopa County. Among all survey respondents, 71% of them live outside of Maricopa County. While stark, this difference is not significant, likely due to the small (n=13) subsample size.

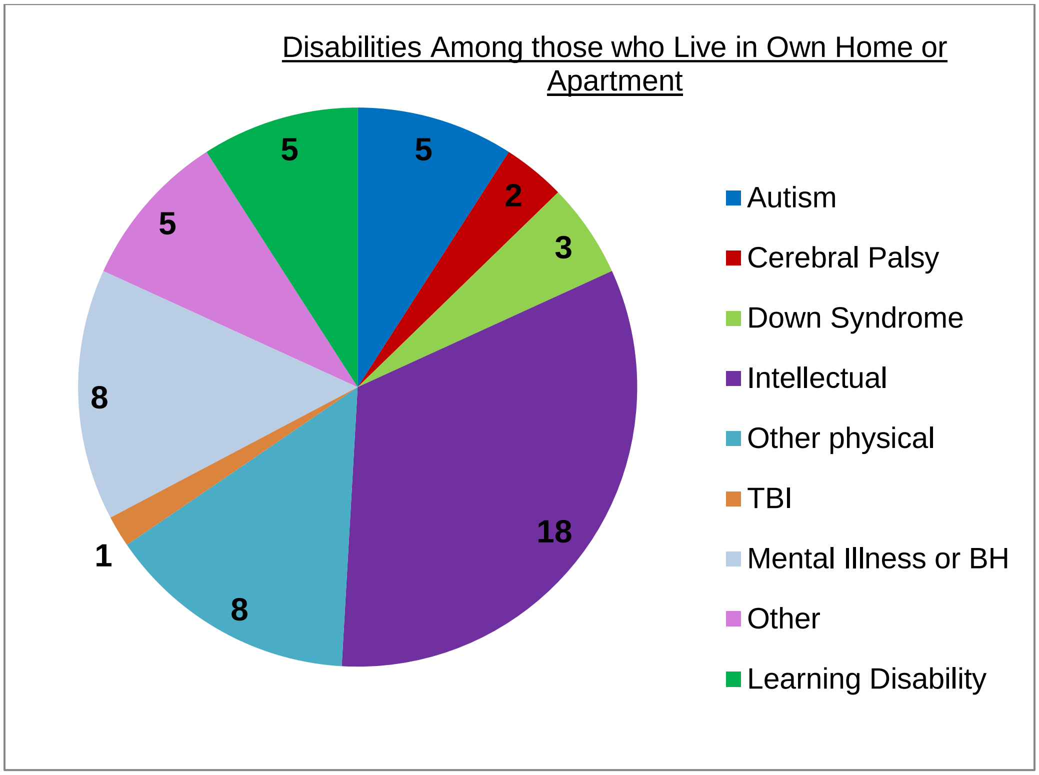


<u>Question:</u> For those who share a house or apartment, or have their own house or apartment, who are they, by disability?

<u>Methods:</u> The survey question, “Where do you currently live?” was examined for those who responded either “I share a house or apartment” or “My own house or apartment.”

<u>Results:</u>

1. *Thirty-nine survey respondents stated that they have their own house or apartment or share a house or apartment. Of these 39, they represent 56 disabilities (respondents were able to list more than one disability). Their 56 disabilities are represented in the pie chart below.

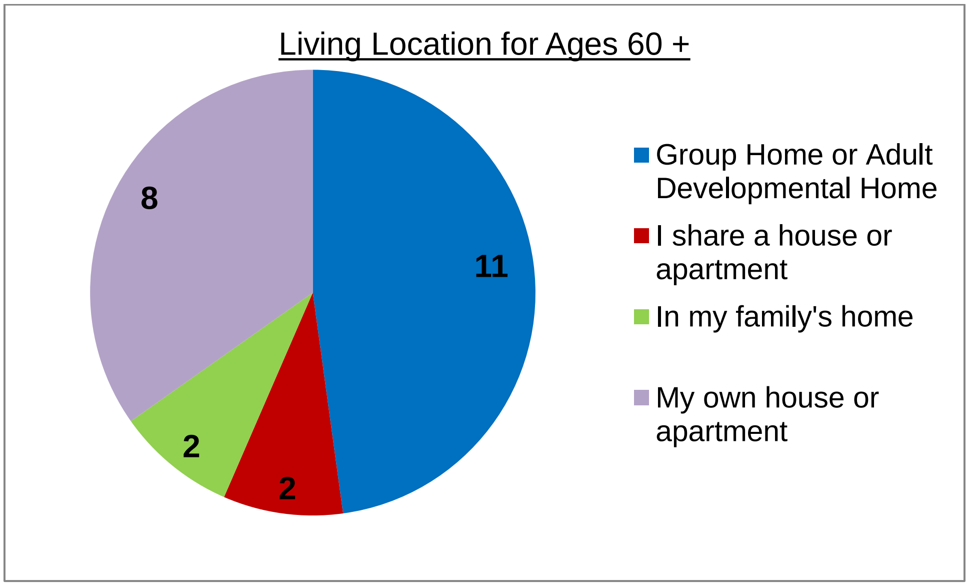


Question: **For those who are 60 years old and older, where are they living?**

Methods: The survey question, "Where do you currently live?" was examined among those who are age 60 and over. Other key survey questions were examined for responses among those aged 60 and over.

Results:

1. Among the 23 survey respondents who are age 60 and over, the vast majority of them live in a group home or adult developmental home, as shown below.



2. The most common worries among respondents ages 60 and over are their health and not having enough money.

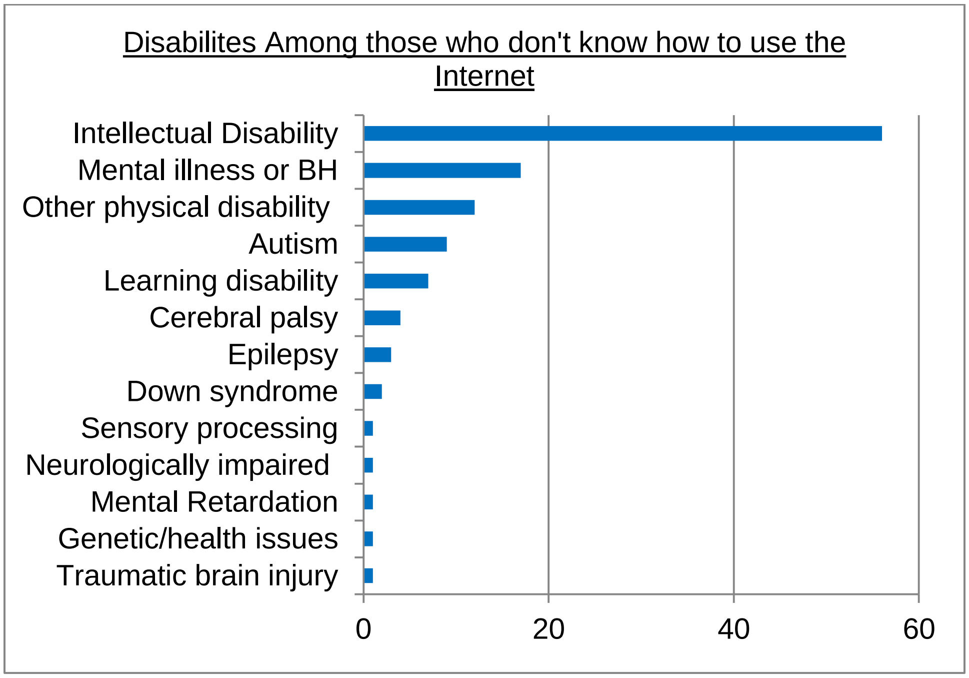
3. Almost all of the 60+ respondents (91%) are not waiting for any type of services.

<u>Question:</u> For those who say they don't know how to use the internet, who are they by age, disability, and geographic location?

Methods: Survey respondents who responded "No, I don't know how" to the question, "Do you use the internet regularly?" were examined for their age, disability, and geographic location.

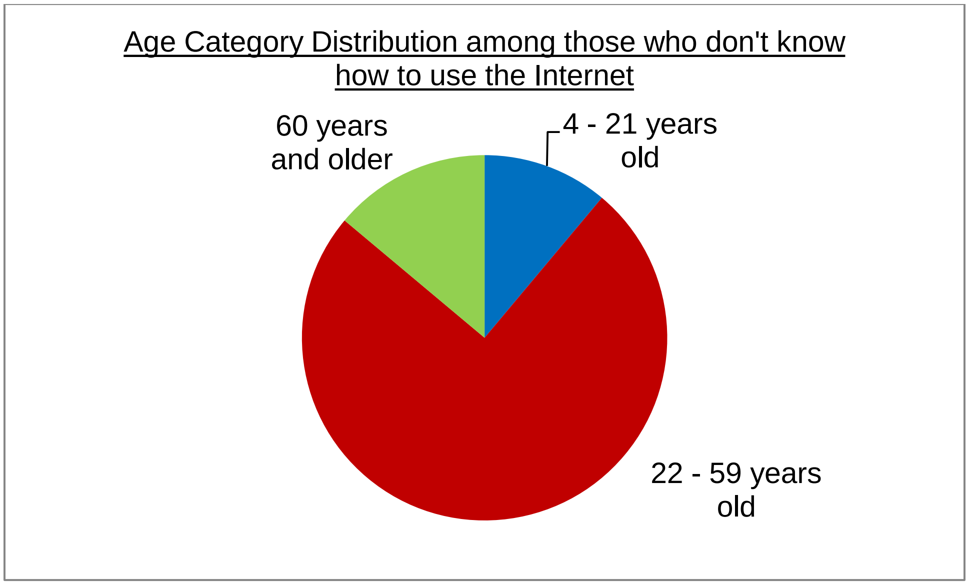
Results:

1. *Seventy-five survey respondents do not know how to use the internet. These 75 represent 109 disabilities (respondents were able to list more than one disability). These 109 disabilities are represented in the figure below.

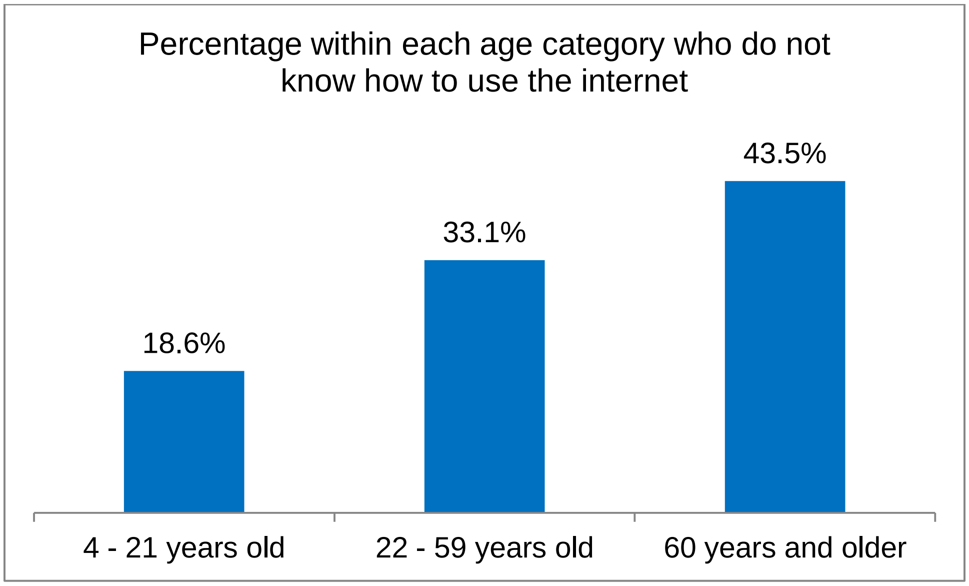


Note: Sensory processing, neurologically impaired, mental retardation, genetic/health issues, and traumatic brain injury were written-in responses provided by survey respondents.

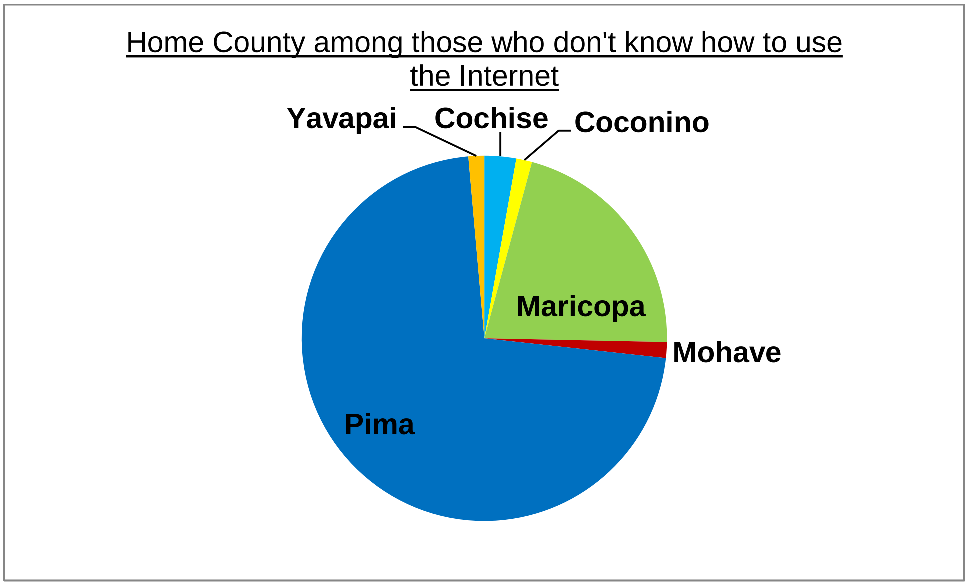
2. The vast majority of those who don't know how to use the internet are between the ages of 22 and 59 (72%). For comparison, 50% of all survey respondents are between the ages of 22 and 59. This is shown in the figure below.



*Overall, over 31% of respondents don't know how to use the internet. Older respondents are more likely than younger respondents to not know how to use the internet. And, 35.7% of Pima County respondents do not know how to use the internet.



3. Over 71% of those who don't know how to use the internet live in Pima County compared with 63% of the full sample.



Crosstabulations

Question: Are those whose disability is either mental illness and/or behavioral health-related more or less likely to have had police interaction? And, are these respondents likely to receive behavioral health services?

Methods: The survey questions, "Have you ever called the police as a victim of a crime" and "Have you ever been arrested?" were examined for those whose disabilities are either mental illness and/or behavioral health. Then, among these whose disability is mental illness or behavioral health AND have had police interaction, their receipt of behavioral health services was examined.

Receipt of behavioral health services was assumed to have occurred when respondents stated their happiness level in response to the question, "If you have had any of these services (behavioral health services) in the last five years, how happy were you with them?" In other words, respondents were not asked whether they have had this service, but rather were given the chance to state that they had not had this service, due to the question wording.

Results:

1. Among respondents who have ever called the police as a victim of a crime, almost 35% of them list mental illness or behavioral issues as a disability. This rate is significantly more prevalent than among those who have never called the police as a victim. Along with these two types of disabilities, intellectual disabilities are another common disability among those who have ever called the police as a victim.

2. Among respondents who have ever been arrested, over 64% of them list mental illness or behavioral issues as a disability. This rate is significantly more prevalent than among

those who have never been arrested. These are by far the most common disabilities listed among those who have ever been arrested.

3. Hearteningly, everyone who has ever called the police as a victim AND whose disabilities are either mental illness and/or behavioral health have received behavioral health services in the last five years. Similarly, everyone who has ever been arrested AND whose disabilities are either mental illness and/or behavioral health have received behavioral health services in the last five years. For comparison, among all respondents regardless of police interaction history, 82% of those whose disabilities are either mental illness and/or behavioral health have received behavioral health services in the last five years.

<u>Question:</u> What is the relationship between those who don't use the internet regularly or have a cell phone and their day program activity?

<u>Methods:</u> Respondents who were in the following categories were considered for this question:

"Do you use the Internet regularly?"
- No, but I would really like to.
- No, I don't know how.
- No. I don't care.

"Do you have a cell phone?"
- No, but I really need one.
- No, I don't know how to use a cell phone.
- No. Don't care.

Among respondents in these categories, their day program activities were examined.

<u>Results:</u>

1. Over 66% of respondents fall into one of the 'no technology' categories listed above. Among these, 47.6% of them go to a day program for people with developmental disabilities. Conversely, among those who attend a day program, 78% of them do not use the internet or a cell phone.

<u>Question:</u> What is the relationship between those who don't use the internet regularly or have a cell phone and the types of activities they do? What is the relationship between those who don't use the internet or don't have a cell phone and the likelihood they will speak up for themselves all of the time?

<u>Methods:</u> Respondents who were in the following categories were considered for this question:

"Do you use the Internet regularly?"
- No, but I would really like to.
- No, I don't know how.
- No. I don't care.

"Do you have a cell phone?"
- No, but I really need one.

- No, I don't know how to use a cell phone.
- No. Don't care.

Among respondents in these categories, their activities were examined.

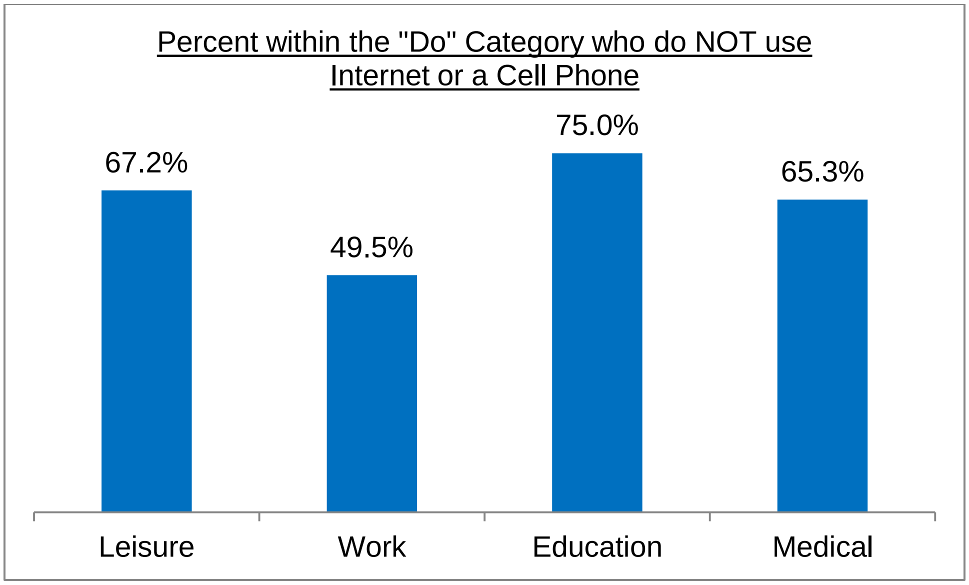
Four categories of activities were examined, as follows:

- "Leisure" consists of going out to eat, going on vacation, going shopping, going to a church / synagogue / temple, playing sports, and/or exercising.
- "Work" consists of working and getting a paycheck or being self-employed.
- "Education" consists of going to school.
- "Medical" consists of those who have had any type of physical, speech, occupational, applied behavior analysis or sensory therapy in the last five years.

As well, the question "Which of the following statements about speaking up for yourself apply to you?" was also examined among those who do not use technology.

Results:

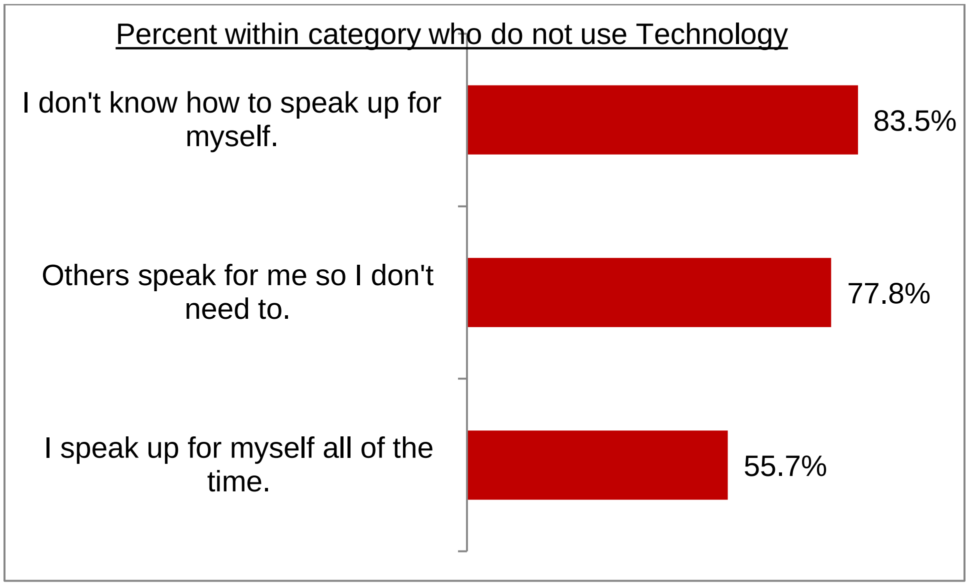
1. Among those who work, they are the least likely to not use internet or a cell phone. However, those who go to school are the most likely to not use the internet or a cell phone. Those who work and get a paycheck are significantly less likely to not use technology than those who do not work. These proportions are shown in the figure below.



*Yet who are these that go to school and do not use technology? Of the 36 respondents who do not use technology and go to school, 93% of these are less than 22 years old. They fall within the "4-21" age category, and may be very young.

2. Those who speak up for themselves all of the time are significantly less likely to not use technology than all other respondents. Those who don't know how to speak up for

themselves are significantly more likely to not use technology than all other respondents. The percentage of respondents who do not use internet or a cell phone within these categories is shown in the figure below. Only three categories of the “speaking up for yourself” question are usable, due to small category sample counts.



Question: What is the relationship between those who speak up for themselves and their feelings about the minimum wage, and how does this differ by disability?

Methods: The following two survey questions were examined – “Which of the following statements about speaking up for yourself apply to you?” and “Please select the answer that best fits your feelings about the minimum wage and workers with disabilities.”

Results:

1. Those who speak up for themselves all the time are significantly more likely to know what the minimum wage is than those who do not speak up for themselves. Similarly, they are also significantly more likely to think that everyone should be paid the minimum wage and also significantly more likely to not care whether they receive the minimum wage, as long as they get paid, compared to respondents who do not speak up for themselves.

2. Page 3 shows a figure depicting the most common disabilities among those who speak up for themselves all of the time.

3. Some significant differences were found in feelings about the minimum wage among different disabilities. For example, those with autism are significantly more likely to think that everyone should be paid the minimum wage, and significantly less likely to not care whether they get paid the minimum wage than those without autism. These same results hold for those with learning disabilities.

Conversely, those with an intellectual disability are significantly less likely to think that everyone should be paid the minimum wage, and significantly more likely to not care whether they get paid the minimum wage than those without intellectual disabilities.

Insignificant differences were found among those with behavioral health issues, mental illness, and other physical disabilities.

Question: Was there a difference in frequency in type of community participation between those that were 21 and under and over 21? It's the "I do the following" question.

Methods: The following two survey questions were examined – "I do the following…" and "age," re-coded to reflect those 21 and younger and those older than 21.

Results:
Only three of the "do" activities show a statistical difference between the 21 and under category and the older respondents. None of the other "do" activities showed a difference related to age.

1. Respondents who are 21 or younger are significantly more likely to go to school than those who are older than 21.

2. Respondents who are 21 or younger are significantly less likely to work and get a paycheck than those who are older than 21.

3. Respondents who are 21 or younger are significantly less likely to go to a day program for people with developmental disabilities than those who are older than 21.

Open-Ended Questions Summary

Full responses to both open-ended questions in the ADDPC Consumer Survey are listed in Appendix A at the end of this report.

"As a family member, please list any other concerns that have not been addressed that you think we should know to help us in our planning efforts."

Responses to this question tended to circle around the following issues:

1. Frustration with DDD eligibility and/or quality of service.
2. Limited funding for services and financial concerns.
3. Transportation challenges.
4. Access to services in rural areas.
5. Frustration with schools and provision of services.

"As a person with a disability, if there are any other comments that would help us in our planning efforts, please list them here."

Responses to this question tended to circle around the following issues:

1. Not everywhere is “disability-friendly.”
2. Transportation challenges.
3. A need for activities where the disabled are accepted.
4. Frustration with DDD.
5. Finding a job and not being discriminated against when in that job.
6. Better therapy providers.

<u>As a family member, please list any other concerns that have not been addressed that you think we should know to help us in our planning efforts.</u>
My daughter can not do ANYTHING for herself. She lives in a group home. She doesn't know anyone, she doesn't speak or doesn't even respond when she's talked to and is confined to a wheel chair. This survey did not really pertain to her at all but I answered the questions as best I could for her.
There is inadequate funding for programs and/or activities (vacations) for the developmentally disabled. Caregivers are underpaid and burning out because of overwork. Not enough monies to attract and keep good caregivers who are willing to do a good job. State laws prohibit the disabled to enjoy many things other "normal" people can. They cannot gamble and keep their earnings, they are limited as to how much money they can accumulate in savings yet insurance doesn't cover necessities such as anesthesia ($950 last year) for dental cleanings. My son's shoe (one shoe) is $573 as he wears a brace and needs an extra depth shoe, has to have a lift on the one shoe, and has two different size shoes, when a complete pair is ordered it is over $600. If he cannot save for money for these types of expenses, then he has to go without. The government is regulating this part of the population too much and needs to be more aware of how these regulations affect this portion of the population. They used to go away for a week up north to get away from the heat but there is no money to pay for staff and again the state has put restrictions on how far they can go. I could go on and on but it is a waste of time. Not enough parents are involved to demand things be changed.
We are very lucky to be in Desert Survivors program. They have provided a warm and safe place that our son enjoys going to everyday. Before being accepted in their program there were not many options available for disabled adults. / / Our biggest issue is with the transportation.. The sate sold the contract to another vendor, Sun Shuttle Dial a Ride. since then we have had nothing but issues. Handi Van was awesome.
My son is 4yrs old and has cochlear implant hearing devices. We live in Lake Havasu and have to travel to Phoenix weekly to receive speech and occupational therapy services. This is due to the lack of education with speech therapists working with cochlear implants and no pediatric occupational services. We have been making this trip for the last 2 years and still have 2 more years before he is mainstreamed into public school. I fear for him the services he will receive with our public school system, lacking the knowledge and education to work with children with cochlear implants. Knowing that all I can do is provide him with the most appropriate education for him now, hopefully he will be ready for public school when he turns 6 and will need minimal services.
This county needs services badly, and better programs for our local schools. The IE program here is a joke, and people here do not have access to quality doctors that can provide a diagnosis. There needs to be more training, and support for families in regards to having a child with a disability. / / Therapy services are key, the only pediatric therapy companies are in Havasu. Otherwise children simply go without and it isn't fair. We as parents have no voice here, because to join a board for special needs education we have to live in the Maricopa area to maintain attendance and so we continue to be forgotten, and ignored.

Coding? glitch did not allow me to explain why he is unhappy taking the bus. The bus system in Tucson is unreliable, extremely slow, does not go beyond city limits (where he has lived until recently,) and makes no provision for bad weather. In fact there is really nothing good to say about it. / / He benefited greatly from what services he received in school and as a child, but needed more of them. He particularly needed a much longer time in a residential treatment center for behavioral health than the six months the state gave him.
safety in the community. Busy street crossings. Panhandlers
Ask if the child believes that they are receiving the same education as their non-disabled peers. The more parents I talk to I am finding that children with IEP's are not getting the same education.
We have been struggling to get an actual DDD and AHCCCS support for our son who really is not fully independent on his daily care and diabetic care. His autism alone was not sufficient enough, Type 1 diabetes itself is not even considered, but he can't even self administer his insulin shots via insulin pen or traditional syringes at age 12 1/2 as his motor skill is affected by his autism. We have explained this to the interviewer/nurse from AHCCCS office but they simply do not understand. We checked Social Security also but not eligible. We do not want our son to get lost in the policies because one he is 18, he will not be able to be independent, period. It has been VERY frustrating.
Civil Rights are not upheld in the school system. When a parent advocates there is retaliation; putting all family members in harms way. Parents do not have the right for a quality education; however, civil rights should not be an issue nor retaliation at the sake of the family and the child's physical well-being.
Transportation is a huge issue for these young adults. That's our main concern these days.
1) It should not be left to families to enforce FAPE and LRE in schools. It's simply too hard. It's like they passed IDEA and forgot to tell the educators. Most schools are stuck in the 1970s. / 2) We need to attract more therapists (PT, speech, OT, sensory) so the kids get the therapies they need. / 3) We need to spend more $$ on pre-K-12 education.
There is a major lack of certified teachers and therapists in this area. The children, families, and schools are suffering greatly because of it. No one is doing anything to help things at a higher level.
my son is in school he would be a freshman this year but for the last 3 years, 6,7,8th grade is has not had any schooling they have put him in a home school situation and if they can they send a teacher to the home sometimes he has been out of school this last year more that he was in they never have any consistency in his education and when I tried to hire someone they would not pay for it when they were not providing some one. He is to start high school and they have not contacted me all summer and we have nothing in place for him to start. He was to have services all summer for the schooling he has missed and we had nothing all year. better trained competent teachers and aids are need through school age kids. With a proper system I think my son would be doing much better and have a better chance after school.
What kind of help would be most valuable to you to achieve independence? / Do you want to be independent? / How do you see your future? / What would you like your future to be and how do you think you can achieve it? Who needs to be involved in your goals?
A much better behavioral health care for adults on the spectrum. More experienced people working with our adults.
DDD and SSI Eligibility. Insurance coverage.
Transportation, More well trained Respite providers to better support families caring for their family member.
Getting information regarding her immediate future after high school graduation - job, living outside of family home, colleges with educational programs for people with disability.
Our son is graduating high school in two weeks, but our biggest frustration has always been

lack of good summer programs that are not sports camps or low-functioning, etc. Especially for teens.
Need help finding a job that won't have me standing on my feet all day or talking on the phone with my auditory processing and club feet. I can work. I just need a chance
Is difficult to find and receive services suitable for the special needs of my son
Lack of support for independent living
Accessibility to what mental and disability services are available in Arizona is so important for families, family members, guardians of those who really have special needs. When we came to Arizona 5 years ago from a different state, we had to search and scramble to get our daughter the support services she had immediate need of. Often we were stymied by "red tape" and phone trees for certain agencies to which we contacted but either never had our calls returned or were treated like numbers within a system which didn't help or address our immediate concerns. / We have since watched as friends, neighbors with either a child, young adult or adults with special needs requires. Whether it be a child , young adult or older person struggled to just find out what Arizona has to offer its citizens. / To be able to find these services in a timely manner within various agencies (educational, medical or psychiatric) a new citizen is tasked with this responsibility plus finding other services to keep the standard of care for their loved one in place. No matter what the condition there are certain protocols that have to remain constant if the security and safety of the affected person are to be kept constant! / If your planning efforts would enable those in need of giving their loved the appropriate help, mishaps of all types could be avoided. If it takes less time to research where to go and provide assistance to the family, the family won't get stuck "in the system." It creates frustration and sometimes crisis for a family member who has to have help and the family can't find the services or links to addressing immediate concerns! / To have agencies where a family member can be identified, diagnosed quickly and provided with support for areas and concerns in their lives would streamline the care that all Arizona's citizens need to feel successful and move on towards independence and a level of managed care that they deserve. Mental and physical disabilities also touch other areas of the individual's life of the caregivers so PLEASE CONTINUE to address these needs as all Arizona citizens who deserve your trust! Some physical and mental conditions do not "go away" so families know that the care is ongoing and need this help.
getting a person centered plan from DDD on her annual. the assessment tool for services is not family friendly. support coordinators not well informed on how to get a voice output device. you did not address individuals who are non verbal. voice output devices and the wait time, providers non trained, lack of use in group homes.guardians vs public fudicary and payees.
My son is 8 and I wish I could find more after school activities with other children who have disabilities so he can interact with others like him. He is in an MIDI classroom and this will be his 5 summer with Camp Fiesta and its great but just wish there were more after school or weekend activities for him to do.
We have not been able to find a physician to can work with a patient that can't communicate or express their medical problems. Doctors are unwilling to think outside the box to help us get medical testing done. Leaving us hanging in limbo until symptoms get so bad or obvious, it will be too late to do anything about them. As one doctor told us, "we won't find out whats wrong with her until after she's dead." Hospitals won't bother to examine her anymore.
not enough volunteer opportunities that are welcoming to persons with disabiities / not enough provider staff to meet my needs
Where to find listings of housing for young adults with disabilities along with costs.
She really 2anta to work and DDD has been giving her the run arounds for the last 6-9 months.

Rampant abuse in the school system towards individuals on the Autism Spectrum. We had to file Due Process against Tempe Union High School District because they failed to provide Transition services ever but wanted to graduate our 18 year old son anyway....This creates an underclass of people destined for a life in poverty, prone to more abuse. The school system fails our Special Needs children, have seen the line to childabuse within the schoolsysten crossed multiple times.Our child's Complex Trauma has been caused by the schoolsystem and their failure in knowing how to deal with autism in an appropiate manner, without discrimination.
Help with financing psychological testing acceptable by DDD or SS.
I think it's just awful for HAB-M services to be automatically discontinued at first grade!!! More often than not behaviors get extremely worse/harder as they get older. And insurances are still denying these services as well!!
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I think it's just awful for HAB-M services to be automatically discontinued at first grade!!! More often than not behaviors get extremely worse/harder as they get older. And insurances are still denying these services as well!!
Get rid of team model for AZ Early Intervention Program. The state is double billing therapy hours and the model really hurts the children because it reduces badly needed therapy time. Hire competent therapists with the level of college degrees required by outpatient rehabilitation centers.
My child has long term care and DDD, but we receive no help from any programs except the public school in the district we live in. We self pay for our own therapy services. We've been with DDD for few years and do not know how the system works or to navigate it. We keep getting numbers to call with no return calls back or responses. We have also been denied SSI. My question is how do we find more help for my son?
Be fair to all individuals with disabilities.
DDD is ridiculously over regulated. Providers spend too much their precious time and staff dollars on paper work.
If you could not work at subminimum wage, how would you spend your day? Many are going to say they will have to go back to a day program. This is a step backward them and in AZ it is not allowable to receive pay in a day program so they will not be allowed to work.
you need to know that paid work activities saved my life, I was depressed unable to work had not worked for 8 years, easing back into work through paid work literally in my opinion saved my life. I participated in paid work for three years until I was ready to work with a job developer at the same agency who helped me apply for jobs I am now employed. All this bad talk about paid work centers is wrong let us make our own decisions on if we want to participate because they do make a difference!
I think DDD should stop denying people who clearly have a disability. If they are at within a few points on a IQ cut off a IN-Person interview should be done at that time. They are denying people who are in dire need of service and at such a young age they only have so much time before they are out of their learning range. We right now are awating an approval or denial for the 2nd time. This time since the adult tests were done the IQ is well below cutoff of 75 and I still have a feeling of what happens if its denied once again.

As a person with a disability, if there are any other comments that would help us in our planning efforts?

I would volunteer more if agencies would accept me just as I am. Many say they want volunteers but do not truly embrace the idea of persons with a disability being part of their effort and make excuses so I am not accepted. / / The people who work at DDD are mostly new in the field and have no institutional knowledge, so tend to be box checkers and paper pushers. Their services are now very impersonal. In the past it was not like this at all. Plus, my family advocate does most of the work for me, including having to rectify mistakes with my service hours made by a paid program provider. It would be fantastic if I could manage my own services and have more flexibility in my choices. There are very few programs that meet my needs well.
Hope this will get taking seriously.
Lisa likes to travel and always thought maybe she could travel to Paris someday
Support groups / Local trainings (IEP's, 504's, Tools to help our kids) / Playgroups / Events for children with disabilities / Local advocated / Ensuring the local school boards follow IDEA 2004 (They don't) / Pediatric Developmental Pediatricians or Neuropsychologist (Traveling is fine) /
I'm doing fine now but am "behind schedule" for someone my age. I could have used more support when I was in school.
My family member hates being reminded that he has a disability. He refuses to tell anyone and is not likely to avail himself of any services that require him to identify as disabled, even when it's obvious he could benefit greatly from doing so.
We need quality providers, who need more than a clearance card to be left alone with a individual with disabilities whom cannot tell you what is wrong or if something went wrong. /
my son is non verbal and does not communicate well with out side people. this is a big concern for us and him
N/A
The vocational counselor a need to be more familiar with the effects of disabilities in the workplace
Need a transportation system, where I live
did not want to comment when asked.
People with disabilities are discriminated on the job but they find other reasons to dismiss them.
We need separate therapy treatments by specialized therapists for Stroke victims rather than combining treatments meant for physical ailments such as brokenbones, hip, knee replacements, etc., items that in time repair themselves. A Stroke does not repair itself. / / Stroke victims are afflicted by parts of thedamaged brain which makes it unable to instruct parts of the body to function and move, such as muscles, joints, etc. as in normal functioning people. / / These are different situations that require different treatments and Stroke victims require specialized treatment by qualified therapists. As it is today, one can compare it to a General Practicioner doing surgery on a cancer patient. None of us would want that, yet that is what is being done today to Stroke victims. The difficulty in that is that the Stroke victim is shortchanged and his life is inalterably condemned to a lifelong disability that did not have to be.
would like more vacations and day trips
Since my disabilities are basically not visible to people, I note that people at times think I use a cane and a motorized shopping cart for no reason at all. A friend has suggested that with my non-epileptic seizures that I should look into getting a service dog. However, the cost is very high and at the current time because my doctor (whom I plan on changing) put me into assisted living, I am on the verge of bankruptcy. I was 'evicted from the assisted living place (I owe them about &16,000) and am back in a house purchased on a reverse mortgage thru BOA. I almost lost the house by not living in it, the Real Estate agent had no idea of what was what. An Estate Management Service did a sale and I owe them just under $10,000. I have hardly any furniture and no ramp to really get my scooter out to use it. The doorbell unit was sold (it was a special

wireless unit), I had to have the washer serviced (I was told it was never moved, but it was in a different position and it turns out the water lines were reattached incorrectly). I had a friend that had been very helpful, but after the assisted living place called and asked them for $$ to cover my costs, they are no longer really willing to be of much help. I wish that there was a way to put people in the places that are around and get their input as to what they note regarding the food, service, etc. Note I did manage to get laundry done twice from the middle of Nov. 2014 thru April 2015. And with meals included, they charge if they bring a tray to a room, or if you are at the hospital or hospitalized, or don't eat because of not feeling well.
Injustice is done towards individuals with disabilities. Discrimination is rampant. I should never have been arrested and put in jail for sending former teachers e-mails to try to find closure from my Complex Trauma. Tempe Union High School District should never have filed an Injunction Against Workplace Harassment against me for sending e-mails to my former teachers who abused me by not following my IEP. The Tempe Union High School District was at fault, and they tried covering up their mistakes by putting the blame on me, hence causing my Complex Trauma.
Transportation is non-existent in our part of Mesa. Now I live in Apache Junction, and there is nothing there either. I ride my bike 5 miles one-way to work each day.
Often times I encounter situations or places that are not disability friendly. It would be nice to have a central reporting system and possible consequences for continuous offenders. I have found that cities will respond quickly to cut out curb difficulties but stores and malls are totally non responsive.
people with disbaility who live in anthem az has no transportaion at all so we feel like we cant live life they way other people can and it hard on us having to deal with not beabe to go out and do stuff when we want to it sucks i just wish there was a bus ling in anthem or any transpertaion for people like us living in anthem with a disbauility and we all want to feel indepent and beable to live with out help
Email about this survey will state my notes
you need to know that paid work activities saved my life, I was depressed unable to work had not worked for 8 years, easing back into work through paid work literally in my opinion saved my life. I participated in paid work for three years until I was ready to work with a job developer at the same agency who helped me apply for jobs I am now employed. All this bad talk about paid work centers is wrong let us make our own decisions on if we want to participate because they do make a difference!
I want to work and get some of my own money but I also do not want to lose my social security beneifts. I like working on a crew because my friends are there too and we get to laugh a lot but still get paid
on the bank account, my name is on the account, but my dad has his name too and he takes care of all my money and I have to ask him to give me some so I can buy a snack when at class or working. I like my life just the way it is - I have friends at work and in class, I get to have a snack when I ask and I like living with my family. I get to earn a small check each week and I like that it gives me more money. My dad worries it will take away my social security.

APPENDIX D: PROVIDER SURVEY AND ANALYSIS (2015)

ADDPC Provider Survey -Frequencies

What type of organization do you work for?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Non-profit organization that is not a provider (e.g. disability organizations, faith-based organization, support groups	11	7.9	11.3	11.3
	A provider for people with developmental disabilities (DD) (e.g. day programs, in-home care, job training programs, grou	53	37.9	54.6	66.0
	A government agency (e.g. DDD, RBHA, Division of Aging and Adult Services, a city program)	16	11.4	16.5	82.5
	I am a paid family caregiver.	4	2.9	4.1	86.6
	Other: Please describe.	13	9.3	13.4	100.0
	Total	97	69.3	100.0	
Missing	System	43	30.7		
Total		140	100.0		
What type of organization do you work for?-TEXT					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		127	90.7	90.7	90.7
	Adult Ed. instructor for DD population	1	.7	.7	91.4
	Community Action Agency	1	.7	.7	92.1
	county health department, offering community mobilization and collaboration	1	.7	.7	92.9
	Education for children with disabilities	1	.7	.7	93.6
	for-profit government contractor providing services for people with physical and emotional/behavioral/psychiatric disabilities	1	.7	.7	94.3
	guardian	1	.7	.7	95.0
	I was a paid provider for my child he has since passed away	1	.7	.7	95.7
	Non-Profit Organization that IS a provider	1	.7	.7	96.4

	non-profit provider	1	.7	.7	97.1
	Private practice sign language interpreter	1	.7	.7	97.9
	public school	1	.7	.7	98.6
	School District	1	.7	.7	99.3
	Teacher	1	.7	.7	100.0
	Total	140	100.0	100.0	

What types of functions take the majority of time in your current / position?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Executive: Planning, administering, monitoring, staffing	48	34.3	51.1	51.1
	Administrative: Clerical, record-keeping, organizing	11	7.9	11.7	62.8
	Direct Service: Direct client contact and support	28	20.0	29.8	92.6
	Other: Please describe.	7	5.0	7.4	100.0
	Total	94	67.1	100.0	
Missing	System	46	32.9		
Total		140	100.0		

What types of functions take the majority of time in your current position? - TEXT

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		133	95.0	95.0	95.0
	Care provider for child, total care diapering feeding ect	1	.7	.7	95.7
	Clinical support/not direct care	1	.7	.7	96.4
	Follow-up, authorization, face to face reviews	1	.7	.7	97.1
	Habilitation	1	.7	.7	97.9
	instructor	1	.7	.7	98.6
	parent and provider training	1	.7	.7	99.3
	Respite	1	.7	.7	100.0
	Total	140	100.0	100.0	

Hourly pay among direct service workers:
Mean hourly pay = $17.34
Median hourly pay = $14.95

As a paid or family caregiver, how many people with disabilities do you care for?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	2	1.4	50.0	50.0
	2	2	1.4	50.0	100.0
	Total	4	2.9	100.0	
Missing	System	136	97.1		
Total		140	100.0		

Of which of the following groups do you provide care for?

	Frequency	Percent
People with mental illness	54	38.6
People with intellectual disabilities	68	48.6
People with physical disabilities	65	46.4
Developmental disabilities	0	
Dementia, memory loss…	0	

What ages of individuals do you serve?		
	Frequency	Percent
Children 0-3	26	18.6
Youth ages 4-17	52	37.1
Adults 18-59	76	54.3
Older adults ages 60+	51	36.4

How many hours per week do you work?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1-10	1	.7	1.1	1.1
	11-20	5	3.6	5.7	6.9
	21-31	2	1.4	2.3	9.2
	32-40	18	12.9	20.7	29.9
	40+	61	43.6	70.1	100.0
	Total	87	62.1	100.0	
Missing	System	53	37.9		
Total		140	100.0		

race - combined variable from survey question					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	native American	3	2.1	3.8	3.8
	Asian	2	1.4	2.5	6.3
	Latino	17	12.1	21.3	27.5
	white	56	40.0	70.0	97.5
	other	2	1.4	2.5	100.0
	Total	80	57.1	100.0	
Missing	System	60	42.9		
Total		140	100.0		

county					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	maricopa	20	14.3	25.6	25.6
	pima	20	14.3	25.6	51.3
	yuma	16	11.4	20.5	71.8
	mohave	16	11.4	20.5	92.3
	cochise	2	1.4	2.6	94.9
	santa cruz	1	.7	1.3	96.2
	apache	1	.7	1.3	97.4
	yavapai	2	1.4	2.6	100.0
	Total	78	55.7	100.0	
Missing	System	62	44.3		
Total		140	100.0		

How old are you?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	18-24 years old	4	2.9	4.8	4.8
	25-45 years old	30	21.4	35.7	40.5
	46-60 years old	39	27.9	46.4	86.9
	61-70 years old	9	6.4	10.7	97.6
	71-80 years old	2	1.4	2.4	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

What is your gender?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	20	14.3	23.8	23.8
	Female	64	45.7	76.2	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

Have you ever had training in person-centered planning or using person first language?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	67	47.9	74.4	74.4
	No	12	8.6	13.3	87.8
	I don't know	11	7.9	12.2	100.0
	Total	90	64.3	100.0	
Missing	System	50	35.7		
Total		140	100.0		

Overall, how satisfied are you with your job?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	46	32.9	51.1	51.1
	Somewhat Satisfied	33	23.6	36.7	87.8
	Neutral	6	4.3	6.7	94.4
	Somewhat Dissatisfied	4	2.9	4.4	98.9
	Very Dissatisfied	1	.7	1.1	100.0
	Total	90	64.3	100.0	
Missing	System	50	35.7		
Total		140	100.0		

How likely will you leave your job within the year?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very likely	7	5.0	7.9	7.9
	Somewhat Likely	8	5.7	9.0	16.9
	Unlikely	74	52.9	83.1	100.0
	Total	89	63.6	100.0	
Missing	System	51	36.4		
Total		140	100.0		

Why?	
	Frequency
Poor pay/benefits	5
Too many hours	3
Clients/families are too difficult	2
Inadequate training	1
I want to find a job in a different field.	1
Workload is too heavy.	2
have enough points to retire, will seek other employment	1
The demand for support supervisors to be available 24/7 on a salary that breaks down to $12.07 is too bearing especially for those of us with families of our own. More often than not we are spending more money being at work more than 40 hours a	1
Too Many students with one teacher. Adult to student ratio: 1:4. Students with moderate to severe cognitive impairments.	1

Average number of years working at current agency:	10.1
Median number of years working at current agency:	6.9
Average number of years working in this field:	16.7
Median number of years working in this field:	15

What motivated you to go into this profession?		
	Count	Percent
Make a difference	63	26.5%
Help people	60	25.2%
Personal experience	45	18.9%
Qualifications match	28	11.8%
Other	14	5.9%
Scheduling	9	3.8%
Shortage ofpeople	8	3.4%
Pay and/or benefits	7	2.9%
Location of the job	4	1.7%
Other text:		
Accidental - direct care was a great part time position in college and the field stuck with me.		
Enjoy the satisfaction of teach skills for them to achieve independence		
Family member		
Funding Opportunities allow us to expand our Community Health Assessment to include the special needs population		
I love teaching and seeing people change and evolve as they learn.		
I wanted to become a special education teacher		
I wanted to help parents with their child that has a cognitive impairment.		

I wanted to learn how to assist my daughter, who has a disability, navigate through school.		
My child had a rare brain disorder		
My granddaughter is autistic and needed me		
The benefit of making my own schedule, but since has changed.		
There is a shortage in people in the field with the intention of benefiting the quality of life for the individuals. Many see it as a job and they do not notice the individuals we serve are people too.		
This is the most amazing type of work!		
wanted to help grow the agency		

How much do you agree with each of the following statements about the abilities of most adults with developmental disabilities?

They should be able to date and marry					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	2	1.4	2.7	2.7
	Disagree	1	.7	1.4	4.1
	Agree	34	24.3	46.6	50.7
	Strongly Agree	34	24.3	46.6	97.3
	Don't know	2	1.4	2.7	100.0
	Total	73	52.1	100.0	
Missing	System	67	47.9		
Total		140	100.0		

They can be taught to live on their own with some supports

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	2	1.4	2.4	2.4
	Disagree	1	.7	1.2	3.6
	Agree	40	28.6	47.6	51.2
	Strongly Agree	39	27.9	46.4	97.6
	Don't know	2	1.4	2.4	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

The current formal system does a good job maximizing their independence

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	10	7.1	13.9	13.9
	Disagree	31	22.1	43.1	56.9
	Agree	28	20.0	38.9	95.8
	Don't know	3	2.1	4.2	100.0
	Total	72	51.4	100.0	
Missing	System	68	48.6		
Total		140	100.0		

Families overprotect them

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	1	.7	2.3	2.3
	Disagree	4	2.9	9.1	11.4
	Agree	29	20.7	65.9	77.3
	Strongly Agree	9	6.4	20.5	97.7
	Don't know	1	.7	2.3	100.0
	Total	44	31.4	100.0	
Missing	System	96	68.6		
Total		140	100.0		

Agencies and providers overprotect them

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	8	5.7	15.7	15.7
	Disagree	20	14.3	39.2	54.9
	Agree	19	13.6	37.3	92.2
	Strongly Agree	2	1.4	3.9	96.1
	Don't know	2	1.4	3.9	100.0
	Total	51	36.4	100.0	
Missing	System	89	63.6		
Total		140	100.0		

They have enough outside social activities and opportunities to make friends

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	10	7.1	13.9	13.9
	Disagree	32	22.9	44.4	58.3
	Agree	25	17.9	34.7	93.1
	Strongly Agree	2	1.4	2.8	95.8
	Don't know	3	2.1	4.2	100.0
	Total	72	51.4	100.0	
Missing	System	68	48.6		
Total		140	100.0		

To what extent do you believe that the following statements are true about the abilities of most adults with developmental disabilities?

They can work in the community and earn at least minimum wage with appropriate accommodations

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Disagree	9	6.4	10.3	10.3
	Neither Agree nor Disagree	13	9.3	14.9	25.3
	Agree	42	30.0	48.3	73.6
	Strongly Agree	21	15.0	24.1	97.7
	Don't know	2	1.4	2.3	100.0
	Total	87	62.1	100.0	
Missing	System	53	37.9		
Total		140	100.0		

Enclaves or group supported employment with others with disabilites is best for them, because it offers protection while allowing them to earn a paycheck

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	2	1.4	2.4	2.4
	Disagree	11	7.9	12.9	15.3
	Neither Agree nor Disagree	34	24.3	40.0	55.3
	Agree	34	24.3	40.0	95.3
	Strongly Agree	3	2.1	3.5	98.8
	Don't know	1	.7	1.2	100.0
	Total	85	60.7	100.0	
Missing	System	55	39.3		
Total		140	100.0		

It doesn't matter if they are getting paid minimum wage or not. They are proud just to get a paycheck.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	7	5.0	8.2	8.2
	Disagree	19	13.6	22.4	30.6
	Neither Agree nor Disagree	18	12.9	21.2	51.8
	Agree	24	17.1	28.2	80.0
	Strongly Agree	16	11.4	18.8	98.8
	Don't know	1	.7	1.2	100.0
	Total	85	60.7	100.0	
Missing	System	55	39.3		
Total		140	100.0		

I believe that they are capable of representing themselves as advocates on issues critical to their quality of life					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	2	1.4	2.4	2.4
	Disagree	17	12.1	20.0	22.4
	Neither Agree nor Disagree	24	17.1	28.2	50.6
	Agree	28	20.0	32.9	83.5
	Strongly Agree	12	8.6	14.1	97.6
	Don't know	2	1.4	2.4	100.0
	Total	85	60.7	100.0	
Missing	System	55	39.3		
Total		140	100.0		

There are not enough interesting jobs with more challenging tasks accessible to them.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	3	2.1	3.5	3.5
	Disagree	13	9.3	15.3	18.8
	Neither Agree nor Disagree	12	8.6	14.1	32.9
	Agree	30	21.4	35.3	68.2
	Strongly Agree	23	16.4	27.1	95.3
	Don't know	4	2.9	4.7	100.0
	Total	85	60.7	100.0	
Missing	System	55	39.3		
Total		140	100.0		

Nowadays, they encounter minimal physical barriers when out and about.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	3	2.1	3.6	3.6
	Disagree	37	26.4	44.0	47.6
	Neither Agree nor Disagree	22	15.7	26.2	73.8
	Agree	19	13.6	22.6	96.4
	Strongly Agree	2	1.4	2.4	98.8
	Don't know	1	.7	1.2	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

It is easy for them to get most formal services, like services through DDD, etc.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	9	6.4	10.7	10.7
	Disagree	36	25.7	42.9	53.6
	Neither Agree nor Disagree	22	15.7	26.2	79.8
	Agree	15	10.7	17.9	97.6
	Strongly Agree	1	.7	1.2	98.8
	Don't know	1	.7	1.2	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

Medical professionals mostly treat them with respect and honor their individual choices.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	1	.7	1.2	1.2
	Disagree	25	17.9	29.8	31.0
	Neither Agree nor Disagree	29	20.7	34.5	65.5
	Agree	24	17.1	28.6	94.0
	Strongly Agree	1	.7	1.2	95.2
	Don't know	4	2.9	4.8	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

I often worry about the safety of some of them when I am not with them.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	2	1.4	2.4	2.4
	Disagree	8	5.7	9.5	11.9
	Neither Agree nor Disagree	29	20.7	34.5	46.4
	Agree	36	25.7	42.9	89.3
	Strongly Agree	5	3.6	6.0	95.2
	Don't know	4	2.9	4.8	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

Why do you worry about them?
and I worry about my group passing away I have worked with some of my consumers a long time and have spent a lot of my time with them that the thought of losing one of them is just as difficult as if it were one of my own family members
Afraid someone will take advantage of them.
Because safety is not an issue that is taught as much as it should be.
Because they continue to be vulnerable and people continue to not respect them. / Education is needed to help children grow into better adults, reduce the bullying that is so prominent.
Due to the fact that most disabled people use public transportation, and are vulnerable to criminal minded people taking advantage of them, it is hard to imagine a situation that would be optimum.
Heat, violence, all the work and support they give us with out even getting well paid.
I am concerned about exploitation.
I don't think the people responsible for providing support always have the individuals' best interests at heart. People get careless and can be extremely controlling.
I feel there are some consumers who live on their own but are not metally or physically capable to do so. They have care for a set amount of hours a day but the risks and possible dangers are when they are left unaccompanied by supports. Also,
I worry about all people. I believe that is why I became a counselor. I worry about my clients because they are not given opportunities to talk and to express themselves the same and I do. This is not good for most mental illnesses. I also worr
I worry about my students. I worry if they are being taken care of at home and if they are safe. I worry about how I can help them become more independent and help their parents understand the importance of early interventions.
I worry because I believe some who live independently may be victimized by criminals.
I worry that our individuals may be taken advantage of, may be endangered by careless or thoughtless behavior of others, or on rare occasions may engage in behavior that creates problems--e.g. become angry and frightened and act in ways that fr
In our time, there are still many people that have little or no time spent with this population of people, most dont know how to interact or behave around our members, this makes me most uncomfortable to know that our members will be going thro

Inadequate preparation for situations that might harm them
It is easy for society to prey on them.
its very sad that they are not treated like adults at home, or they are used for their pay checks and not allowed to do anything. Some could do so much more but families dont want to bothers others cant do much and are taken advantage at home -
just to ensure continuity of service is delivered in the care of everyone(providers)
Like of education in our community about the needs of our membrs.
Many of my clients have poor safety skills and make choices that may not be to their benefit
Not sure they have the support from families/other agencies to be successful
Predators, lack of caring in community, lack of understanding of community regarding disabilities.
safety reasons
Safety, for some. The ability to advocate on their own behalf when in the community. Parental influence that may not have thier best interest. Being taken advantage of.
Some people are inconsiderate and tend to take their frustration on those who are burnable.
That the providers are caring for them like I would or a good family.
The interest of the caregivers. / I have seen caregivers on cell phones, instead of focusing their attention on the client.
the stigma of mental illness place them in community social situations to be disrespected and or taundeted
Their ability to process a situation and then take appropriate action in a timely manner depending on the event or situation.
There is a large turnover in residential staff and not always certain that members are being treated with dignity and respect especially those that are non-verbal and unable to voice their wants and needs.
They are a vulnerable population & there are those that can take advantage of them.
They are easily influenced and trusting.
They may not be able to help themselves
They may not be aware of the dangers and could be easily swayed.
Though they are always with paid staff, some of the paid staff are inexperienced,immature,and are at the agency only for a paycheck .This is not a career choice for them,only a job.
TOO MANY REASONS
We have had a couple of circumstances when our consumers were out in the community on their own, and have been either abused by the general public, or have put themselves in situations that would be considered unfavorable to the general public.

Based on your interactions with the following agencies, how satisfied are you with the following services and their responsiveness to clients?

Early intervention or early childhood services					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No interaction	28	20.0	33.7	33.7
	Very dissatisfied	4	2.9	4.8	38.6
	Dissatisfied	6	4.3	7.2	45.8
	Neutral	17	12.1	20.5	66.3
	Satisfied	21	15.0	25.3	91.6
	Very Satisfied	7	5.0	8.4	100.0
	Total	83	59.3	100.0	
Missing	System	57	40.7		
Total		140	100.0		

Why dissatisfied with early intervention? (# choosing that option)			
Did not give services based on what my client needed or wanted	5		
My client had to wait a long time to get services	5		
Once the services started, they were not always delivered when they were supposed to be	6		
He/she did not seem trained	1		

School-based special education services					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No interaction	7	5.0	8.5	8.5
	Very dissatisfied	8	5.7	9.8	18.3
	Dissatisfied	24	17.1	29.3	47.6
	Neutral	22	15.7	26.8	74.4
	Satisfied	18	12.9	22.0	96.3
	Very Satisfied	3	2.1	3.7	100.0
	Total	82	58.6	100.0	
Missing	System	58	41.4		
Total		140	100.0		

Why dissatisfied with special education? (# choosing that option)			
Did not give services based on what my client needed or wanted	22		
My client had to wait a long time to get services	7		
Once the services started, they were not always delivered when they were supposed to be	16		
He/she did not seem trained	8		

Services provided by DDD					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No interaction	2	1.4	2.4	2.4
	Very dissatisfied	3	2.1	3.6	6.0
	Dissatisfied	17	12.1	20.2	26.2
	Neutral	20	14.3	23.8	50.0
	Satisfied	34	24.3	40.5	90.5
	Very Satisfied	8	5.7	9.5	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

Why dissatisfied with DDD? (# choosing that option)	
Did not give services based on what my client needed or wanted	9
My client had to wait a long time to get services	10
Once the services started, they were not always delivered when they were supposed to be	8
He/she did not seem trained	7

Behavioral health					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No interaction	5	3.6	6.0	6.0
	Very dissatisfied	13	9.3	15.5	21.4
	Dissatisfied	26	18.6	31.0	52.4
	Neutral	23	16.4	27.4	79.8
	Satisfied	17	12.1	20.2	100.0
	Total	84	60.0	100.0	
Missing	System	56	40.0		
Total		140	100.0		

Why dissatisfied with BH? (# choosing that option)	
Did not give services based on what my client needed or wanted	25
My client had to wait a long time to get services	23
Once the services started, they were not always delivered when they were supposed to be	20
He/she did not seem trained	12

Vocational rehabilitation services					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No interaction	22	15.7	26.5	26.5
	Very dissatisfied	9	6.4	10.8	37.3
	Dissatisfied	15	10.7	18.1	55.4
	Neutral	24	17.1	28.9	84.3
	Satisfied	11	7.9	13.3	97.6
	Very Satisfied	2	1.4	2.4	100.0
	Total	83	59.3	100.0	
Missing	System	57	40.7		
Total		140	100.0		

Why dissatisfied with VR? (# choosing that option)	
Did not give services based on what my client needed or wanted	6
My client had to wait a long time to get services	15
Once the services started, they were not always delivered when they were supposed to be	9
He/she did not seem trained	6

Foster care					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No interaction	30	21.4	36.6	36.6
	Very dissatisfied	7	5.0	8.5	45.1
	Dissatisfied	13	9.3	15.9	61.0
	Neutral	23	16.4	28.0	89.0
	Satisfied	6	4.3	7.3	96.3
	Very Satisfied	3	2.1	3.7	100.0
	Total	82	58.6	100.0	
Missing	System	58	41.4		
Total		140	100.0		

Why dissatisfied with foster care? (# choosing that option)		
Did not give services based on what my client needed or wanted	7	
My client had to wait a long time to get services	4	
Once the services started, they were not always delivered when they were supposed to be	5	
He/she did not seem trained	9	

Therapies					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No interaction	14	10.0	16.9	16.9
	Very dissatisfied	5	3.6	6.0	22.9
	Dissatisfied	10	7.1	12.0	34.9
	Neutral	29	20.7	34.9	69.9
	Satisfied	24	17.1	28.9	98.8
	Very Satisfied	1	.7	1.2	100.0
	Total	83	59.3	100.0	
Missing	System	57	40.7		
Total		140	100.0		

Why dissatisfied with therapies? (# choosing that option)		
Did not give services based on what my client needed or wanted	5	
My client had to wait a long time to get services	11	
Once the services started, they were not always delivered when they were supposed to be	8	
He/she did not seem trained	1	

<u>Crosstabulations – Erica's Questions</u>

<u>Question:</u> Among those providers who have had person-centered training, what are their jobs? Who are these providers?

<u>Methods:</u> The survey question, "Have you ever had training in person-centered planning or using person first language?" was examined for those who responded "Yes." Those who answered yes were examined for their job functions and organization type.

<u>Results:</u>

1. Among those who have received person-centered training, over half of them work for a provider for people with developmental disabilities. Their organization type is listed in the chart below:

<u>Type of Organization</u>	**<u>Frequency</u>**

A provider for people with developmental disabilities (DD) (e.g. day programs, in-home care, job training programs, group	37
A government agency (e.g. DDD, RBHA, Division of Aging and Adult Services, a city program)	12
Non-profit organization that is not a provider (e.g. disability organizations, faith-based organization, support groups	8
I am a paid family caregiver.	1
Adult Ed. instructor for DD population	1
Community Action Agency	1
county health department, offering community mobilization and collaboration	1
Education for children with disabilities	1
for-profit government contractor providing services for people with physical and emotional/behavioral/psychiatric disabilities	1
Non-Profit Organization that IS a provider	1
public school	1
School District	1
Teacher	1

2. Among those who have received person-centered training, over half of them spend the majority of their time in executive functions, as shown in the chart below:

"What types of functions take the majority of your time in your current position?"

	Frequency	Percent
Executive: Planning, administering, monitoring, staffing	37	55.2%
Direct Service: Direct client contact and support	16	23.9%
Administrative: Clerical, record-keeping, organizing	10	14.9%
Other: Please describe.	4	6.0%
Total	**67**	**100.0%**

Question: Among those who are newer in the field, how do they compare with those who have been in the field longer with respect to training, wages, job satisfaction, and retention?

Methods: The data on the number of years a respondent has worked in this field was separated into quartiles. The results follow. The lowest quartile was compared to the highest quartile on numerous factors.

Results:

Quartiles of the number of years respondents have worked in this field:

1st quartile	0 - 8.4 years
2nd quartile	8.5 - 15 years
3rd quartile	15.1 - 24.7 years
4th quartile	24.5 years and over

85 respondents provided information about the time they have worked in the field, resulting in 21 respondents in the lowest quartile and 21 respondents in the highest quartile. These two quartiles were compared.

No differences were found with job satisfaction between the 1st quartile and the 4th quartile.

The 1st quartile was significantly more likely to state that they are "somewhat likely" to leave their job within the year than the 4th quartile.

Nineteen out of 20 respondents in the 4th quartile were unlikely to leave their job within the year.

Although the 4th quartile respondents are slightly more likely to have person-centered training than 1st quartile respondents, the difference is insignificant.

Fourth-quartile respondents are more likely to be in Executive positions than 1st quartile respondents, but the difference is insignificant. Fourth-quartile and 1st quartile respondents are equally likely to be in Direct Service positions.

Mean and median hourly pay for the 1st and 4th quartiles are shown in the following table:

	Mean Hourly Pay	Median Hourly Pay
1st Quartile	$12.73	$12.53
4th Quartile	$15.29	$12.50

Data show that some 4th quartile respondents are paid much higher than their counterparts, with some receiving up to $25.00 per hour.

Question: Among those who are newer in the field, how do they compare with those who have been in the field longer with respect to training and perceptions of disabilities?

Methods: As above, the data on the number of years a respondent has worked in this field was separated into quartiles. The lowest quartile was compared to the highest quartile on training and perceptions of disabilities.

Results:

As stated above, there is no statistical difference between 1st quartile respondents and 4th quartile respondents in whether they have received person-centered training.

Second, an attempt was made to distinguish the disability perceptions between 1st quartile respondents who have had training and 1st quartile respondents who have not had person-centered training. However, the cell counts were too small (<10 at times) to reliably conclude any differences. A similar pattern occurred with 4th quartile respondents.

Next, perceptions of disabilities were compared between 1st quartile respondents and 4th quartile respondents, regardless of training. Again, this crosstabulation yielded cell counts too small (<20) to conclude any trends.

However, one consistent pattern was found – 4th quartile respondents who have worked in the field the longest were always less likely to answer "I don't know" or "neither agree nor disagree" than 1st quartile respondents to statements regarding their perceptions about the abilities of adults with developmental disabilities. In other words, those who have been in the field longer are surer of their opinions than newer workers.

Question: Are Pima County respondents more or less likely to have received person-centered training than respondents from all other Counties?

Methods: Respondents from Pima County were compared with respondents from all other counties as to their frequency of stating they had received person-centered training.

Results:

Pima County respondents are more likely to have received person-centered training than respondents from all other counties (90% vs. 70%), but the difference is statistically insignificant. Note – only 19 respondents were from Pima County.

Open-Ended Questions Summary

"What do you do to promote community inclusion for people with developmental disabilities?"

Many, many responses mentioned integrating the general community with those they work with who have developmental disabilities. "Community" was the most common word among these responses. Other key themes include:

- Providing training and education, and supporting training;
- Supporting work, providing employment, or helping link to employment;
- Providing equal treatment and basic kindness;
- Advocating or speaking up for others.

"How can these efforts to support community inclusion be better facilitated or supported?"

Numerous responses spoke of the need to promote awareness and understanding in communities. Other key themes include:

- Increased funding for services and for DDD;
- More employment opportunities for those with disabilities;
- Better staff / more therapists / better DDD workers;
- Help for rural areas;
- Better transportation options.

"Please describe any concerns you have."

Responses to this question tended to circle around the following issues:

- Lack of pay, training and benefits for workers providing services;
- Lack of resources and options in rural areas;
- DDD needs an overhaul / better reimbursement and documentation practices at DDD;
- Schools are under-resourced;
- Self-determination of those with disabilities;
- Lack of trained providers;
- Lack of community awareness;
- Overmedication.

“What do you do to promote community inclusion for people with developmental disabilities?”

develop and implement training to Direct Support professionals
support the idea of people with DD's to work in all areas of community
MANY THINGS
Go out into the community with my client, walking the mall or reading in the library.
support and train in therapeutic recreation
Church
get them out in the community to show how wonderful they are.
I am a role model for others in that I treat all people without bias and kindness
Within the parameters of my job,I take them anywhere they want to go. I research the venue to assess the problems that might occur and ways around that.I treat them as my friends not as someone that I have to take care of.i try to keep them out in the community and involved with others, not just their "peers".(hate that word)
Support them with resources available to them.
Group Supported Employment / Enclaves / Advocacy
Training and power point presentations.
Attempt to develop contracts with employers in the area that are willing to have this population in their businesses cleaning or working a recycling program. Sit on the leadership team for a local coalition that promotes employment for individuals with disabilities.
promote art events to aid students and provide funds for projects
I do not do much, I would like to do more.
Ensure that they are treated with respect and dignity. We validate their feelings and honor their rights.
executive director of a dd agency--part of our mission and everyday work
I do my job every day and I am part of the Employment First Core Team. I'm also working with a parent who is trying to start a socialization group for individuals who have developmental disabilities.
Participate in community outings as well as invite members to my home for the holidays or family events
attend fair jobs or participate in the community events
At reviews discuss with guardians/family members the importance of community participation. Review community happenings and encourage particpation in activities. Having the members be out with other people not just peers so that they too can have a better quality of life.
Let providers know about things in the community that they can do on outings.
Encourage family and group home staff to take people with developmental disabilities out to the community.
We provide services to individuals with severe disabilities and include them to local events and activities.
I advocate within the community. I speak to them and about them without making a difference between them. I seek community services to include them with the community without confining them only to activities specialized for individuals with disabilities.
Advocate for providers to engage our members in community outings, integrate them with what is happening in the community such as; comminuty happenings, volunteering, ect ...

talk to business owners, and people arount the community
follow weekly and/or monthly activity schedule
Take my children, with disabilities, everywhere I go. I have high expectations for them at school, home and in the public. / / I work at a place that provides services for individuals with disabilities and we also have high expectations for them and for the public we deal with on a daily basis. / / I try to educate the public anytime I can and help other parents when needed.
I talk to people that I know in different businesses and see if there are positions available for them in their businesses as well as promoting my own agency.
Talk to them and their teams as often as I can.
Provide CBE, GSE, ISE, and ESA services to maximize their vocational potential with eventual placement in the community.
I promote independence and free choice. I promote a safe work environment with plenty of work options.
advocate for them.
Seek vocational opportunities in the community
Get them out into the community for visual awareness...grocery shopping, craft store shopping, etc.
I encourage people to participate and joining community art, music, and other special events. I am very open about my job and the population I work with. I constantly ask people to consider approaching a situation with less abilities. Talking is powerful in helping others consider situations they are not aware of.
I provide good community based work for many people with developmental disabilities and encourage interaction with the general public.
I run a Group Supported Employment program for adults with disabilities. We teach these individuals what it means to have a job and everything that goes along with that. Being on time, following direction, calling in sick, respecting co workers ETC. As they learn we try to move them to independent employment and then on to competitive employment. Their place of work is in a retail plant nursery so they get used to being around the shoppers and non-disabled co workers. We also have crews that work on maintaining the River walks/parks in Tucson through a contract with Pima County. Again our crews work along side county workers and meet members of the public who use the river walks.
We provide services that utilize community resources every day. Meaning, each of our consumers is venturing into the community with their peers and a support staff to learn independent living skills, job skills, or are actually woking in either group enclave or independent work situation.
We offer resources within the community that will enrich the individual and those around them. Offering opportunities for them to help others. We teach basic social skills such as being respectful, waiting for your turn to talk, saying please and thank you, so that the community does not segregate them because they are socially unable to interact with others. We offer vocational opportunities within the community. We teach independent living skills that will promote healthy self esteem when in the community.
Organized Mohave County Special Needs Advocacy Coalition. Developed a resource guide and website. Support local health and information fairs throughout the county.
Advocate strongly. Model by actions. Provide services.
Running/expanding our art studio and gallery program by promoting individuals abilities and presence of our artists with intellectual and developmental disabilities (IDD). / Teaching and mentoring health and education related fields for their field and scholarly work involving individual with IDD. / Keeping direct contact and teaching time outside of administrative work with individuals with IDD.

I train staff across Yuma, La Paz and Mohave Counties in preschool settings
support inclusion at a young age in school
Advocate for the services they need.
Educate the public, teach families and disabled youth to advocate, Encourage participation in community events.
Attend ASL social events and encourage deaf community members to attend as well.
I include people with developmental disabilities in every day activities. I teach children about living full lives in acceptance, respect, and to help one another. I promote learning to live together, because the world is our class room for our fool life.
I am part of the local SNAC group which identifies needs and ways to improve services, but primarily support individual students in working toward their personal post school goals.
I serve thru the church, courts and other foundations
Actually I am not highly involved in working with people with developmental disabilities. I mostly work with other types of disabilities. I am a passive supporter of greater community acceptance/inclusion in general for people with disabilities of all types.
Age appropriate field trips.
I tell the public what there capabilities the disable population can do
I attempt to provide job opportunities in the community for individuals with disabilities.
Outings, volunteerism, events and activities, community-based employment, community awareness events /
our group is intergrated on a daily basis . they are treated as adults and we try to educate families to do the same. we give lots of opprtunities and expieriences, we have rules boundries etc. each person is taught and shown respect, courtesy manners, consequences, and held accountable for their actions behavior and desicions
Educate parents, teachers and other administrators on community resources and how these resources would benefit these students. I also spend time building up our transition program within the schools to accommodate a broader range of students with disabilities to better prepare them to lead a more independent life once they leave school.
advocate for them. take them into the community and educate people who may have questions. children, usually have the most questions to my group and they are great with children I know for one of my consumers she wanted children in her life but was not able to have that opportunity so she takes a great deal to them in the same manner a grandmother would.
Advocate.
Attend community events where a wide variety of people are involved. From street fairs to free concerts to sports events to health events.
Encourage our members to work, play and interact in the community. Help them participate in groups that give them a voice.
Bring trainings to the community and try to stay informed.
I take clients into the community and arrange involvement in community activities and opportunities.
teach mental health awareness
Part of my work capacity is that of a staff trainer, so I am always encouraging our employees to encourage independence of the people we support. I try to challenge our employees to help individuals take risks that will ultimately lead to a more independent lifestyle.
I have some adults with developmental disabilities as friends. I chat on the phone and go out to eat with them.

“How can these efforts to support community inclusion be better facilitated or supported?”

Improved transportation, increased available activities
PRMOTE AWARENESS, TOLERANCE AND ACCEPTANCE-UPDATE THE COMMUNITY ON HOW OUR CLIENTS ARE REALLY DOING
hire and train more recreational therapists
Better understanding
People can develop an understanding, awareness and love for them and see potential.
Successfully employ more people with disabilities and show more people their value in society.
I don't know.One person at a time. Hiring staff that are motivated, unafraid to take their clients out of the bubble. The community is generally not the problem. I encounter less resistance from the community than from providers who simply don't want to do the work that it takes to include their client in the community.I don't have an answer.
Share information to individuals and their families about community events and things to do.
Community Awareness
Increased funding through the state.
By breaking down stereotypes in the community.
Administration could be even minimally supportive
We need companies willing to hire people with disabilities in our community
People who live in rural areas often go without services. Agencies have a hard time staffing people in outer areas because there is no mileage reimbursement or higher pay offered for providers to be willing to travel to such areas to provide services. The state does not pay mileage and provider agencies cannot afford to eat the cost.
more funding
We need the community to be more inclusive and we need family members of adults to continue advocacy efforts.
Community needs to be outreached with more information on adults with disabilities
Because you make a difference and others see you and it can be done
Not sure.
to be able to have more programs in the community for
If they had a one to one caretaker but that is not always good for the provider.
more awareness.
If others did the same thing it would be more likely for people to change their mentality. If we expose the abilities of those with disabilities people wouldnt frown upon them as much as they do. People need to understand what it is like to have a disability. Knowledge is power.
Working towards integration within the community not developing special groups for our poplutation as an example ... instead of developing a talent show for members with disabilites within the community; develope a talent show for members in the community to include people with disabilities.
more programs
if only the funding agency acknowledges the rural or remoteness of where the services is delivered.

Additional funding for programs working with this population. Staff retention is difficult, as pay is very low for the amazing jobs these individuals do everyday with our children, neighbors, and family members. Countless people do this job daily out of love, but love doesn't pay the bills.
Better information to families and more outreach by agencies to businesses, as well as using businesses that are currently employing people with developmental disabilities to tell other businesses about their successes.
DDD rate structure, particularly for ISE and ESA needs to be analyzed and increase significantly to better support community inclusion efforts.
With the team effort.
more structure
Lucrative government aid to organisations hiring people with disabilities
Word of mouth, Maybe bringing the events to the individuals. Individuals do not seem to rely on "Facebook invites" as mean of event planning anymore. Having the DDD population participate in "up-in-coming" event ideas.
More community based work
I believe we could get more individuals in competitive employment if there was more funding for long term supports. More training for staff providing employment support would also really help
By providing incentives of knowledge for the general public to hire individuals with disabilities. Also providing more general knowledge to our communities at-large about our population and their capabilities in regards to contributing to that community.
Offering the community a better picture of the whole person rather than the disability may help support or even facilitate more opportunities. /
Funding to support a full time person to maintain the networking and meetings throughout the county.
The notion of "dignity of risk" seems to have gone from the discussion amongst professionals. DD Support Coordinators tend to be paternalistic towards the people on their caseloads. Also, if someone is not under legal guardianship, the DD support coordinator will make decisions for that individual rather than taking the time to explain all of the ramifications for informed consent especially if they believe that the person will make a decision that is different than what the DD SC would want. They also tend to side on the part of the parent even if the parent's wishes run counter to the individual on their caseload.
Our program provides training opportunities for future professionals who provide services to individuals with IDD. Most of our student interns will work in health and education related fields. Artworks is a catalyst site for driving change in the wider community. Through the day-to-day practice of our program mission, the long-term impact on the entire community includes improved service learning opportunities on the university campus, greater inclusion of adults with IDD in community life, greater awareness of the normalcy of individuals with IDD, and improved quality of life for adults with IDD and other IDD stakeholders. People who have experienced the value of our strength-based mutual learning carry this perspective into their communities.
Marketing to school districts so they can support professional development opportunities
Train service providers how to support inclusion in the community
More resources.
More opportunities for families to learn about advocacy, disability rights, and empowerment.
With more knowledge, more caring, more acceptance, and more programs.
Skilled staff in voc rehab and DDD positions would help tremendously. Outreach to the community which describes the capabilities of people with disabilities could be helpful--our

schools try, but the business community often thinks of us as, those people who always need more money, and are not always open to other messages.
If someone showed me something I could do to help, I would try to do it. I have no idea at the moment how I can make a difference without investing a great deal more time and energy than I have.
We need more money to bring our students out in the public.
Public awareness
We need to break down the barriers and stigma associated with individuals with disabilities. We need to educate the community on the individual's strengths.
f
programs are not funded properly and expected to do miricles, staffing is usually paid the minimum and most people just dont care and staff turn over is horrendous
We could certainly use more resources/funding to help support this. Also, more incentives for local businesses to hire individuals with intellectual disabilities.
awareness could promote funding or programs
More funding.
Make sure there is appropriate and safe ways for people without vehicles to get to the events. / Have a wider range of methods to get the word out about safe and free community events. / Have the sponsors of events take the initiative to find out how to reach the families and caregivers who support individuals with Developmental Disabilities other then sending an email to DDD.
Develop safe TRANSPORTATION that will give them opportunities to go places after work and on weekends.
Making community resources/activities better known.
staff support
It may sound like a cliche, but more funding helps. Having the ability to pay our employees a higher wage than they would get flippin' burgers helps our staffing situation and helps bring in a more highly educated employee.
The legislators need to fund DDD better so there are enough people to do the work and that the good people who work for DDD do not leave because their case load is unrealistically high.

“Please describe any concerns you have.”

Lack of adequate funding for nutritious food, fear of losing benefits when accepting a job, fear of losing housing funding if looking at other options
I THINK DDD NEEDS A SERIOUS OVERHAUL ON THEIR POLICIES, HOW THEY HAMDLE CLIENTS/FAMILIES, TRAINING THEY PROVIDE TO THEIR SUPPORT COORDINATORS AND EVERYTHING ELSE. STOP MAKING IT SO DIFFICULT FOR FMAILIES TO GET AND THEN CONTINUE SERVICES. EFERYTIME AND I MEAN EVERY TIME THERE IS A 90 DAY MEETING COMING OR AN ANNUAL ISP, MY FAMILIES ARE FREAKING OUT!!!!!! THAT IS JUST WRONG! NO SC DOES THE JOB THE SAME OR TELLS THE SAME INFORMATION. AND THEY MAKE THE CHLDREN FEEL UNCOMFORTABLE TOO. THEY ARE STRANGERS WHO SHOULD KNOW BETTER THAN TO GET IN THE FACE OF A PERSON WITH SPECIAL NEEDS. ALSO, THERE NEEDS TO BE A BETTER SYSTEM OF PAPERWORK. EACH AGENCY HAS DIFFERENT PAPERWORK AND IT IS ALL EXTREMEMLY CONFUSING AND MAKES NO SENSE ON WHAT DDD IS REALLY LOOKING FOR!

driving to people's homes unpaid very cost prohibitive and a dis-incentive to work in this field, lack of any benefits is a problem area and main reason for "looking elsewhere"
Lack of trained workers. Lack of training for care givers.
School SPED is over worked with not enough support with the needs of the students. its a glorified baby sitter. More money should go to help that failing system.
My recent concern is the federal mandate that has made it impossible for service providers to work over forty hours.That has been a huge blow to families and providers!! I used to work 50 + hours with one of my clients and now I can't because the agency cannot pay me overtime. I understand that because the reimbursement to the agency is little more than I make. The down side is that families are losing services from their well trained,trusted providers and it is having a huge impact on the clients that we are trying to support.As a provider, I am more than willing to work 50+ hours for that same $9.50 an hour but due to the shortsightedness of the powers that be, I have to refuse services to my client/family after forty hours even in an emergency. Families are getting thrown under the bus. There are not enough trained providers to fill this void that they suddenly find themselves in.
None.
The program I work in is staffed by people with little to no training in issues and needs of the DD population.
Cant think on any at the moment
We really, really need to engage employers, and not in the way we currently see success. It needs to be standard practice for folks to hire individuals who have difference into their workplaces. Microenterprise and the random good hirers aren't enough.
respect families times
Having the people that love them the most understand that they can do more than what they are doing.
none
na
none
I want funding agency or administrator to know what the real urban and rural is to base their rate cost. also to have office and licensure & regulatory agency to know some of home community base services providers live in traditional setting with dirt road, limited resources, limited infrastructures, costly wear and tear to deliver services, etc
Behavior health in Cochise County is very insufficient. ACTS/SEABHS/CIA are all very difficult and unprofessional to work with. (I have worked with them at a previous job as well and have tried to use their services for my family as well) They are all in dire need of reorganization.
N/A
I do have concerns about quality of services of people with disabilities. I try to advocate for all people we serve but there are times that you wish you could be a small fly on the wall.
none
The pay for this field isn't very good. This is why there's a big turn-over in staff.
I would like to see Group homes transition to being more like living assistant environments.
Overmedication
Where as I completely support the Employment First initiative, I also recognize that there are some individuals who will always need supported employment, my son being one of those individuals. Please let's not forget those individuals in our all important shift to competitive employment

Helping the school districts with the teacher, staff, student and family interactions. Create avenues for continued education, instructional information for parents on school process and programming, offer them in different social media formats. / / Offer training for health care providers to feel comfortable supporting a special needs person and their families. / / Respite care opportunities. /
The system is increasingly looking at regulations and requirements from providers for putting in documentation practices around regulations. Often the documentation practices are not clearly defined even when clarification is requested but providers will be held accountable for that "murky" definition. It makes it difficult to look at providing more innovative services because everyone is paying attention to liability (not from a risk perspective but from a lack of documentation/payment perspective.)
-Current service reimbursement structure from DDD does not favor aging population with disabilities or individuals with complicated health issues. As individuals age, many individuals have complicated health conditions and lessened energy level to attend
I feel the pay is not reasonable for all the care and responsibilities we have.
not sure
That our community does not offer enough of the kind of services that children and adults with disabilities need. Parents/families complain consistently about having to travel to the larger cities (Phoenix/Flagstaff) to get basic services like therapies and medical care. Also, there is limited access to therapy (speech, OT, PT) in our area due to lack of therapists.
Amount of available providers for speech, OT, PT, child psychologists in the northern rural areas of Arizona. Lack of special day schools, career training opportunities for adults with disabilities, lack of work placements for adults with disabilities.
We have too much discrimination.
I would really like to know that agency heads are expecting their folks to work with individuals, families and schools in order to support our students/clients. Almost always our students know what they want or need, as do their families. Too often, despite the fact that we serve our students every day, for most of the day, and usually for many years, agencies want to dictate to our students and to us, what will be. I understand that every agency has specific mandates, and their staff members probably need more options.
Lack of services in rural geographic areas.
This survey seems mostly geared towards services other than the kinds I provide at my agency.
We need to get area businesses on board with understanding that hiring or contracting with agencies that employ individuals with disabilities is a win/win for everyone. We also need to educate the communities on the benefits of employing individuals with disabilities versus viewing them as "less than".
Self-determination often seems secondary to federal and state rules and regulations. Consumer choice is often not primary in dealing with DES/DDD officials, more specifically new AHCCCS rule requiring ISP meetings to be held in family homes unless compelling reasons are presented to the contrary. Most often, consumers are not given the choice and frequently providers are not invited to the meeting
there are many programs that do not have facilities consumers spend lots of hours sitting at parks malls libraries or any where they can be. Although they have rules that they are not supposed to be there at those places hanging out they do becomes some companies do not have enough space to provide a place for all the consumers at one time due to poor funding. You get what you pay for and if companies have to pay rent utilities etc. they take on way to many clients to make it profitable and clients suffer

I am very concerned about the lack of awareness our community has of individuals with intellectual disabilities, their barriers to independence and belief in what they are capable of with the proper supports. We have made progress in this area from an education stand point, but still have a lot of work to do.
agencies are going to start losing site supervisors in large amounts here soon especially agencies that pay a salary instead of hourly wage, There is a lot of talk amongst many of us who do not want to give up our jobs and love what we do but must also make personal and family decisions of our own with the growing economy and prices rising all around us it is impossible for most of us to work 2 jobs or return to school but at the same time we can no longer continue in our positions realistically when one of our staff at $8.25-$8.44 pay rate steps into overtime at 8 hours of overtime our staff start to make more money than we do and lately the ability to mandate our own work schedule has been taken from us so the benefits of the position are really no longer there and are far too demanding. I do not mind paperwork or long work hours, it is the lack of sufficient staffing in the home and getting reprimanded that my paper work is not completed but because I am working as one of my staff I do not have the time to do the paperwork and there have been times that due to the lack of staffing I have had to come in to see to the shift being completed and had to bring my children with me because daycares are not open at 10pm and I am a single mother but if I do not cover the shift I am defying my job requirements and if I do but with my kids I am defying company policy its a lose lose situation on a constant basis
None.
We (caregivers and families/friends) need to understand that teaching individuals with a Developmental Disability how to build the life they want (NOT the life we expect them to live) is of great importance and that often we make it more difficult by not understanding that we must first begin to understand how to build our OWN life. / It's difficult (if not impossible) to teach something we don't know ourselves!
Rates for services could be improved, so we can be able to train staff better and maybe pay them for all their hard work.
Budget issues seem to bring barriers that are hard to overcome
none

APPENDIX E: ARIZONA PUBLIC POLL ANALYSIS (2015)

The sample size is 898. 122 are primary caregivers to someone with a disability; 167 have a disability. Approximately 30% of Arizonans have a disability or are the primary caregiver to someone with a disability.

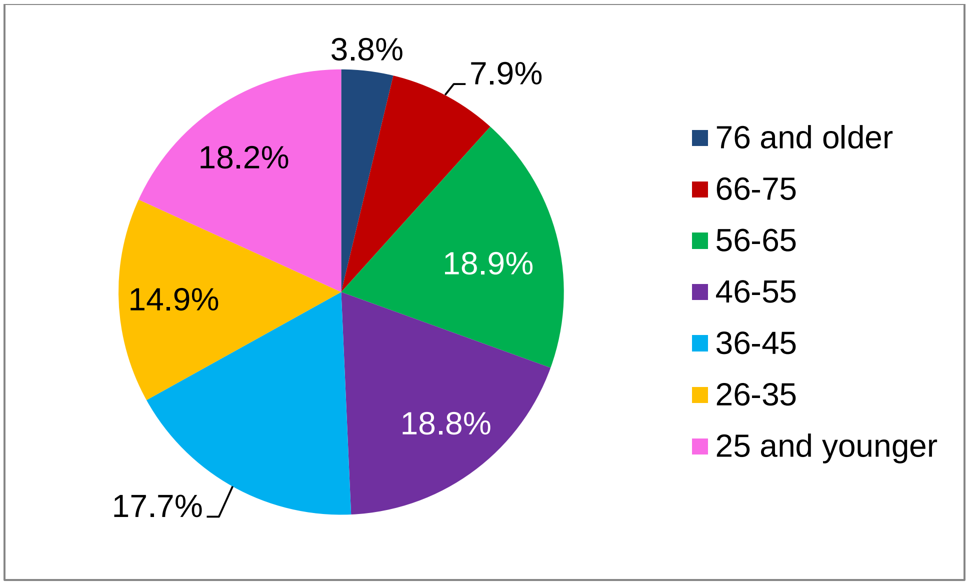
Crosstabulations

Question: Among those who have the primary responsibility for care of a person with a disability, how old are they?

Methods: The survey question, "Do you have the primary responsibility for the care of a person unable to fully care for himself or herself?" was examined. Among those who answered "Yes," their ages follow in the figure below.

Results:

Over half are between the ages of 36 and 65. Age categories of those who care for a person are shown in the figure below:

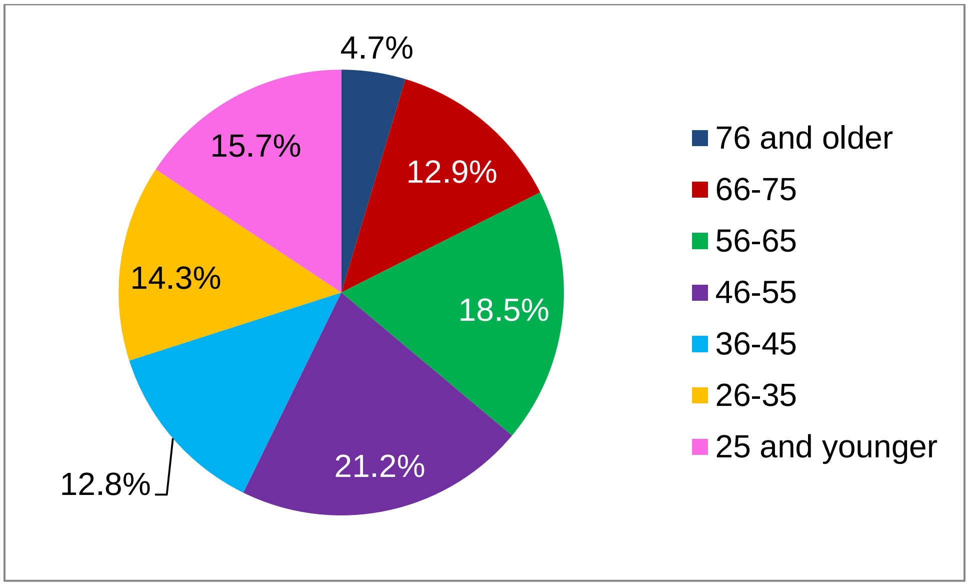


<u>Question:</u> What are the ages of those who have a disability?

<u>Methods:</u> The survey question, "Do you yourself have any type of disability, …" was examined for the age of respondents.

<u>Results:</u>

Over half are between the ages of 36 and 65. Age categories of those who have a disability are shown in the figure below:



<u>Question:</u> Do those who either have a disability or care for someone with a disability differ in their agreement on the disability-related questions than all others?

<u>Methods:</u> Agreement with the survey questions related to disabilities was compared between those who are either disabled or caring for someone with a disability and all others.

<u>Results:</u>

"Children with intellectual disabilities should be educated in the same classrooms as other kids their age." *(No real differences here)*

Percent Stating "Agree" or "Strongly Agree."

Disabled or Caring for Person with Disability	All Others
29.9%	29.7%

"Special education funding is diverting funding away from other students who don't need these services." *(No real differences here)*

Percent Stating “Agree” or “Strongly Agree.”

Disabled or Caring for Person with Disability	All Others
42.1%	42.5%

“Workers with disabilities perform at the same level as their counterparts without disabilities.” **The difference below is statistically significant.*

Percent Stating “Agree” or “Strongly Agree.”

Disabled or Caring for Person with Disability	All Others
47.4%	39.1%

“People with significant disabilities should receive financial assistance from the federal government.” *(No real differences here)*

Percent Stating “Agree” or “Strongly Agree.”

Disabled or Caring for Person with Disability	All Others
79.3%	78.2%

“Those families who help care for people with significant disabilities should receive financial assistance from the federal government.” *(Those who are disabled or caring are slightly more likely to strongly agree than all others.)*

Percent Stating “Agree” or “Strongly Agree.”

Disabled or Caring for Person with Disability	All Others
78.2%	78.1%

“I would be comfortable employing someone with significant disabilities.” *(Those who are disabled or caring are slightly less likely to disagree.)*

Percent Stating “Agree” or “Strongly Agree.”

Disabled or Caring for Person with Disability	All Others
79.7%	78.1%

“I would have a more favorable opinion of my employer if my company made a committed effort to recruit, hire, and promote people with disabilities.” **The difference below is statistically significant.*

Percent Stating “Agree” or “Strongly Agree.”

Disabled or Caring for Person with Disability	All Others
81.2%	73.2%

“I would prefer to give my business to companies that hire people with disabilities.” **The difference below is statistically significant.*

Percent Stating “Agree” or “Strongly Agree.”

Disabled or Caring for Person with Disability	All Others
84.6%	75.9%

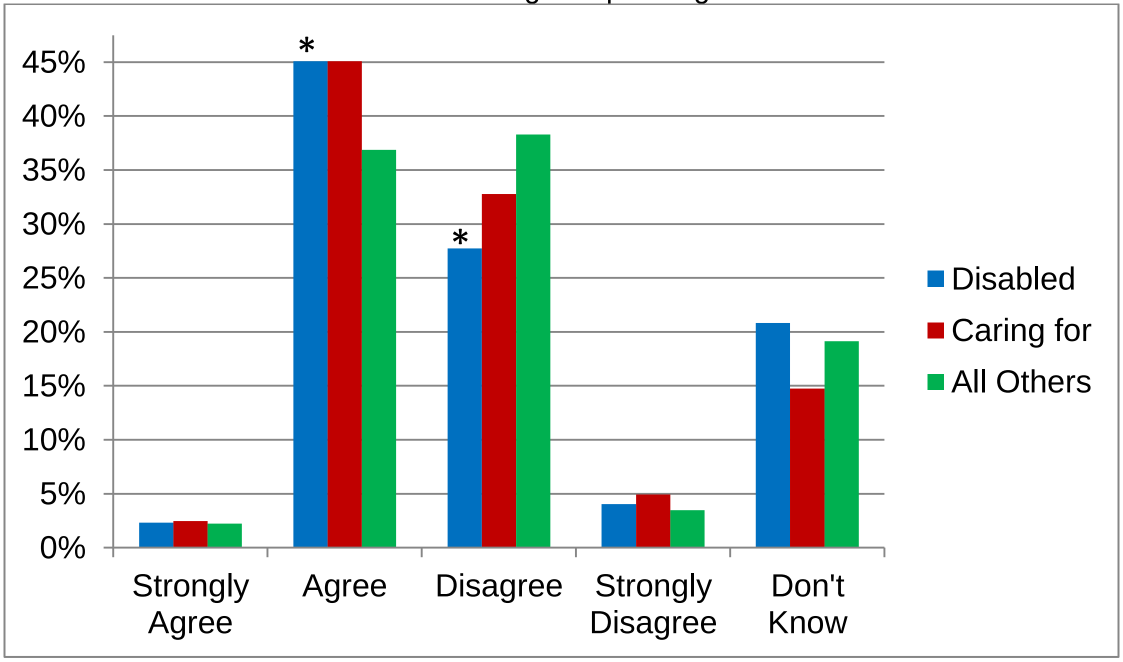
Question: Do those who either have a disability or care for someone with a disability differ from all others in their agreement regarding workers with disabilities?

Methods: The survey question, “Workers with disabilities perform at the same level as their counterparts” was examined further for differences among those with a disability, those who are caring for someone with a disability, and all others.

Results:

29 respondents of this survey note that they are both disabled themselves AND caring for someone with a disability. Differences in agreement with the statement are reflected in the figure below. Statistically significant differences are found between the following two pairs: “Disabled” and “All Others” who Agree; and “Disabled” and “All Others” who Disagree.

Percentage responding:

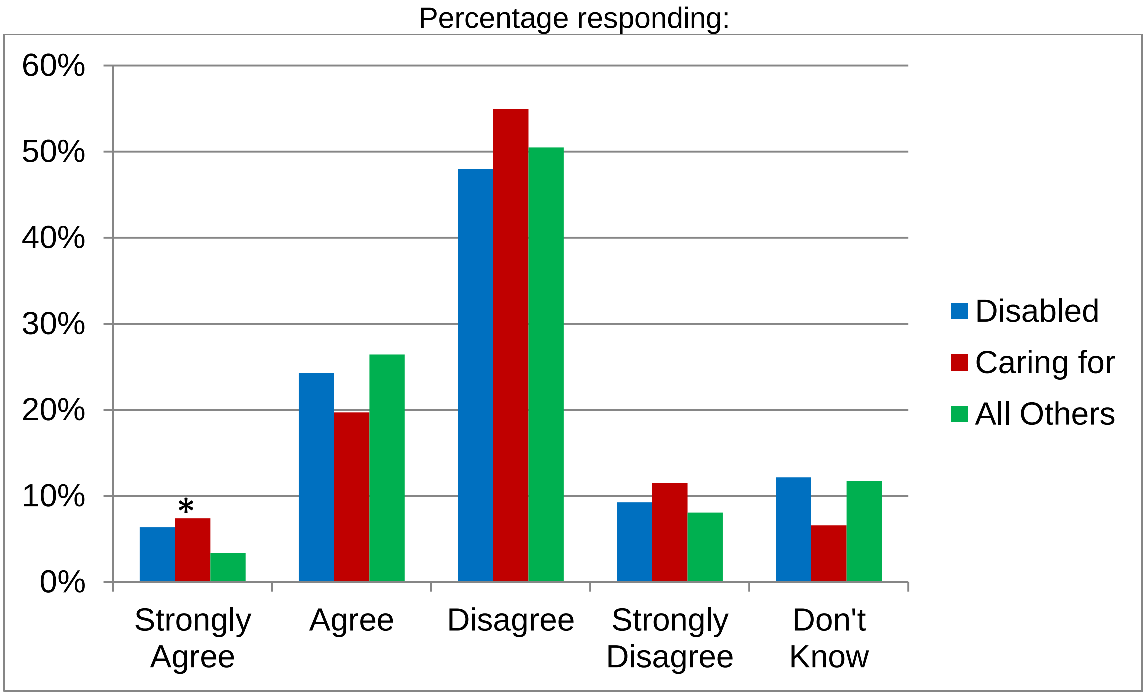


Question: Do those who either have a disability or care for someone with a disability differ from all others in their agreement regarding education of children with intellectual disabilities?

Methods: The survey question, "Children with intellectual disabilities should be educated in the same classrooms as other kids their age" was examined further for differences among those with a disability, those who are caring for someone with a disability, and all others.

Results:

Differences in agreement with this statement are reflected in the figure below. Statistically significant differences are only found between the following pair: "Caring for" and "All Others" who Strongly Agree.



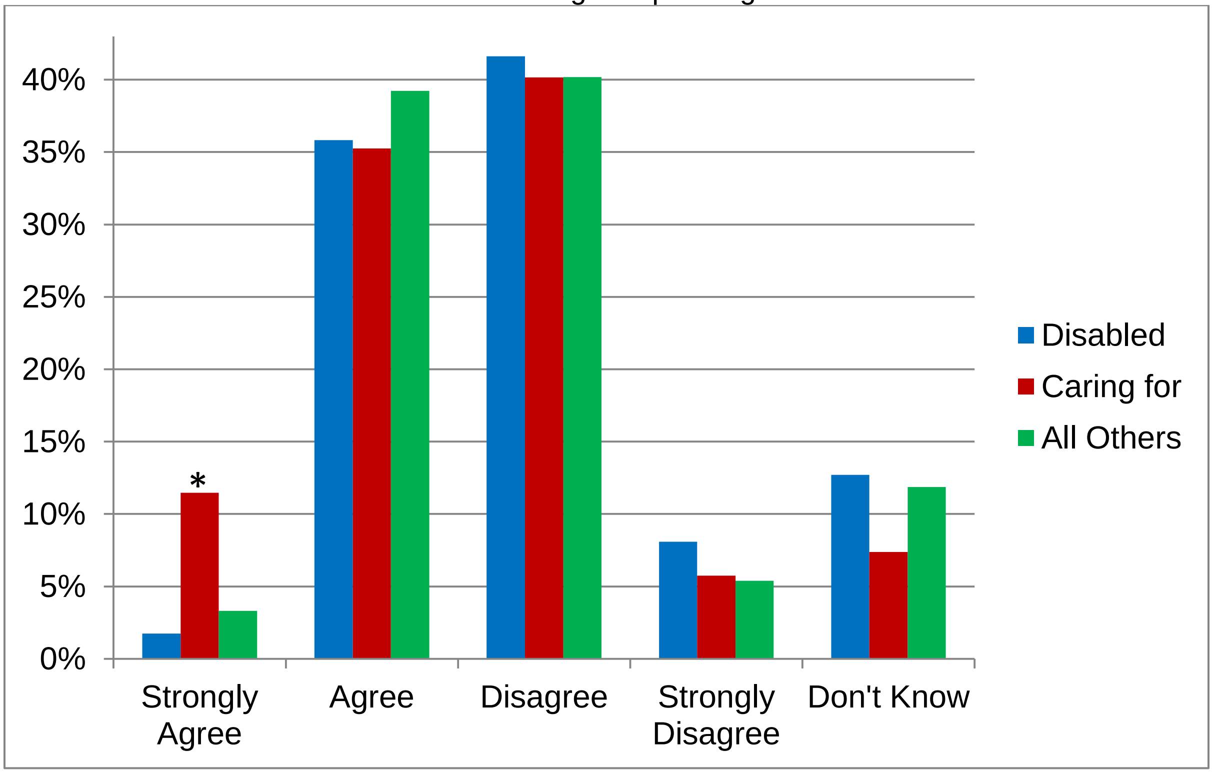
Question: Do those who either have a disability or care for someone with a disability differ from all others in their agreement regarding special education funding?

Methods: The survey question, "Special education funding is diverting funding away from other students who don't need these services" was examined further for differences among those with a disability, those who are caring for someone with a disability, and all others.

Results:

Differences in agreement with this statement are reflected in the figure below. Statistically significant differences are only found between the following pair: "Caring for" and "All Others" who Strongly Agree.

Percentage responding:

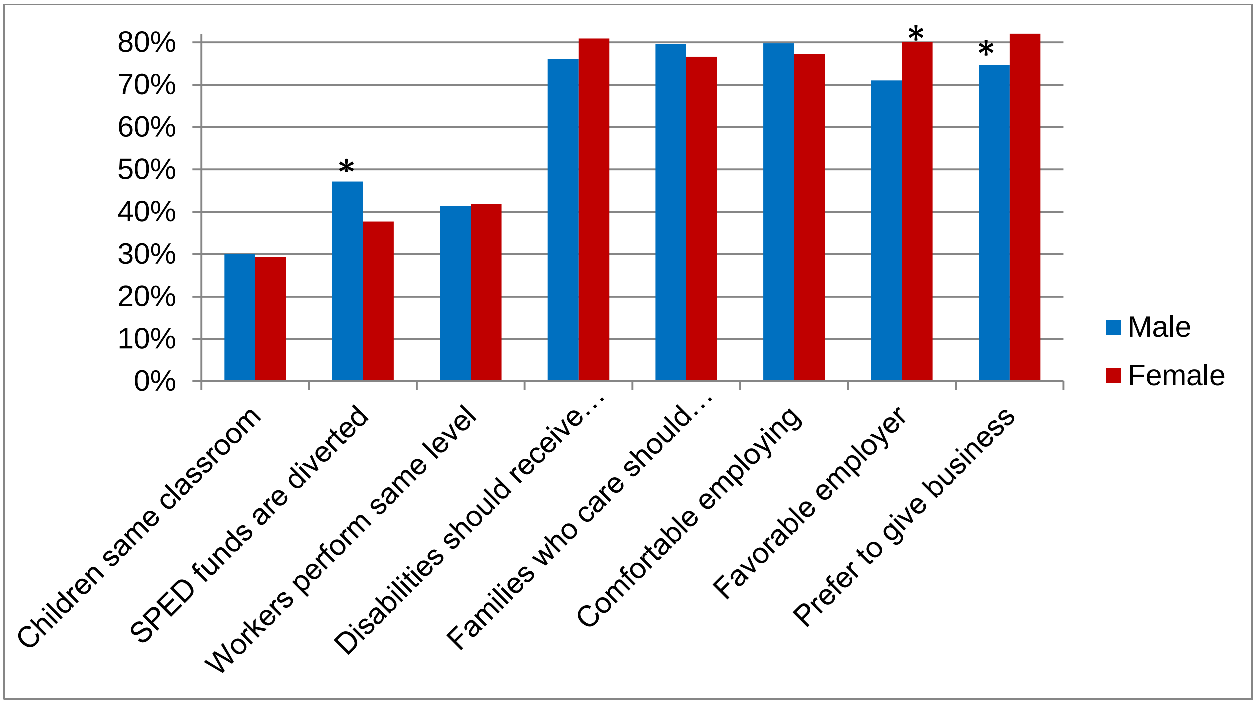


Question: Do those who agree with the disability-related statements differ by gender?

Methods: The survey statements related to disabilities were examined by gender.

Results: The following figure shows the percentage who either “Agree” or “Strongly Agree” with each of the statements, by gender.

Percentage Who “Agree” or “Strongly Agree”



Statistically significant differences are found between men and women who either agree or strongly agree with the following statements:

- *Special education funding is diverting funding away from other students who don't need these services.*
- *I would have a more favorable opinion of my employer if my company made a committed effort to recruit, hire and promote people with disabilities.*
- *I would prefer to give my business to companies that hire people with disabilities.*

REFERENCES

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[i] CMS, Nursing Home Data Compendium 2013 Edition. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/Downloads/nursinghomedatacompendium_508.pdf

[ii] The Early childhood Technical Assistance Center. (2015). Outcomes for children served through IDEA's

[iii] Ibid.

[iv] Arizona Department of Health Services. (2014). Arizona state health assessment. Retrieved from http://www.azdhs.gov/documents/director/managing-excellence-program/az-state-health-assessment.pdf

[v] Murphy, Sheila, 2011. 2011 Report: Oral Healthcare for Adults with DD in Arizona. https://addpc.az.gov/sites/default/files/Council_Documents/Council_Documents/OralHealthcareElect2012.pdf

[vi] National Core Indicators, Adult Consumer Survey, 2013-2014. https://des.az.gov/sites/default/files/nci_adult_consumer_survey_summary2014_0.pdf

[vii] Arizona Department of Administration, Arizona's Workforce Employment Report. November 19, 2015. https://laborstats.az.gov/sites/default/files/documents/files/Emp-Report.pdf

[viii] U.S. Bureau of Labor Statistics, Alternative Measures of Labor Underutilization for States, Fourth Quarter of 2014 through Third Quarter of 2015 Averages, October 23, 2015, http://www.bls.gov/lau/stalt.htm.

[ix] NCI, Adult Consumer Survey, 2013-2014.

[x] United Cerebral Palsy, 2015, The Case for Inclusion. http://cfi.ucp.org/

[xi] Arizona DES-DDD, Family Support Annual Report, 2014.

[xii] ICA, Substantive Policy Statement Regarding Application of Arizona Minimum Wage Act to Work Activities Performed By Individuals with Disabilities, March 29, 2007.

[xiii] Title XIX DDD Provider Reimbursement Rates Study, October 1, 2014.

[xiv] Email announcement from Letitia LaBrecque, RSA Administrator, September 30, 2015.

[xv] ASD Committee, Technical Workgroup Notes, http://www.azahcccs.gov/shared/Downloads/ASD/110215AdultsASDNotes.pdf

[xvi] Percentage of Total Workers, Self-Employed, American Community Survey, Public Use Microdata Sample (PUMS), 2009-2013 Arizona Persons File.

[xvii] Arizona Rehabilitation Services Administration (AZRSA), Annual Review Report, FY 2013, September 5, 2014.

[xviii] Self-Employment for People with Disabilities, report prepared for the U.S. Office of Disability Employment Policy, December 15, 2013, http://www.dol.gov/odep/pdf/2014StartUp.pdf.

[xix] AZRSA, Annual Review Report, FY 2009.

[xx] http://www.employmentfirst.net/

[xxi] The Kaiser Family Foundation's State Health Facts. (2015b). Data Source: SSI Annual Statistical Report, 2014. Social Security Administration, Office of Retirement and Disability Policy, Office of Research, Evaluation, and Statistics. SSA Pub No. 13-11827, October 2015. "SSI Beneficiaries with Disabilities" [http://kff.org/medicaid/state-indicator/ssi-with-disabilities/]

[xxii] AZDES, Annual Welfare Reform Report, FY 2014.

[xxiii] Ibid.

[xxiv] American Community Survey, Public Use Microdata Sample (PUMS), 2013, 1-year sample.

[xxv] AZDES, Annual Welfare Reform Report, FY 2014.

[xxvi] AZDES, DDD Family Support Program Annual Report, FY 2014

[xxvii] UCP, Case for Inclusion, 2015. http://cfi.ucp.org/data/

[xxviii] http://www.leadingage.org/uploadedFiles/Content/About/Center_for_Applied_Research/Publications_and_Products/Direct%20Care%20Workers%20Report%20%20FINAL%20(2).pdf

[xxix] Beamish, Rita, Older Americans Act Limps Along at 50, Stressing Local and State Agencies, March 4, 2015, http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/3/04/older-americans-act-limps-along-at-50-stressing-local-and-state-agencies

[xxx] DDD Family Support Report, 2014.

[xxxi] Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, Valuing the Invaluable: 2011 Update

---

The Growing Contributions and Costs of Family Caregiving, AARP Public Policy Institute, http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf

[xxxii] http://www.azdhs.gov/bhs/pdf/reports/annual/2015-smi-annual-report.pdf

[xxxiii] Native American Disability Law Center, The Needs of Native Americans with Disabilities, 2007.

[xxxiv] https://des.az.gov/content/community-teams

[xxxv] http://supportstofamilies.org/about/goal-of-supporting-families/

[xxxvi] http://www.communityworks.info/articles/microboard.htm

[xxxvii] Office of the Arizona Attorney General, 2015 Annual Report, https://www.azag.gov/sites/default/files/sites/all/docs/annual-reports/2015AnnualReport.pdf

[xxxviii] Lightfoot, E. & Hill, K. (2009). Prevalence of Children with Disabilities in the Child Welfare System: An Analysis of State Administrative Data, http://cascw.umn.edu/wp-content/uploads/2013/12/PrevalenceChildrenDisabilitiesSubSum.pdf

[xxxix] U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau. (2015). Child maltreatment 2013. Available from http://www.acf.hhs.gov/programs/cb/research-data-technology/statistics-research/child-maltreatment

[xl] Chapin Hall and University of Chicago, AZ DCS Independent Review, July 29, 2015 http://www.azauditor.gov/sites/default/files/AZ_Dept_of_Child_Safety_Supplemental_Report_2.pdf.,

[xli] http://azchildren.org/wp-content/uploads/2015/10/DCS-Charts-and-Graphs-u_10_7_15.pdf

[xlii] https://dcs.az.gov/sites/default/files/SEMIANNUAL-REPORTING-REQUIREMENTS-10-14-3-15_FINAL-Revised-080515.pdf

[xliii] http://www.acf.hhs.gov/programs/cb/research-data-technology/statistics-research/child-maltreatment

[xliv] http://www.domesticviolenceservices.com/disability-children.html

[xlv] SB 1375 Report, October 1, 2015, https://www.azahcccs.gov/shared/Downloads/News/SB1375Report10-1-15.pdf

[xlvi] http://www.azahcccs.gov/shared/Downloads/News/SB1375Report10-1-15.pdf

[xlvii] http://azchildren.org/wp-content/uploads/2013/02/Youth-Opportunities-Initiative-BR-2-22-13.pdf

[xlviii] Homeless Coordination Office, Department of Economic Security, Division of Aging and Adult Services, Homelessness in Arizona, Annual Report, 2014

[xlix] http://www.zerotothree.org/policy/docs/changing-the-course-for-infants-and-toddlers.pdf

[l] Bureau of Justice Statistics, May 21, 2015, http://www.bjs.gov/content/pub/press/capd0913stpr.cfm

[li] Adult Protective Services Annual Activity Report, FY 2014.

[lii] http://www.napsa-now.org/wp-content/uploads/2012/06/BaselineSurveyFinal.pdf

[liii] Adult Protective Services Annual Activity Report, FY 2014.

[liv] Analysis of Impediments to Fair Housing Choice, State of Arizona, 2015. https://housing.az.gov/sites/default/files/documents/files/State%20of%20Arizona%20Analysis%20of%20Impediments.pdf

[lv] https://www.azag.gov/sites/default/files/sites/all/docs/annual-reports/2015AnnualReport.pdf

[lvi] http://www.housingwire.com/articles/print/35242-hud-hands-out-38-million-to-fight-housing-discrimination

[lvii] ADOT, ADA: Final Transition Plan for Public Rights of Way, 2012, https://www.azdot.gov/docs/default-source/ada-library/ada_transition_plan-prow_final_1212.pdf?sfvrsn=2%27

[lviii] D. Deka, The role of household members in transporting adults with disabilities in the United States Transportation Research Part A: Policy and Practice, 69 (2014), pp. 45–57.

[lix] Title XIX Reimbursement Rate Study, 2015.

[lx] Bureau of Justice Statistics, Disabilities among Prison and Jail Inmates, 2011-2012, (December 2015), http://www.bjs.gov/content/pub/pdf/dpji1112_sum.pdf?utm_source=juststats-121415&utm_medium=email&utm_content=DPJI1112%20Summary&utm_campaign=juststats&ed2f26df2d9c416fbddddd2330a778c6=qoozlllrzr-qliniino

[lxi] http://www.thearc.org/NCCJD

[lxii] U.S. Department of Education Office for Civil Rights, Civil Rights Data Collection, Data Snapshot: School Discipline, March 2014, http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf

[lxiii] ADE, The Use of Seclusion and Restraint: A Guidance Document on Best Practices, 2015, https://cms.azed.gov/home/GetDocumentFile?id=560987ecaadebe150c51daa5

[lxiv] Martin, J. E., & Marshall, L. H. (1995). ChoiceMaker: A comprehensive self-determination transition program. Intervention in School andClinic, 30, 147-156. (ERIC Document Reproduction Service No. EJ497 548)

[lxv] Arizona Department of Education. (January, 2015). *Educator Retention and Recruitment Report.* Retrieved from www.azed.gov/wp-content/uploads/2015/02/err-initial-**report**-final.pdf

[lxvi] Office of Post Secondary Education. (March, 2014). *Teacher Shortage Areas Nationwide Listing: 1990-1991 through 2014-2015* (U.S. Department of Education). Washington, D.C. Retrieved from: http://www2.ed.gov/about/offices/list/ope/pol/tsa.pdf

[lxvii] U.S. Department of Education, Institute for Education Sciences. (November, 2015). *Teaching Vacancies and Difficult-to-Staff Teaching Positions in Public Schools.* National Center for Education Statistics. Retrieved from http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2015065

[lxviii] U.S. Department of Education, Institute for Education Sciences. (November, 2015). Teaching Vacancies and Difficult-to-Staff Teaching Positions in Public Schools. National Center for Education Statistics. Retrieved from http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2015065

[lxix] Ibid.

[lxx] Arizona Department of Education. (2014). Cohort 2011 - 2014 year graduation rate. http://www.azed.gov/research-evaluation/graduation-rates/

[lxxi] Siperstein, G., Parker, R., & Drascher, M. (2013). National snapshot of adults with intellectual disabilities in the labor force. Journal of Vocational Rehabilitation, 39, 157-165.

[lxxii] Wehman, P., Scott, L., & Michelle, J. (2013). Applications for youth with intellectual disabilities. In *Life Beyond the Classroom* (Ed. P. Wehman). Baltimore, Maryland: Brookes Publishing Co.

[lxxiii] University of Massachusetts-Boston, Think College. (2015). TPSID Grantees 2015-2010. http://www.thinkcollege.net/images/stories/TPSID_map_cohort2.png

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

[lxxv] UCP Case for Inclusion 2014.

[lxxvi] Michael Orr, October 2015, Monthly Housing report.

[lxxvii] Data derived from Technical Assistance Collaborative, Database of Vouchers for People with Disabilities

[lxxviii] Arizona Department of Health Services, Health Status Profile of American Indians in Arizona, 2013 Data Book.

[lxxix] NADLC, The Needs of Native American with Disabilities: 2007 Assessment.

[lxxx] Williamson, H.J. &Perkins, E.A. (2014) Family Caregivers of Adults with Intellectual and Developmental Disabilities: Outcomes Associated with U.S. Services and Supports. Intellectual and Developmental Disabilities, 52(2). DOI:10.1352/1934-9556-52.2.147

[lxxxi] Janicki, M. P., McCallion, P., & Dalton A. J. (2000). Supporting people with dementia in community settings. In M. P. Janicki & E. F. Ansello (Eds.) Community supports for aging adults with lifelong disabilities (pp. 387-414). Baltimore, MD: Brookes Publishing Company.

[lxxxii] Heller, T., Caldwell, J., &, Factor, A. (2007). Aging family caregivers: Policies and practices. Mental Retardation and Developmental Disabilities Research Reviews 13(2), 136.

[lxxxiii] CMS Nursing Home Data Compendium, 2013.

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