

Final Report on the Comprehensive Review and Analysis of Developmental
Disabilities Services and Supports in the State of Arizona

Prepared for the Arizona Developmental Disabilities Planning Council by the
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Introduction

The Sonoran UCEDD, beginning in June of 2010 and under contract with the Developmental Disabilities Planning Council (DDPC) undertook a *Comprehensive Review and Analysis* (CRA) of the developmental disabilities landscape in the state of Arizona. The purpose of the CRA is to inform the development and creation of the DDPC's next Five-Year Plan due to the federal Administration on Developmental Disabilities (ADD) in August of 2011.

The CRA was divided into a series of primary and secondary data collection efforts. The first report delivered to the DDPC provided a summary review and analysis of existing programs in Arizona providing services, supports and other assistance to persons with developmental disabilities (DD) and their families. It is located in the appendix as attachment 1. The second report delivered to the DDPC provided an environmental scan of existing and contemplated legislation and policies at the state and federal levels and is included in the appendix as attachment 2. The next step of the CRA focused on collecting primary data from statewide DD stakeholders using a combination of surveys, focus groups and key informant interviews.

This document is a review and analysis of this primary data. Since the DDPC has already received summary reports of secondary data collection, this final report concentrates on describing and summarizing the primary data collection process and findings. The ultimate goal is to provide reliable, relevant and timely information that the Council may use to inform the new Five-Year Plan for the Administration on Developmental Disabilities (ADD).

One of the main goals of the CRA is the identification of themes and issues important to persons with developmental disabilities, their families, and providers of DD services. It was decided when designing the CRA in the Spring of 2010 that the best way of obtaining high quality first-hand stakeholder perspectives would be to use a combination of surveys, focus groups and interviews with key informants from Arizona's developmental disabilities community. We decided on ten key informant interviews, five focus groups, and two surveys to identify emerging themes, issues and trends. The following sections describe and analyze the survey findings followed by a review and analysis of focus group and key informant interview findings.

Survey Methodology and Findings

The *stakeholders* we were interested in surveying included persons with developmental disabilities, their families, along with advocates, providers of services and supports to persons with developmental disabilities and their families, administrators of governmental and not-for-profit organizations that provide DD services and supports, and policy makers responsible for shaping the rules that govern the delivery of DD services and supports.

To reach this wide and diverse audience we developed two surveys. One survey was aimed at persons with developmental disabilities and their families (consumers of DD services). The *consumer* survey is a 44-item instrument combining open and closed-ended responses focused on identifying the issues most important to persons with developmental disabilities and their families. The *provider* survey is a 32-item instrument also combining open and closed-ended responses. It targeted DD service providers, advocates, administrators, and other DD professionals. This survey was aimed at identifying and exploring the important issues from the perspective of providers, advocates, and other professionals working in the field of DD.

Surveys were not randomly distributed, meaning that we did not pick respondents randomly; rather they picked themselves. We are confident that we captured a reasonably representative sampling and are comfortable making some limited inferences from that sample

because we mounted a vigorous outreach effort to publicize the survey project. Information about the survey and solicitations for participants was circulated widely throughout the DD community across the state. Our DD Network partners all participated in the recruitment and outreach by, for example, including a link to our surveys on their websites, notifying potential respondents thru their newsletters, describing the survey in public forums, and various other similar methods. Both surveys were made available in a paper version as well as an electronic version via the Web. We used the popular Survey Monkey website to design the survey and collect responses. Both surveys went live the first week of December of 2010 and concluded their data collection by the end of February 2011. Both surveys emphasized confidentiality and encouraged honest and frank responses to a range of questions and topics relevant to persons with developmental disabilities, their families, as well as providers and other DD professionals.

The consumer survey generated a total of 80 responses and the Provider survey a total of 186 responses, combining to net 266 completed surveys. Full copies of each survey including response frequencies are included in the appendix. The surveys also collected basic demographic information that Tables One and Two summarize.

**Table One
Consumer Survey Basic Demographics (n=80)**

County	Maricopa	Pima	Coconino	Pinal	Graham, Mohave, Santa Cruz	
	43.7%	39.4%	5.6%	7.0%	4.6%	
Gender	Male			Female		
	57.1%			42.9%		
Race /Ethnicity	White	Hispanic	African American	Asian	Native American	Native Hawaiian or Pacific Islander
	79.2%	15.3%	8.3%	2.8%	1.4%	1.4%
Living Situation	With their family	In their own home	Group or Developmental Home	Foster care or host home	Share a home	
	63%	17.8%	8.2%	4.1%	4.2%	
Internet Access	Yes, I have regular access			No, I do not		
	69.9%			30.1%		

**Table Two
Provider Survey Basic Demographics (n=186)**

County	Pima	Maricopa	Coconino	Apache, Cochise, Mohave, Navajo, Pinal, Santa Cruz, Yavapai, Yuma		
	59.1%	22.1%	7.1%	11.8%		
Gender	Male			Female		
	21.9%			78.1%		
Race /Ethnicity	White	Hispanic	African American	Asian	Native American	Other
	76.6%	16.8%	1.6%	1.1%	3.3%	0.6%

First, the summary of the demographic patterns show that the vast majority of responses to both surveys came from Maricopa and Pima counties. Second, while gender was split roughly evenly in the consumer survey (57% male - 43% female), nearly 80% of the provider survey respondents identified as female with only 20% identified as male. This apparent imbalance may be reflecting the preponderance of women working in the field. Third, the majority of respondents to both surveys were White, followed by smaller percentages of Hispanic, African-American, Asian, and Native American respondents – except in the provider survey where Native American respondents slightly outnumbered Asian respondents. And finally, 63% of the consumer survey respondents reported living with family and nearly 70% reported regular access to the Internet.

The survey questions were organized around the following topics:

- Special education
- Transition to adulthood
- Community inclusion
- Early intervention and early childhood services
- Services provided by the Division of Developmental Disabilities
- Rehabilitative services
- Medical, oral health, and behavioral health care
- Transportation services and recreation opportunities
- Self-advocacy
- Employment issues
- Restraint and seclusion
- Housing and independent living
- Assistive technology

These topics informed the development of survey questions, and they also animated focus group discussion and key informant interviews. Later in this report discussion focuses on the ten recurring topics resulting from the qualitative data analysis of individual and group interviews.

Consumer Survey Findings

The reader will find in the appendix a copy of the consumer survey including summary output and response frequencies. Provided below is a general overview and analysis of findings, including information of particular relevance to the development of the Five Year Plan. It is important to remember that the results described below are based on 80 respondents. This is not a large number, but insofar as they represent the feelings and judgments of 80 individuals who took the time and effort to complete the survey, they deserve attention and consideration. Table 3 lists the individual survey topics and the questions associated with each topic.

Table 3
Consumer Survey Topics

Topic	Associated Survey Question(s)
Healthcare, including medical, oral, behavioral health, and health insurance	Questions 2, 3, 4, 5, 6, 17, 29, 30, 31
Recreation and Day Activities	Questions 1, 9, 10
Self Advocacy	Questions 11, 12
Transportation	Questions 13, 14
Services and Supports	Questions 15, 18
Special Education	Questions 19, 20, 21
Seclusion and Restraint	Question 22
Early Intervention/ Early Childhood Services	Questions 23, 24, 25
Rehabilitative Services	Questions 32, 33, 34
Work	Question 35
Aging adult caregivers	Questions 36, 37
Transition to adulthood	Question 16
DDD Services	Questions 26, 27, 28

Healthcare

The survey devoted 9 of the 44 questions to healthcare in all of its forms – medical, oral, behavioral health and health insurance status. **Respondents appeared generally satisfied with their medical health care. Seventy-six percent agreed that their medical practitioner understood and respected their disability and health care needs; 21% chose the *not sure* option; and 3% disagreed.** The overwhelming majority of respondents rated as *very important* the indicators of high quality health care including medical knowledge and expertise, compassion, dedication to patients, and clear communication. **Results from questions on oral health care revealed some issues around satisfaction and access.** When asked if they were satisfied with the condition of their teeth and mouth, 62% said yes, **but another 32% said no**, representing nearly 1/3 of the total sample. Sixty-four percent reported having had a dental exam in the past year, but another **37% reported no dental exam in the past year**. When asked why, **29% cited cost**, while 15% said they could not find a dentist who accepts patients with special needs. When asked how satisfied they were with behavioral health services, 24% reported either *somewhat dissatisfied* or *very dissatisfied*, while 30% reported *very* or *somewhat satisfied*. On the other hand, **39% reported having no experience with behavioral health services**. Question 31 which asked if you ARE NOT satisfied with behavioral health services, please tell us what you think could be improved generated 22 separate written responses critical in some way or another of the existing system. These written responses are included in the copy of the survey in the appendix. Finally, question 17 asked about whether people had health insurance to help pay for health care costs. **Thirty-nine percent reported they had Arizona-Long-Term Care System (ALTCS) coverage**, another 27% said Arizona Health Care Cost Containment System (AHCCCS), 22% said employer sponsored private insurance, 5% reported individually purchased private insurance, and 1.4% said they had no health insurance.

Recreation and Day Activities

Three questions (1, 9, 10) asked about daily activities and recreational opportunities. Question 1 offered respondents a 12-item activity list and asked them to check all that applied to their lives. Options included such activities as going out to eat, shopping, school, and paid employment. The percentile responses range from a low of 12% (social club) to a high of 77% (going out to eat). Other notable high percentile items include vacation (51%), **shopping (74%)**, religious or other spiritual services (57%), and school (58%). Table 4 provides the complete list.

Table 4
“I Currently Participate in the Following Activities”

Activity	Percentile Response
Day program	16%
Eating out	77%
Vacation	51%
Shopping	74%
Religious/spiritual activity	57%
Recreation	32%
Volunteer	23%
Social club	12%
Sports (including Special Olympics)	22%
Paid employment	18%
Exercise	12%
School	58%
Other	11%
Horseback riding, work programs at school, Project Search internship, Work Enclave	

Self-Advocacy

Two questions (11 and 12) examined the role of self-advocacy in respondent’s lives. One question probed for the importance of self-advocacy in people’s lives by asking people to respond to the following question on a 5-point scale: “Self-advocacy, or the ability to speak up for myself, helps me live the life I want to live.” Fifty-nine percent strongly agreed and 22% agreed. Sixteen percent were neutral and 3% disagreed. No one strongly disagreed. **The overwhelming proportion of responses either strongly agreed at 81%, while only 3% disagreed.** A second question asked if a sufficient number of self-advocacy training opportunities exist in my area. Here, 5% strongly agreed, 12% agreed, 39% were neutral, 30% disagreed, and 14% strongly disagreed. **The findings appear to support the importance of self-advocacy in people’s lives, while a sizeable number (44%) feel that not enough training opportunities exist.**

Transportation

Questions 13 and 14 asked about transportation needs and experiences. Respondents were asked first to rate the adequacy of public transportation for getting them to where they need to be in the community. Nine percent responded with always and 17% said often, while 51% said sometimes and 23% said never. The follow-up question asked if finding transportation was difficult, what was the reason. Respondents were offered six choices. Thirty-four percent said “I do not have difficulty finding adequate transportation,” 32% said it was inconvenient, 21% said

it was not available where they live, 26% said it was too slow, 9% said it was not accessible, and 4% said it was too expensive. Respondents were allowed to select as many responses as applied, so the percentages will not sum to 100%. Another 23% included **written responses which reinforced the closed-ended findings, demonstrating frustration over inflexible scheduling, too few pickup times, lack of coverage, and bus stops too far from home.**

Services and Supports

Respondents were asked to identify services and supports they currently use in question 15 and then rate the importance of a broader range of items in question 18. Again, this being a non-random sample makes it difficult to generalize to the larger DD population in Arizona, but it does provide a clear picture of survey participants. Table 5 below reports the percentage of respondents who identified services and supports they currently use.

Table 5
Which of the Following Services and Supports do You Currently Use?

Special Education (52%)	Respite (46%)	Speech Therapy (45%)
Habilitation (44%)	Occupational Therapy (33%)	Behavioral health (26%)
Attendant care (14%)	Day program (14%)	Music Therapy (14%)
Para-Transit 11%)	Employment services (10%)	Housing (10%)
Early intervention/early childhood (5.5%)	ABS Therapy (1.4%)	
None of the Above (8%)		
Other (22%) Included physical therapy, VR, Case management, social skills, and transitional program		

Reading the table across and down, the services and supports are listed by order of frequency, ranked from highest to lowest percentage of reported use with the exception of *None of the Above* and *Other*. **Slightly more than half of respondents reported using Special Education services and supports. Respite, Speech Therapy, and Habilitation follow closely behind.** Twenty-two percent used the *Other* category to report using physical therapy, vocational rehabilitation, case management, social skills, and transitional programs. Eight percent reported using none of the services and supports listed.

Question 18 took a different approach to this issue by asking respondents to rate the importance of selected services and supports to the mission of the DDPC. People had four choices to choose ranging from Very Important to Not Very Important. Table 6 below summarizes their responses.

Table 6
Importance of Selected DD Services and Supports to Mission of DDPC*

	Very Important	Important	Somewhat Important	Not Very Important
Aging services	47%	32%	16%	4%
Special education	71%	22%	4%	3%
Caregiver support and education	61%	33%	5%	0%
Child care related initiatives and activities	46%	32%	14%	8%
Dental care related initiatives and activities	59%	33%	5%	3%
Early intervention	61%	27%	8%	4%
Education K-12 initiatives and activities	60%	34%	3%	4%
Employment related initiatives and activities	68%	23%	7%	3%
Health service related initiatives and activities	68%	31%	1%	0%
Housing related initiatives and activities	62%	28%	8%	1%
Post-secondary options for young people with developmental disabilities	77%	18%	4%	1%
Advocacy initiatives and activities that ensure the excellence of services and supports	74%	25%	1%	0%
Recreation related initiatives and activities	61%	31%	8%	0%
Training of direct service providers	69%	27%	3%	1%
Transportation related activities	60%	28%	11%	1%
Other services offered or available to individuals in a community including formal and informal community supports that affect quality of life	68%	25%	5%	1%

Not all columns sum to 100% due to rounding.

Numerical values decline from left to right, not a surprising trend given the survey audience. The column that provides the most useful information is that titled *Very Important*. The percentages in this column provide us with some sense of the relative value assigned to the various services and supports. **The item receiving the highest value is Post-secondary options for young people with developmental disabilities (77%), followed closely by Advocacy initiatives ... (74%), then Special education (71%).** This question also appears on the provider survey and we will compare and contrast the two in the summary of primary data findings.

Special Education

Questions 19, 20, and 21 ask people if they are satisfied with special education services, what they like about those services, and if they are not satisfied, what they would change. Nine percent reported having no experience with these services, 15% said they were very satisfied, 31% were somewhat satisfied, 11% were neutral, 20% were somewhat dissatisfied, and 13% were very dissatisfied. **Forty-six percent reported some degree of satisfaction while 33% reported some degree of dissatisfaction.** On question 20, 42% said that the services have helped me progress in life and meet goals and expectations, 15% said the services met their individual needs, 42% said the staff responds to my concerns and treats me with respect, and 24% responded with mixture written comments some positive and others critical. While not exactly representative of all comments, one comment was particularly poignant: "It's been many years but I don't feel like the special education I received prepared me for much besides dependency and letting others fight my battles." Written responses to question 21 asking about what people would change produced a total of 39 separate responses **grouped mainly around**

the issues of transition to adulthood/post secondary education, more training and support for teachers, inclusion, and Individualized Education Plans (IEP). One person did write: “I would like them (the schools) to teach us how to speak up for ourselves,” another indicator of the importance of self-advocacy.

Seclusion and Restraint

A question on seclusion and restraint was included simply asking if the respondent or some one they knew had been restrained or secluded while at school. **Forty-two percent responded affirmatively, 43% said no, and 16% reported not knowing.**

Early Intervention/ Early Childhood

Experience with early intervention and early childhood services were examined with three questions (23, 24, 25). As with special education, they asked people if they are satisfied with early intervention services, what they like about early intervention services, and if not satisfied, what they would recommend to improve the early intervention systems of services and supports. In response to the first question, 24% reported having no experience with early intervention, while 21% said they were very satisfied, 20% somewhat satisfied, 12% neutral, 13% somewhat dissatisfied, and 8% very dissatisfied. **Almost twice as many people (41%) reported satisfaction than dissatisfaction (21%).** On question 24, 40% reported having no experience with early intervention or early childhood, 16% higher than responding the same on the question 23. Whether respondents were confused or reconsidered their response is not clear. We simply take note of it and attribute it to reporting error. Thirty-three percent said the services have directly improved my child’s quality of life, 20% said that the services met their child’s individual needs, 29% said the staff responds to my concerns and treats my child with respect, and 17% offered written comments. Those comments were a mix of critical and supportive. Written responses to question 25 asking about what people would change produced a total of 17 separate responses **grouped mainly around the issues of access to services and the availability of service providers.** One person wrote: “emphasis on inclusive practices, including students with all degrees of disability,” a comment that overlaps with concerns expressed around special education as well.

Rehabilitative Services

Questions 32, 33, and 34 all dealt with rehabilitative services – how satisfied people are with the services, what rehabilitative services do well, and what could be improved. Over half or 52% said they had no experience with rehabilitative services, 16% were very satisfied, 17% were somewhat satisfied, 3% were neutral, 6% were somewhat dissatisfied, and 6% were very dissatisfied. **A much higher proportion (33%) reported satisfaction then dissatisfaction (12%).** On question 33, 48% said they had no experience with rehabilitative services, 31% said that the services have directly improved my quality of life, 26% said they met their individual needs, 29% agreed that the staff responded to their concerns and treated them with respect, and 12% offered written comments. The comments (7) fell mainly on the negative side with no discernable grouping or patterning. One person mentioned better needs assessment, another cited problems with their durable medical equipment (DME), and another cited the need for more trained providers. Written responses to question 34 asking about what people think could be improved generated 14 separate comments, **grouped mainly around access to services, DME**

issues, and more training for staff. One respondent wrote: “better training for staff, more providers, holding staff and agencies accountable for their poor care.”

Work

Question 35 asked “Are you/your family member with a developmental disability working in a job where you receive minimum wage or above? **Twenty percent said yes, 31% said no, and 49% reported not working.**

Aging Adult Caregivers

Two survey questions were included (36 & 37) to measure age, one to measure the age of the person with a developmental disability and a second question measuring the age of potential caregivers. The first question asked directly “what is your age or the age of the person with a developmental disability you are assisting in filling out this survey?” 3% responded 0-3 years, 64% responded 4-21 years, 30% said 21-55, and 3% said over 55. **Sixty-seven percent were between 0 and 21, while 33% were 21 to over 55.** The second question asked, “If you are a person with a developmental disability currently living with an adult family member, what is the adult family member’s age?” Responses included room for three adult family members as applicable (Adult 1, 2, and 3). Thirty-three percent reported Adult One 25-45 years old, 29% report Adult One 46-60 years old, 8% said Adult One was 61-70 years old, and 3% said Adult One was over 80 years old. Twenty-five percent said Adult Two was 25-45, 27% said Adult Two was 46-60, 6% said Adult Two was 61-70, and 2% said Adult Two was over 80. A third adult was reported in only 3 cases, 2 were 25-45 and 1 was 46-60. **A sizeable proportion of Adults One and Two were over age 46 – 40% for Adult One and 35% for Adult Two,** reinforcing the concern over aging care givers.

Transition to adulthood

Question 16 dealt specifically with the transition issue by asking respondents if “sufficient supports exist to help persons with developmental disabilities transition from high school and to plan for life after high school, including work or post secondary education?” One percent strongly agreed with this statement, 8% agreed, 32% neither agreed nor disagreed, but 23% and 36% disagreed and strongly disagreed respectively. **Clearly there is much dissatisfaction with services and supports around transition with nearly half (49%) of people reporting disagreement or strong disagreement and only 9% strongly agreeing or agreeing.** On the other hand, nearly 1/3 would neither agree nor disagree.

DDD Services

The level of satisfaction with the Division of Developmental Disabilities was another focus of the consumer survey. Questions 26, 27, and 28 asked how satisfied people are with DDD services, what DDD does well, and what could be improved, respectively. On question 26, 12% said they had no experience with the Division, 24% said they were very satisfied, 40% somewhat satisfied, 4% neutral, 9% somewhat dissatisfied, and 11% very dissatisfied. **A much higher proportion (64%) reported satisfaction than dissatisfaction (20%), by more than a 3 to 1 ratio.** On question 27, 15% said they had no experience with DDD services, 46% said the services addressed their individual needs, 56% said the staff responded to my concerns and treated me with respect, 41% reported that the services directly improved my quality of life, 41% said the services helped me progress in life and meet goals and expectations, while nearly 18%

provided written comments. **The 12 individual comments split about evenly between those that were critical of the agency and those that were generally positive, and grouped mainly around issues of staffing, resources, and access to services.** Written responses to question 28: “If you are not satisfied with DDD services” and asking about what people think could be improved generated a large number of comments (27), **grouped mainly around staffing (skills, knowledge, and turnover), resources, and access to services.** One person wrote, “I wish they made things easier. Getting in touch with them, returning messages, and not withholding services than can be offered. NEED TO BE AN ADVOCATE.” Another wrote, “don’t like turnover and budget cuts,” and one other wrote, “better training of staff, prompt follow-up to questions and knowledge of community resources.”

Provider Survey findings

The reader will find a copy in the appendix of the provider survey including summary output and response frequencies. As with the consumer survey section, this section offers a summary of findings as well as a more focused analysis of those findings that will be relevant to the development of the Five Year Plan. It is important to remember that the results described below are based on a non-random survey of 186 respondents. Table 7 lists the survey topics and questions associated with each topic.

Table 7
Provider Survey Topics

Topic	Associated Survey Question(s)
Healthcare, including medical, oral, behavioral health, and health insurance	Questions 1, 2, 3, 4, 23, 24, 25
Recreation	Questions 7, 8
Self Advocacy	Questions 9, 10
Transportation	Questions 5, 6
Services and Supports General	Question 11
Special Education	Questions 14, 15, 16
Seclusion and Restraint	Question 17
Early Intervention/ Early Childhood Services	Questions 18, 19, 20
Rehabilitative Services	Questions 26, 27, 28
Transition to adulthood	Question 13
DDD Services	Questions 21,22
Inclusion	Question 12

The topics are nearly identical to the consumer survey; the questions are arranged differently and written for a target audience of DD service providers, advocates, administrators, and other DD professionals. This survey was aimed at identifying and exploring the important issues from the perspective of providers, advocates, and other professionals working in the field of DD.

Healthcare

The survey devoted 7 of the 32 questions to healthcare in all of its forms – medical, oral, behavioral health, a proportion similar to the consumer survey. Questions 1, 2, and 3 asked about oral health. When asked if persons with developmental disabilities were able to see a dentist on a regular basis, only 17% said yes while 55% said no and 28% didn’t know. **These findings**

appear to contrast with data from the consumer survey where 64% reported having had a dental exam in the past year, but are consistent with the 37% reporting no dental exam in the past year. When asked on question two if persons with developmental disabilities have access to a dentist in a timely fashion, 18% said yes, 51% said no and 32% reported no knowing. Question three followed up on question two, by asking about barriers to oral health. **Cost was cited by most with 78% saying cost is not affordable. This contrasts with 29% on the consumer survey.** The second most often cited barrier was not being able to locate a dentist who accepts patients with special needs at 58%. Only 15% cited this barrier on the consumer survey. Another 31% said nearby dentists do not accept health payment plans.

Question four looked at what characteristics contributed to a medical provider's ability to provide quality care to persons with developmental disabilities. **The overwhelming majority of respondents (80% to 91%) rated as Very Important the indicators of high quality health care** including medical knowledge and expertise, compassion, dedication to patients, understanding of disability-related health needs and clear communication. Asking about health care goals appeared less important with only 54% rating is as very important

Questions 23, 24, and 25 all dealt with behavioral health services – how satisfied people are with behavioral health services, what behavioral health services do well, and what could be improved upon. On question 23, 16% said they had no experience with behavioral health services, 4% were very satisfied, 36% were somewhat satisfied, 10% were neutral, 23% somewhat dissatisfied, and 11% very dissatisfied. **The difference between satisfaction (40%) and dissatisfaction (34%) was only 6 percentage points, amazingly the same spread as on the consumer survey where also a slight majority were more satisfied than not.** When asked on question 24 what behavioral health has done well, 19% reported having no experience with behavioral health, 36% said the services address people's individual needs, 41% said the staff is supportive, responsive, and respectful, 37% reported that services directly improved quality of life, and 24% wrote 36 individual comments many critical of the existing behavioral health system for reasons ranging from access, cuts, and failure to follow-thru. Written responses to question 25 asking what could be done to improve the behavioral health system generated 71 individual comments. Some comments mirrored those from question 24, but many additional issues were raised including staff turnover, staff expertise, timely access, funding cuts, med reviews, working with a DD population, and bureaucratic squabbling.

Recreation

Question 7 asks if there are adequate opportunities for recreation in the community for persons with developmental disabilities. Thirty percent said yes, 53% said no, and 17% didn't know. For those who said no, 13% acknowledged that while recreational opportunities exist, they are difficult to access. Another 13% judged that recreational opportunities for persons with developmental disabilities do not exist, **while 74% said there are just not enough recreational opportunities for persons with developmental disabilities.**

Self-Advocacy

Questions 9 and 10 measure provider's views on self-advocacy. Asked if persons with developmental disabilities and their families are capable of representing themselves on issues critical to their quality of life, 14% strongly agree, 34% agree, 25% neither agreed nor disagreed, while 23% disagreed and 5% strongly disagreed. Nearly half (48%) agreed or strongly agreed while just over a quarter (28%) disagreed or strongly disagreed. On the survey of consumers

59% strongly agreed and 22% agreed when responding to the statement “Self-advocacy, or the ability to speak up for myself, helps me live the life I want to live,” **suggesting that consumers exhibit more confidence in the self-advocacy skills than do providers within the context of these two surveys.** When asked on question 10 if a sufficient number of self-advocacy training opportunities exist in my area, 2% strongly agreed, 20% agreed, 35% were neutral, 37% disagreed, and 7% strongly disagreed. Less than a quarter (22%) agreed on any level while twice as many or 44% disagreed and strongly disagreed. **When the identical question was asked of consumers, the same 44% also said that not enough training opportunities exist.**

Transportation

Providers were asked to evaluate the quality of public and para-transportation on questions 5 and 6. When asked to what degree public and para-transportation is available to persons with developmental disability, 7% said always, 35% often, 53% sometimes, and 5% never. Twenty-three percent of consumers said never, **suggesting a more skeptical view of transportation availability.** When providers were asked why, 28% said it is not accessible, 43% said it’s not available where people live, 42% said it’s too slow, 49% said it is too inconvenient, 28% too expensive and 29% included written responses reinforcing the closed ended responses.

Services and Supports General

Providers were asked to respond to the same question as consumers, asking respondents to rate the importance of selected services and supports to the mission of the DDPC. People had four choices to choose from Very Important to Not Very Important. Table 8 below summarizes their responses, with percentile responses from the consumer survey in parentheses.

Table 8
Importance of Selected DD Services and Supports to Mission of DDPC

	Very Important	Important	Somewhat Important	Not Very Important
Aging Services	58% (47)	36% (32)	5% (16)	1% (4)
Special ed.	63% (71)	31% (22)	5% (4)	1% (3)
Caregiver support and education	70% (61)	28% (33)	2% (5)	1% (0)
Child care related initiatives and activities	51% (46)	37% (32)	11% (14)	2% (8)
Dental care related initiatives and activities	55% (59)	37% (33)	7% (5)	1% (3)
Early intervention	80% (61)	16% (27)	3% (8)	1% (4)
Education K-12 initiatives and activities	64% (60)	31% (34)	5% (3)	1% (4)
Employment related initiatives and activities	69% (68)	27% (23)	3% (7)	1% (3)
Health service related initiatives and activities	68% (68)	29% (31)	3% (1)	1% (0)
Housing related initiatives and activities	62% (62)	32% (28)	5% (8)	1% (1)
Post-secondary options for young people with developmental disabilities	56% (77)	36% (18)	8% (4)	1% (1)
Advocacy initiatives and activities that ensure the excellence of services and supports	73% (74)	25% (25)	1% (1)	1% (0)
Recreation related initiatives and activities	46% (61)	41% (31)	11% (8)	2% (0)
Training of direct service providers	71% (69)	25% (27)	3% (3)	1% (1)
Transportation related activities	55% (60)	37% (28)	7% (11)	1% (1)
Other services offered or available to individuals in a community including formal and informal community supports that affect quality of life	59% (68)	33% (25)	6% (5)	2% (1)

Just as with the consumer survey, numerical values decline from left to right, not a surprising trend given the survey audience. The column that provides the most useful information is titled *Very Important*. The percentages in this column provide a measure of the relative value assigned to the various services and supports. For the sake of contrast and comparison, the percentages from the consumer survey are in parentheses next to the provider percentages. The item receiving the highest percentile value is Early Intervention (80%), [Post-secondary options for young people with developmental disabilities (77%)], followed closely by Advocacy Initiatives (73%) [Advocacy initiatives (74%)], then Training of Direct Service Providers (71%) [Special education (71%)]. The consumer survey choices are shown in brackets. **Both consumer and providers agree on advocacy initiatives, but diverge in other areas.**

Special Education

Questions 14, 15, and 16 ask providers if they are satisfied with special education services, what they like about the services, and if not satisfied, what would they change. Twelve percent reported no experience with special education, 9% were very satisfied, 29% somewhat satisfied, 10% neither, 27% somewhat dissatisfied, and 13% very dissatisfied. **Thirty-eight percent reported some measure of satisfaction while 40% some degree of dissatisfaction.** (Consumers were 46% vs. 33% respectively). On question 15, 52% said services meet individual educational needs, 45% said the staff responds to my concerns and treats me with respect, 43% said the services met their individual needs, 15% said they had no experience with school-based special education, and 20% responded with a mixture of written comments, some positive and others critical. Similar to the consumer survey, the written responses **grouped mainly around the issues of transition to adulthood/post secondary education, more training and support for teachers, inclusion, and Individualized Education Plans (IEP).**

Seclusion and Restraint

As with the consumer survey a question on seclusion and restraint was included asking respondents if they knew of any instances where an individual had been restrained or secluded while at school. Forty-six percent said yes, 38% said no, and 16% said they didn't know. **Responses from the consumer survey to a similarly phrased question were 42%, 43%, and 16% respectively, remarkably similar to provider responses.**

Early Intervention/ Early Childhood Services

Early intervention and early childhood services were explored with three questions (18, 19, 20), asking respondents how satisfied they were with early intervention services, what they like about early intervention services, and if not satisfied, what they would like to see changed. In response to the first question, 24% reported having no experience with early intervention, while 18% said they were very satisfied, 29% somewhat satisfied, 12% neutral, 13% somewhat dissatisfied, and 4% very dissatisfied. **Nearly three times the percentage of respondents reported some degree of satisfaction (47%) over dissatisfaction (17%).** On the consumer survey **almost twice as many people (41%) reported satisfaction than dissatisfaction (21%).**

On question 19, 30% reported having no experience with early intervention or early childhood, 45% said the services meet individual needs, 51% said the services have directly improved people's quality of life, 51% said the staff is responsive and respectful, while 13% offered 22 separate written comments. Written responses to question 20 asking about what people would change if they were not satisfied currently produced 44 individual written

comments. As on the consumer survey, **comments were grouped around issues of access to services and service providers, including the impact of budget cuts.** For example, one person wrote, *“The impact of budget cuts, increase in pay and services, and lack of support to therapy providers have all bee detrimental to individuals with disabilities.”*

Rehabilitative Services

Three questions (26, 27,28) asked about rehabilitative services -- how satisfied are you with rehabilitative services, what they like about rehabilitative services, and if not satisfied, what would you like to see changed? Twenty-two percent said they had no experience with rehabilitative services, 10% were very satisfied, 33% somewhat satisfied, 15% neutral, 13% somewhat dissatisfied, and 7% very dissatisfied. **The percentage (43%) reporting some level of satisfaction was more than double of that reporting some level of dissatisfaction (20%).** On the consumer survey the percentage reporting some level of satisfaction (33%) was nearly triple the percentage reporting some degree of dissatisfaction (12), where only 3% were neutral. When providers were asked what they liked about rehabilitative services, 23% said they had no experience with rehabilitative services, 35% said the service meets people’s individual needs, 47% said the services had directly improved people’s quality of life, 43% said staff responds to concerns and treats people with respect, and 17% left written comments. **The comments mirrored those on the consumer survey insofar as they were largely critical of the system.** Question 28, asking respondents, if not satisfied with rehabilitative services what they would change netted 47 written comments, also grouped around access to services, staff training, as well as preparing people for work. For example one person wrote, *“With the order of selection, most applicants are put on a waiting list. Rehabilitative services should be about meaningful employment, however many individuals do not have jobs.”*

Transition to adulthood

Question 13 asked for responses to the following statement: “High school transition planning is effective in preparing students with developmental disabilities for adult living including employment.” In response, 35% strongly agreed, 20% agreed, 17% neither agreed nor disagreed, 17% disagreed, and 10% strongly disagreed. About double the percentage of responses fell into the strongly agree and agree category (55%) versus the disagree and strongly disagree category (27%). **These findings are essentially the reverse of how consumers responded to the same question, where 49% reported some degree of dissatisfaction and only 9% reported some degree of satisfaction.** But another 31% neither agreed nor disagreed.

DDD Services

Two questions on the provider survey probed provider’s attitudes toward the DDD. When asked how satisfied they were with DDD services, 2% reported having no experience with the Division, 15% said they were very satisfied, 50% somewhat satisfied, 11% neutral, 17% somewhat dissatisfied, and 6% very dissatisfied. **A noticeably higher proportion of respondents (65%) reported some degree of satisfaction than some degree of dissatisfaction (23%). These outcomes closely mirror those of the consumer survey, where a much higher proportion of respondents reported satisfaction (64%) than dissatisfaction (20%).** When asked “what stands out when you reflect on your experience with DDD services?” 2% said they had no experience with DDD services, 36% said services effectively address individual needs, 54% said services directly improved people’s quality of life, 57% said the services helped people

progress in life and meet goals and expectations, 53% said staff responded to concerns and treated people with respect, and 33% responded with written comments (57). **But, unlike the consumer survey where the comments were split between those critical of DDD and those supportive of DDD, here the vast majority express dissatisfaction. That dissatisfaction is sometimes aimed directly at DDD, and in other cases seems to reflect a more general frustration of the DD system of which the Division is a part.**

Inclusion

One final area of inquiry involved inclusion, asking respondent to rate the importance eight “facets of daily life” to maintaining inclusion for persons with developmental disabilities. The results are displayed in Table 9 below.

Table 9
Rating the Importance 8 Facets of Daily Life for Maintaining Maximum Inclusion*

Facet of Daily Life	Very Important	Important	Somewhat Important	Not Very Important
Being around other people	79%	19%	2%	0%
Being part of a community	80%	18%	3%	0%
Being treated with respect	93%	7%	0%	0%
Having a job, going to school, or engaging in meaningful activities	85%	15%	1%	0%
Liking one’s neighbors	41%	43%	15%	1%
Making one’s own choice	75%	22%	3%	0%
Not feeling lonely	72%	25%	3%	0%

*Because of rounding, results may not sum across columns to 100%.

Being treated with respect rates the highest in importance to maintaining maximum inclusion, followed by having a job, going to school, or engaging in other meaningful activities. Being part of a community and being around other people also rated in the top half of choices. Liking one’s neighbors rated lowest in importance.

Summary of Survey Data Analysis

The consumer and producer survey results share some common findings and exhibit some notable differences. The bullet points below summarize the key findings.

- Consumers and providers appeared generally satisfied with their medical care. Providers rated high quality medical care as very important.
- One-third of consumers expressed dissatisfaction with the condition of their teeth and mouth.
- Providers and consumers both exhibited slightly more overall satisfaction than dissatisfaction with behavioral health services.
- The top two consumer-reported payer sources for health care were ALTCS at 39% ACHCCCS at 27%.

- Consumers exhibited more confidence in their self-advocacy skills than did providers, but both groups agreed that not enough training opportunities exist.
- Consumers and providers both expressed frustration over transportation options, but providers offered a more skeptical view of transportation availability than consumers.
- Consumers ranked special education services first on their list of services and supports they currently use, with respite, speech therapy, and habilitation following closely behind.
- Consumers and providers both ranked advocacy initiatives most important to the mission of the DDPC, but diverged on their ranking of other services and supports.
- Consumers reported more satisfaction with special education services than dissatisfaction, while providers reported greater dissatisfaction than satisfaction.
- Substantially more providers acknowledged knowing of an instance(s) of seclusion and restraint in the schools than reported not knowing of one, while just slightly more consumers responded affirmatively than negatively to the same question.
- The proportion of providers reporting satisfaction with early education/early childhood services was nearly three times that of those reporting dissatisfaction. The proportion of consumers reporting satisfaction was twice that of those reporting dissatisfaction.
- The Proportion of providers reporting satisfaction with rehabilitative services was more than double that of those reporting dissatisfaction. Nearly three times as many consumers reported satisfaction then dissatisfaction.
- One-fifth of consumers said yes to working in a job with minimum wage, about one-third said no, and half reported not working.
- About double the proportion of providers reported satisfaction over dissatisfaction with transition services, essentially the reverse of how consumers responded to the same question, where nearly half reported dissatisfaction and only 1/10 reported satisfaction.
- Providers reporting satisfaction with DDD services were nearly three times the proportion of those reporting dissatisfaction. These outcomes closely mirror the consumer survey, where the proportion reporting satisfaction was just over 3 times greater than those reporting dissatisfaction.
- Providers said being treated with respect was most important to maintaining maximum inclusion, followed by, in order of rating, having a job, going to school, or engaging in other meaningful activities.

Qualitative Data Collection and Analysis: Focus Groups and Key Informant Interviews

We begin this section with an explanation of the methodology underlying the focus group and key informant interviews, the two complementary qualitative data collection approaches. We follow that in the findings section with a detailed description and analysis of the qualitative data.

Focus Group Methodology

We conducted five focus groups, their locations chosen to gain geographic and cultural representation; two in Phoenix, one in Flagstaff, one in Tucson, and one in Sells. The UCEDD partnered with community and state-based organizations to recruit between five and ten participants and handle logistics. Each session ran from 1 ½ to 2 hours of facilitated discussion.¹

¹ Thanks to: Raising Special Kids and the Arizona Center for Disability Law in Phoenix; Extreme Parents Advocacy and Support Group in Tucson; the Tohono O’odham Nation’s Health & Human

Ensuring confidentiality and respect for individual privacy was a priority and meant that we did not record names, gender, ethnicity/race, age, or hometown meaning we lack the detailed demographic data that we have for survey participants. But do know that participants across the five focus groups included young and older adults with DD, younger and older parents, grandparents caring for developmentally disabled children and adults, and foster parents. We also know that participants represented a wide range of ethnicity and race, age, gender, and geographic variation. We were also sensitive at the outset that without proper facilitation and guidance, focus groups sessions could turn into complaint sessions. We avoided this by keeping the session focused on specific questions and, when necessary, gently guiding the conversation in such a way as to produce the effective exchange of information, ideas, and perspectives. The focus group sessions were typically facilitated by one or two people.

Key Informant Methodology

Ten interviews with key informants, also chosen with similar representational goals in mind including geographic and cultural diversity, were conducted. We also recruited and interviewed people occupying a variety of distinct roles, responsibilities and backgrounds to ensure that we collected a broad range of perspectives and ideas. Those interviewed included an administrator for Special Education of a large public urban school district; a mother of a special needs child and community organizer from a remote location in rural Arizona; administrators of two state agencies that serve the needs of persons with developmental disabilities and their families; the director of a large tribal agency that delivers services and supports to a largely remote Native American population; a younger adult with a developmental disability; directors of two state-wide not-for-profit organizations delivering services and supports to persons with developmental disabilities and their families; the father of a special needs child from an urban under-resourced school district; the mother of an adult child with multiple developmental disabilities with many years experience trying to obtain the best possible services and supports available.

Interviews were conducted both in-person and by telephone. Interviews typically lasted between ½ to 1 hour. Individual interviews began in early December 2010 and were concluded by late January 2011. As with the surveys and focus groups, we recognized that confidentiality was key obtaining candid responses; interview participants were assured that all reasonable steps would be taken to ensure that their privacy and confidentiality be maintained.

Qualitative Data Collection and Analysis and Findings

The *topics* of focus group discussions and individual interviews overlap considerably with the survey topics and include (1) assistive technology needs, (2) employment, (3) healthcare, (4) housing, (5) independent living, (6) rehabilitation and work, (7) special education, (8) system responsiveness, (9) transition, and (10) transportation. These individual items rose to the level of *Topic* because they appeared regularly and repeatedly as a major constituent in and across different interview contexts. This is different from for example, an issue that arose once or twice in perhaps one or two interview contexts and then disappeared. Topics are significant because of their regular and repeated appearance regardless of time, place, or composition of individuals. Topics may also be considered services and supports.

In addition to the identification of recurring *topics*, qualitative review and analysis also revealed a number of common *themes* – ideas or concerns that also appeared regularly and repeatedly across the individual and group interviews.² These themes appear again and again throughout the interviews and coalesce around (1) access to services and supports, (2) communication between stakeholders, (3) community inclusion, (4) independence, and (5) self-advocacy. These five themes, while articulated in various ways depending upon person and place, manifested themselves regularly across the interview forums – both in the individual interviews as well as the group settings. The interviewees did not necessarily use these exact words or phrases, but these words and phrases are intended to capture and summarize their meaning. It should also be noted that these themes appear in the open-ended responses to survey questions.

The diagram in figure 1 below is meant to graphically represent the relationship between topics and themes.

² To avoid confusion we should make clear what we mean by qualitative review of the data. It means a rigorous and systematic approach to analyzing the content – written notes and in some cases audio records of focus group and individual meetings -- to identify and describe qualitative patterns (themes) that emerge from a careful review of the primary data.

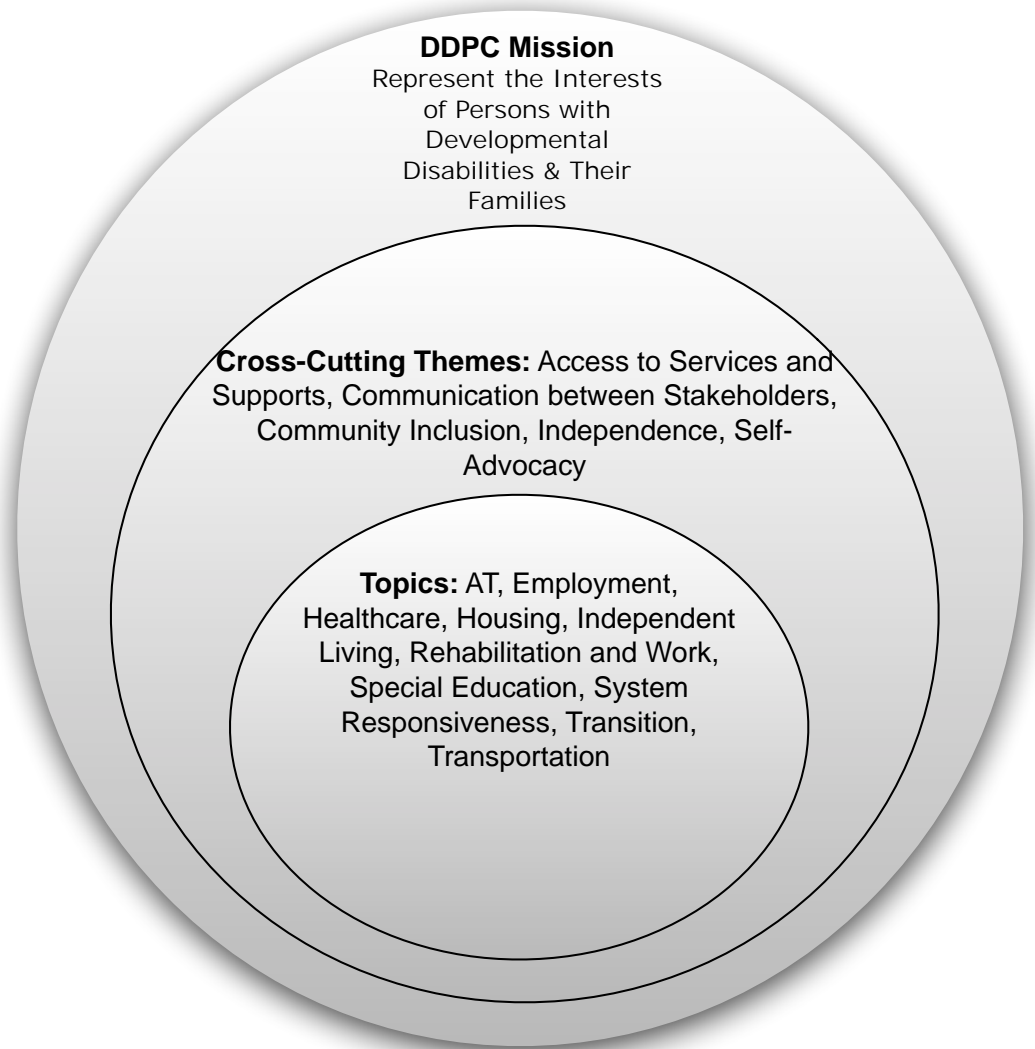


Figure 1

Access to Services and Supports

Access to services and supports was the most frequently mentioned theme of the five. It was articulated with a variety of different words and phrases, but repeated itself often. It appeared in relation to the whole range of DD services and supports including but not limited to appropriate education services, transportation, employment, and housing. Sometimes it appeared in the context of anxiety, as in ... *what will we do if we lose access to* (fill in the blank). Other times it was simply expressed as statement of fact, as in ... *we don't have access to* (fill in the blank), *but if we did outcomes would improve or be different*. Examples and statements include: "If cuts to transportation mean that a disabled person can't get to a job, they won't get that job or keep that job...and if they are relegated to staying at home most of the time they're more likely to get sick and depressed...which ultimately costs society more money" (Administrator). In the context of system responsiveness one parent said, "Parents don't necessarily know what questions to ask and bureaucrats don't provide information unless specifically asked. If people don't know then they don't ask and the state doesn't offer it because they believe it isn't demanded" (Parent). Another observer wrote, "On the Navajo Nation many individuals with DD do not have a primary care physician...they see different practitioners at different visits...and practitioners tend to stay in an area for only a few years and then move on" (Provider or Advocate).

One person spoke about the importance of sustaining programs in the current budget climate, and the challenge of providing quality supports and services that meet people's needs with a finite resources. The reorganization of the DDD statewide district structure is seen by some as a positive move, insofar as it may result in more responsive service to consumers. The reorganization will cut the number of districts from 6 to 5 with the goal of each representing about 1/5 of the state's population.

Communication Between Stakeholders

Here the term stakeholder is as important as the word communication. Stakeholder was a term used to describe focus group and key informant participants and includes everyone and anyone who has any significant interest in the DD system and participated regularly in Arizona's developmental disabilities community. The list includes persons with developmental disabilities and their families, supporters, and advocates, along with the broad ranges of DD service providers, administrators of governmental and non-governmental programs, policymakers, advocates, and other professionals working in the field of DD. This is a very large and very diverse group of people, and while we often label this group of people a *community*, the term community is perhaps more often than not a term of convenience. That is to say that, despite all being involved in Arizona's DD community, all participating actors simultaneously represent diverging and converging interests, priorities, needs, and expectations.

Communication means different things to different people. Depending upon who was interviewed, communication could refer to managing the complexity of how services and systems along with their related actors communicate with each other effectively in a manner that produces intentional and desirable outcomes. Alternately it more often than not referred to the failure to effectively communicate resulting in the lack of coordination of services or the challenge of finding appropriate services in, for example, underserved rural areas. In the context of achieving employment, one advocate said "if they could assess their disability as well as assess their aptitude ... if they could do the two together then maybe they could find a better job link."

Independence

Focused on creating the conditions that foster independent living and ensuring that the right combination of resources exist to support independence. Here the definition is probably widely agreed upon, but how best to achieve that outcome is fraught with disagreement. In the context of getting and maintaining access to services, one person wrote *“with loss of funding for non-title 19 clients you have put a lot of clients out there with no caseworker and no support and they have no where to go ... so we’re seeing an increase in behavioral health problems because it’s harder to keep them on their meds, etc. ... so they’re acting out, threatening more etc. ... which makes it hard to keep them employed or get them employed”* (Administrator). With regard to transportation another person said, *“There needs to be some coordinated effort to teach special needs children how to ride the bus and, where appropriate, how to drive ... because they will need to get themselves to work in the future”* (Parent). And in the context of employment, one person wrote *“we want to be taxpayers not tax takers”* (Person with DD). One person expressed concern over the commitment of the Arizona Legislature to support programs aimed at helping persons with developmental disabilities achieve employment and independence. Some people pointed to the legislature’s willingness to “sweep” funds intended for one program or project into the state’s general fund as a means of filling budget gaps. Another key informant spoke about the challenges created by the current economic and budgetary environment, saying, (in the context of residential living) *“...we have moved away from institutional care which we do not rely heavily on ... instead we favor newer concepts such as shared living and others ... and we need to be looking at other models regardless of the budget because persons with developmental disabilities and their families don’t necessarily want what we currently have to offer.”*

Community Inclusion

Inclusion means ensuring that persons with developmental disabilities have every opportunity to participate fully and completely in societal activities across the entire lifespan. Achieving inclusion prompted a variety of comments. In the context of special education it prompted this quote *“Kids should be mainstreamed from the beginning ... my expectations are higher than the school and I try to be reasonable ...but we know our children and how much they can learn... but the school does not believe that ... they listen to us but they don't hear us”* (Parent). Another participant said in the context of transition *““I was also a team member last year when DDD, Voc. Rehab and the school were all involved with a young lady that did not qualify for ALTCS but was lucky enough to get into ... (job training program)...we all worked together as a team to help her succeed on the job...there were many after school meetings, in-school coaching and on-the-job coaching...it was wonderful to see how all the agencies were working to help this young lady succeed...I know this was made possible by her DDD case manager”* (Provider).

Another person noted that *“Arizona is number one in the country for Medicaid services largely due to how few institutions we use and much we provide services in-home. Arizona does a good job of caring for people in appropriate settings – that is using fewer institutional settings and much more group home, foster home, or shared living, but many of these people could be spending their days in work environments.”* Talking about the importance of employment, one persons said, *“...for transition aged youth who have a mandatory transition plan from age 14 forward it may be easier [as contrasted with older developmentally disabled adults] to begin*

talking about employment earlier especially if we have system partners through vocational rehabilitation, the schools, and families that have more community-based expectations.”

Self-Advocacy

Advocacy and self-advocacy were words that came up often in surveys, focus groups, and interviews. Often the word advocacy was used to mean self-advocacy, but whatever terms were used, the qualitative data uncovered a powerful and widespread orientation toward the critical importance of self-advocacy – that persons with developmental disabilities and their families must have a voice in determining their futures. In the simplest sense, self-advocacy means having the capacity to speak and act on behalf of one’s own interest. But based on data from the surveys, focus groups and interviews, it is clear that self-advocacy means much more than this. A robust and effective self-advocacy system includes self-determination for persons with developmental disabilities, including a service and support system that is participant-driven. It allows individuals to advocate for changes that support the principles of community integration and self-determination. Everyone saw a role for advocacy, but self-advocacy was especially important. In the survey data, consumers exhibit more confidence in the importance of self-advocacy skills than do providers. Providers support self-advocacy, but not as strongly as consumers. The import of self-advocacy appeared in the focus group discussion and in individual interviews typically in the context of some particular topic. For example, with regard to dealing with school districts, one person said, *“If I were to pick one issue to work on it would be self-advocacy in the school environment ... the issues we’re going through now are not just IEP issues it’s attitudinal issues with the district ... a lot of intimidation and retaliation.”* One person, speaking about the importance of learning self-advocacy skills, provided one particularly poignant quote, *“I started my parent advocacy group because the school didn’t respond to our concerns ... and our children are very vulnerable ... Once we started meeting ... and becoming friends and learning what we needed to know ... for example what is an IEP? Most of the parents in the group don’t speak English or work and 1/3 are single moms. The children of these parents tend not to get the school services and supports they need. We took Partners in Policy Making from Pilot Parents ... this is what gave me the get-go to start the group. Write a friendly letter and say please and say thank you even if they treat you like trash.”* Forty-four percent of respondents on the consumer survey thought there should be more self-advocacy training opportunities.

Several dozen disability-oriented self-advocacy groups exist within the state of Arizona, nearly all with 501(c)(3) status, working to promote the interests of their constituents. A list of these groups is included in the appendix.

Summary of Qualitative Data Analysis

Consumers and providers express considerable frustration with what they see as a lack of service coordination and system responsiveness. Many are also frustrated by their inability to secure regular and consistent access to high quality and appropriate services and supports. Consumers and to a lesser degree providers struggle to determine exactly what services and supports are available, their eligibility for services and supports, and how to gain timely access to services and supports. Consumers refer repeatedly to the challenge of achieving independence and community inclusion, especially as they relate to transportation, vocational rehabilitation and work. But some see positive changes on the horizon if employment can become a part of transition plans earlier and helped along by partnerships between vocational rehabilitation,

schools, and families. Many consumers point to the role that self-advocacy has played in helping them secure the supports and services they need. Finally, all groups manifest a high degree of concern and anxiety over the future services and supports landscape and how state and federal budget cuts may affect their lives and the lives of the people they love.

STATE OF ARIZONA

DES

Div Dev. Disabilities

Div ChildrenYouthFamilies

ChildProtectiveServices

Temporary Assistance to Needy Families

Az Early Intervention Program

Rehabilitative Services Administration

Division of Aging & Adult Services

Arizona Area Agencies on Aging

Interagency Council on Longterm Care

DHS

Division of Public Health Services

Office for Children with Special Healthcare Needs

Childrens' Rehabilitative Services

Division of Behavioral Health Services

Regional Behavioral Health Authorities

AHCCCS

Arizona Long-Term Care Services

Acute Care

ADE

Special Education

Exceptional Students Services

Enhancing Arizona Parent Networks

Corrections Dept.

Inmate Special Education Services

Services for Persons with DD

Juvenile Corrections

Education System

Special Education

Behavioral Health

Social Security Administration

Supplemental Security Income

Social Security Disability Income

Advocacy/Not for Profit/Academic

Arizona Technology Access Project

Native American Tribal Data

Arizona Center for Disability Law

U of A Sonoran UCEDD

Raising Special Kids

Independent Living Centers

AzUCD/ Institute for Human Development

Pilot Parents of Southern Arizona

Website List of State & Federal Agencies & Not for Profits Involved with Developmental Disabilities in Arizona

Source/Name	DD Functions	Web Address	Agency Type
Aging and Disability Resource Centers (ADRC's)	Links to county contact information for Aging and Disability Resource Centers, which provide a single point of entry for access to public long-term support programs and benefits	http://www.adrc-tae.org/tiki-index.php?page=CordaMaps&st=AZ	
American Association on Intellectual and Developmental Disabilities (AAIDD)	The AAIDD promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities	http://www.aamr.org	advocacy
American Association on Intellectual and Developmental Disabilities (AAIDD)	The professional association run by and for professionals who support people with intellectual and developmental disabilities. AAIDD, (formerly AAMR -- American Association of developmental disability) is the oldest and largest interdisciplinary organization of	http://www.aaid.org	advocacy
American Association of People with Disabilities	The American Association of People with Disabilities (AAPD), the country's largest cross-disability membership organization, organizes the disability community to be a powerful voice for change. AAPD was founded in 1995 to help unite the diverse community of people with disabilities, including their family, friends and supporters, and to be a national voice for change in implementing the goals of the Americans with Disabilities Act (ADA).	http://www.aapd.com	advocacy
Arizona Statewide Independent Living Council	The mission of SILC is to promote the equality, inclusion, and choice for people with disabilities through collaboration and public policy change.	http://www.azsilc.org/	advocacy
Administration on Aging- Disability Data	A convenient set of links to online statistical information on the demographic characteristics, health, social conditions, and economic condition of older persons. Includes links to almost all known online resources including Census, HHS health statistics	http://www.aoa.gov/AoARoot/Index.aspx	federal
Administration on Developmental Disabilities	The Administration on Developmental Disabilities (ADD) is the U.S. Government organization responsible for implementation of the Developmental Disabilities and Bill of Rights Act of 2000, known as the DD Act. ADD, its staff and programs, are part of the A	http://www.acf.hhs.gov/programs/add/	federal
Agency for Healthcare Research and Quality (AHRQ)	As 1 of 12 agencies within the Department of Health and Human Services (HHS), the mission of the Agency for Healthcare Research and Quality (AHRQ) is to improve the quality, safety, efficiency, effectiveness, and cost effectiveness of health care for all	http://www.ahrq.gov/	federal
American Association of People with Disabilities	The American Association of People with Disabilities (AAPD) organizes the disability community to be a powerful force for change-politically, socially, and economically- and recognizes the value of working in broad coalitions to foster unity, leadership,	http://www.aapd-dc.org/index.html	advocacy
American Community Survey (ASC) User Guide	The American Community Survey is an on-going survey that is sent to a sample of the population; it tells us what the population looks like and how it lives. Includes demographic and statistical information on the population as a whole, including persons	http://www.census.gov/acs/www/Products/users_guide/	federal
American Indian Disability Technical Assistance Center (AIDTAC)	The American Indian Disability Technical Assistance Center (AIDTAC) was inaugurated in October 2000 with an initial five-year grant by the U.S. Department of Education's Rehabilitation Services Administration, as a national center to provide information,	http://aidtac.ruralinstitute.umt.edu/	academic
ArcLink Inc.	The Arc of the United States is the national organization of and for people with developmental disability and related disabilities and their families. They are devoted to promoting and improving the quality of services for consumers and families. They believe t	www.TheArcLink.org	advocacy
Arizona Area Agency on Aging, Region One	A private non-profit corporation that advocates, plans, coordinates, develops and delivers services for seniors (60 years and older), persons of any age who are HIV positive, adults with disabilities and long-term care needs and family caregivers of older adults.	http://www.aaaphx.org/	advocacy/service
Arizona Autism United	Provides services to children with autism spectrum disorders in Arizona. Services include respite, attendant care, and behavioral habilitation	http://azaunited.org/	service
Arizona - AzRHA News and Events	Includes news and events, funding, conference information and much more. Sponsoring organization: Arizona Rural Health Association	http://www.azrha.org/news.html	advocacy
Arizona 2-1-1	Web site, a fully-implemented 2-1-1 system for Arizona that combines information from a wide variety of health and human service providers through a single information network that can easily be accessed by caseworkers and the public at large.	http://az211online.blogspot.com/	State - Shut down due to budget cuts
Arizona Bridge to Independent Living (ABIL)	The Arizona Bridge to Independent Living (ABIL) is a private, non-profit corporation that provides services to persons with disabilities. ABIL's programs include Information & Referral, Peer Support, Home Modifications, Independent Living Skills Instructi	www.abil.org	service
Arizona Center for Disability Law	The Arizona Center for Disability Law is a not for profit public interest law firm, dedicated to protecting the rights of individuals with a wide range of physical, mental, psychiatric, sensory and cognitive disabilities.	www.acdl.com	advocacy
Arizona Commission for the Deaf and Hard of Hearing	The purpose of the Arizona Commission for the Deaf and the Hard of Hearing is to ensure, in partnership with the public and private sector, accessibility for the Deaf and the Hard of Hearing to improve their quality of life. An energetic and innovative te	http://acdhh.org/	state

Arizona Department of Behavioral Health Services	State government, provides resources and information on behavioral health.	http://www.azdhs.gov/bhs/index.htm	state
Arizona Department of Commerce: The Office of Economic Information and Research	The Office of Economic Information and Research serves as the State's clearinghouse for economic information and manages strategic research related to Arizona's economy. The Office also provides information and analyses of trends, opportunities, best prac	http://www.azcommerce.com/Research	state
Arizona Department of Economic Security (DES)	State government, provides an integration of direct services to people in such a way as to reduce duplication of administrative efforts, services and expenditures. Services include: Adoption/Foster Care; Aging and Adult Services; AZ Industries for the Bli	https://www.azdes.gov/aspnew/default.asp	state
Arizona Department of Economic Security: Adult Protective Services	State government, provides assistance and a point of contact where people can report abuse, neglect, and exploitation of Arizona's vulnerable or incapacitated adults.	https://egov.azdes.gov/cmsinternet/common.aspx?menu=620&menuc=100&id=1708	state
Arizona Department of Economic Security: Arizona Industries for the Blind	Arizona Industries for the Blind (AIB) was established in 1952 to provide employment and training opportunities for Arizonans who are legally blind. Most individuals of working age who are legally blind can complete successfully for good jobs if they are	https://egov.azdes.gov/cmsinternet/main.aspx?menu=58&id=984	state
Arizona Department of Economic Security: Division of Developmental Disabilities (DDD)	State government, supports the choices of individuals with disabilities and their families by promoting and providing, within communities, flexible, quality, consumer-driven services and supports.	https://egov.azdes.gov/cmsinternet/main.aspx?menu=96&id=2454	state
Arizona Department of Economic Security: One Stop Centers	A main feature of Title I of the Workforce Investment Act (WIA) of 1998 is the creation of a one-stop customer delivery system. Through this system, customers can access a broad range of employment-related and training services at a single point-of-entry.	https://egov.azdes.gov/CMSInternet/main.aspx?menu=232&id=2214	state
Arizona Department of Economic Security: Rehabilitation Services Administration	Arizona Rehabilitation Services Administration (RSA) programs provide a variety of specialized services for individuals with physical or mental disabilities that create barriers to employment or independent living. RSA offers three major service programs	https://egov.azdes.gov/cmsinternet/main.aspx?menu=32&id=1984	state
Arizona Department of Education	The official website for the Arizona Department of Education with information on services for children and youth with disabilities.	http://www.ade.state.az.us	state
Arizona Department of Education: Exceptional Student Services	State government, promotes the development and implementation of quality education for students with disabilities.	http://www.ade.state.az.us/ess/	state
Arizona Department of Health Services	Arizona Department of Health Services, providing multiple services, resources, information on health issues affecting Arizonans. Health services including education & health promotion, community health, safety, prevention & health preparedness, licensing &	http://www.azdhs.gov/	state
Arizona Department of Health Services, Office of Long-Term Care Licensing	State government, Licenses and inspects Arizona nursing homes facilities. Also perform Medicaid certification inspections for Arizona's Intermediate Care Facilities for the Mentally Retarded.	http://www.azdhs.gov/als/ltc/index.htm	state
Arizona Department of Housing (ADOH)	State government, the state agency that works to provide housing and community revitalization to benefit the people of Arizona.	http://www.housingaz.com/	state
Arizona Department of Veterans Services	Arizona Department of Veterans Services. Additional data at U.S. Department of Veterans Affairs, Public and Governmental Affairs homepage	http://www.azdvs.gov/	state
Arizona Disabilities Advocacy Coalition	The Purpose of AzDAC is to promote public policy that enhances the choice, dignity, rights and responsibilities of individuals with disabilities and their families.	http://www.azdac.org/	advocacy
Arizona Governor's Council on Blindness and Visual Impairment	"To provide the leadership, advocacy, and guidance that promotes opportunities for Arizonans of all ages who are blind or visually impaired that result in increased dignity, respect and independence."	https://egov.azdes.gov/CMSInternet/main.aspx?menu=32&id=1308	state
Arizona Developmental Disabilities Planning Council	The DDPC is Arizona's state planning council for people with developmental disabilities and is authorized under the Developmental Disabilities Assistance and Bill of Rights Act (P.L.106-402).	http://www.azgcd.org/	state
Arizona Governor's Council on Spinal and Head Injuries	The Arizona Governor's Council on Spinal and Head Injuries provides information, services and support for individuals with spinal cord and traumatic brain injuries, their families, and the professionals who serve them.	http://www.azheadspine.org/index.asp	state
Arizona Governor's State Rehabilitation Council	Serving all citizens of Arizona 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 wor	https://egov.azdes.gov/cmsinternet/main.aspx?menu=32&id=1348	state
Arizona Health Care Cost Containment System (AHCCCS)	State government, reaching across Arizona to provide comprehensive, quality health care to those in need. Oversees state Medicaid program and the Arizona Freedom to Work Medicaid Buy-in Program.	http://www.azahcccs.gov/	state
Arizona Health Centers Data	Web site, provides access to information on Federally Qualified Health Centers for the state. Includes a map of FQHC locations, as well as information on the populations served by health centers, services provided, staff, patient visits, costs of care, an	http://www.nachc.com/state-healthcare-data.cfm?State=AZ	advocacy/service
Arizona Health Disparities Center	State government, promotes and protects the health and well being of the minority and vulnerable populations of Arizona by enhancing the capacity of the public health system to effectively serve minority populations and reduce health disparities.	http://www.azdhs.gov/hsd/fs_healthdisparitiescenter.pdf	state

Arizona Health Survey	The Arizona Health Survey (AHS) is an extensive effort to collect data on individual indicators of health status, insurance coverage, access to care, health-related behaviors and various demographic and social/environmental factors related to health. It	http://arizonahealthsurvey.org/	foundation
Arizona KIDS COUNT Data Center (KCDC)	Web site, provides data on child well-being for the state. Sponsoring organization: Annie E. Casey Foundation	http://datacenter.kidscount.org/data/bystate/StateLanding.aspx?state=AZ	foundation
Arizona Public Health Association (AZPHA)	State/regional organization, The Arizona Public Health Association defines and advocates for public health issues, fosters professional development, supports incubator opportunities for emerging public health issues, and promotes public health awareness a	http://www.azpha.org/	advocacy/service
Arizona QuickFacts	Web site, basic demographic and economic statistics for the state, with links to county-level data. Sponsoring organization: U.S. Census Bureau	http://quickfacts.census.gov/qfd/states/04000.html	federal
Arizona Rural Health Association	State/regional organization, Advocates on behalf of the health needs of rural Arizonans at national, state and local levels.	http://www.azrha.org/	advocacy/service
Arizona Rural Policy Institute	(ARPI) pays particular attention to the information needs of northern Arizona and rural communities throughout the state. Involvement in statewide, regional, and national economic and business research activities is critical to the bureau's goals.	http://www.franke.nau.edu/RPI	academic
Arizona State Health Facts	Database, the latest state-level data on demographics, health, and health policy, including health coverage, access, financing, and state legislation. Individual state profiles and 50-state comparisons. Sponsoring organization: Kaiser Family Foundation	http://www.statehealthfacts.org/profileglance.jsp?rgn=4	foundation
Arizona State Office of Rural Health	State government, promotes the health of rural and medically underserved individuals, families, and communities through service, education, and research.	http://rho.arizona.edu/default.aspx	state
Arizona Workforce Informer	Arizona Workforce Informer provides a wide variety of state, region and local labor market, demographic and economic data, including: employment statistics, occupation and industry estimates and projections, wage and price indices, and population/demograp	http://www.workforce.az.gov/	state
Arizona: Demographic and Economic Profile	Sponsoring organization: Rural Policy Research Institute. Presents demographics, economics, and research on Arizona. Includes statistics, data, maps, charts, and graphs. Date: 02/2009	http://www.rupri.org/Forms/Arizona2.pdf	foundation
Arizona-Sonora Health Inventory and Resource Guide	Web site, guide created to inform border residents and health providers of the services that are available in their local area and nationally throughout the region. Information available in Spanish. Sponsoring organization: Arizona Office of Border Health	http://www.azdhs.gov/phs/borderhealth/pdf/english.pdf	state
ASSIST! to Independence	ASSIST! to Independence is a community based, American Indian owned and operated non-profit agency that was established by and for people with disabilities and chronic health conditions to help fill some of the gaps in service delivery.	http://www.assistoindependence.org	advocacy
Association for Persons in Supported Employment	Provides advocacy and education to customers of supported employment (SE), i.e. supported employment professionals, consumers and their family members, and supported employers. Addresses issues and barriers which impede the growth and implementation of in	http://apse.org/	advocacy
Association of University Centers on Disabilities	A network of interdisciplinary Centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities. The Association of University Centers on Disabilities (formerly the American Associat	www.aucd.org/	academic
Border County Health Workforce Profiles: Arizona	Sponsoring organization: Health Resources and Services Administration. Provides information on the health workforce, relevant population characteristics, and basic health indicators for the U.S.-Mexico Border region in the State of Arizona. Date: 05/2007	ftp://ftp.hrsa.gov/bhpr/workforce/border_reports/arizona.pdf	federal
Border Health Information and Education Network	A health education network designed to provide health information free of charge for the people of the border region, both healthcare consumers and healthcare providers. Sponsoring organization: U.S. - Mexico Border Health Association	http://www.bienhealth.org/	service
Bureau of Labor Statistics (BLS)	The Bureau of Labor Statistics is the principal fact-finding agency for the Federal Government in the broad field of labor economics and statistics. With the strongest commitment to integrity and objectivity, the BLS will be premier among statistical agen	http://www.bls.gov/	federal
Childrens Action Alliance	CAA is a non-profit, non-partisan research, education and advocacy organization dedicated to promoting the well-being of Arizona's children and families.	www.azchildren.org/default.asp	
Cochise Ability	CochiseAbility includes a group of Cochise county residents who have an interest in promoting the philosophy of independent living. CochiseAbility is in the process of incorporating as a non-profit 501(c)3 organization. DIRECT, Center for Independence in	www.Cochiseability.org	advocacy
Cornell University 2007 Disability Status Report	DisabilityStatistics.org web site condenses several data sources into a single, user-friendly, accessible, Internet resource. It also provides essential background information on key issues related to disability statistics. What is the history of Disabili	http://www.ilr.cornell.edu/edi/DisabilityStatistics/	academic
Council of Arizona (YAC-AZ)	provides youth with disabilities a group in which they have the opportunity to meet, interact, and work with other youth towards the common goal of promoting self- determination through independence and self advocacy.	http://www.yakkit.org/	advocacy

CyberCil	The mission of CyberCIL of Arizona is to provide innovative, meaningful assistance in accordance with the principles and philosophy of independent living to, and on behalf of, Arizonans with disabilities so that they may attain or continue an independent	http://www.cybercil.com	
DIRECT	DIRECT Center for Independence, Inc. is a consumer-directed, community-based advocacy organization, that promotes independent living and offers a variety of programs for all people with disabilities which encourages them to achieve their full potential an	http://www.directilc.org	advocacy
Directory of Independent Living Centers	Independent Living, Independent Living centers, services, resources	http://www.virtualcil.net/cils/	advocacy/service
Disability and Business Technical Assistance Center (DBTAC)	The Disability and Business Technical Assistance Center (DBTAC) is a national network of 10 regional DBTAC: ADA Centers that provide the most complete and experienced services for up-to-date information, referrals, resources, and training on the Americans	http://www.adapacific.org	
Disability Info.gov	DisabilityInfo.gov provides quick and easy access to comprehensive information about disability programs, services, laws and benefits. You can begin your search by visiting any of the nine subject areas at the top of this page. To find disability resource	http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=500	federal
Disability is Natural	The Disability is Natural web site by BraveHeart Press, the family-owned business of Kathie Snow. The mission of this site is to encourage new ways of thinking about disability and to help create a society in which all people are valued and included.	http://www.disabilityisnatural.com/	advocacy
Disability Online, U.S. Dept of Labor	ETA's Disabilities Program, Disability Online. The Disabilities Program develops and implements workforce disability policy and program initiatives to address structural, programmatic, and systemic employment barriers for people with disabilities. The Dis	http://www.doleta.gov/disability/	federal
Disability Program Navigator ("DPN" or "Navigator")	The Disability Program Navigator (DPN) Initiative focuses on developing new and ongoing partnerships to achieve seamless, comprehensive, and integrated access to services, creating systemic change, and expanding the workforce investment system's capacity	http://www.dpnavigator.net/	
Disability Resources	Disability Resources, inc. is a nonprofit 501(c)(3) organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently.	www.disabilityresources.org/ARIZONA.html	advocacy
Disability Statistics, Cornell University	The DisabilityStatistics.org web site condenses several data sources into a single, user-friendly, accessible, Internet resource. It also provides essential background information on key issues related to disability statistics.	http://www.ilr.cornell.edu/edi/disabilitystatistics/index.cfm?n=1	academic
DisabledPerson.com	An online magazine that is geared specifically towards the Disabled Person.	http://www.disabledperson.com/	advocacy
Division of Developmental Disabilities	The Division of Developmental Disabilities (DDD) with the Arizona Department of Economic Security (DES) provides services and programs to eligible individuals with developmental disabilities. The Division believes individuals can best be served in integra	www.de.state.az.us/ddd/	state
Down Syndrome Network of Arizona	Provides information, advocacy, programs and services, and networking opportunities that promote the health, education, employment, and inclusion of people with Down syndrome.	http://dsnetworkaz.wordpress.com/	state
EarnWorks	The Employer Assistance & Resource Network (EARN) provides federal and private employers with free consulting services and resources to support the recruitment, hiring, and retention of people with disabilities.	http://earnworks.com	advocacy/service
Enable America	Enable America was founded in 2002 by attorney Richard Salem as a nonprofit organization dedicated to helping people with disabilities find employment and live independently. It is the first organization dedicated solely to reducing unemployment among peo	www.enableamerica.org	advocacy
Enhancing Arizona's Parent Network (EAPN)	Enhancing Arizona's Parent Networks (EAPN) is the collaborative effort of parent groups, organizations and agencies that believe all children and families in Arizona should receive appropriate services and support in a timely manner.	www.ade.state.az.us/ess/eapn/default.asp	state
Family Village: A Global Community of Disability-Related Resources	Comprehensive site containing disability-related resources, discussion groups and other information. The Family Village is a web site for children and adults with disabilities, their families, and their friends and allies. Family Village brings together t	http://www.familyvillage.wisc.edu/index.html	advocacy
Federal Office of Special Education	OSEP is dedicated to improving results for infants, toddlers, children and youth with disabilities ages birth through 21 by providing leadership and financial support to assist states and local districts. OSEP administers the Individuals With Disabilities	http://www2.ed.gov/about/offices/list/osers/osep/index.html?src=nr	federal
Healthy and Ready to Work National Center (HRTW)	Addresses youth with special health care needs, chronic health conditions and disabilities who have survived beyond their diagnosis / prognosis. For success in the classroom, in the community and on the job, young people with special health care needs mus	http://www.hrtw.org/index.html	advocacy
Healthy People 2010	A comprehensive statewide prevention agenda designed to improve the health of all Arizonans over the next decade.	http://www.healthypeople.gov/	federal

High School / High Tech (HS/HT) NCWD/Youth, Institute for Educational Leadership	HS/HT is a national network of state and locally operated programs designed to provide young people with all types of disabilities the opportunity to explore jobs or further education leading to technology-related careers. As one of the most promising com	http://www.ncwd-youth.info/HSHT/index.html	service
Institute on Disability and Human Development: University of Illinois at Chicago	Our purpose is to develop model programs that will address the needs of the growing African-American and Latino disability communities within the Chicagoland area. Projects conducted in this program attempt to provide consumers and their families with emp	http://ness2.uic.edu/UL-Service/programs/UIC573.html	academic
Inter Tribal Council of Arizona American Indian Research Center for Health (AIRCH)	Academic/Research, encourages practical research to improve American Indian peoples' health status. A Native American Research Center on Health site.	http://www.itcaonline.com/program_airch.html	
International Center for Disability Information, Disability Tables	The International Center for Disability Information (ICDI) is a department of the College of Human Resources and Education at West Virginia University. The Disability Data Tables contained in this site were obtained from various sources (referenced with ea	http://www.icdi.wvu.edu/disability/tables.html	academic
Job Accommodation Network, Office of Disability Employment Policy	The Job Accommodation Network is a service provided by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). JAN is one of several ODEP programs. JAN represents the most comprehensive resource for job accommodations available. JAN'	http://www.jan.wvu.edu/	federal
Mathematica Policy Research, Inc	As Mathematica enters its fifth decade, we celebrate a generation of research, results, and resources represented in the work we have done to help our clients move effective policymaking forward. In health care, disability, education, family well-being, e	http://www.mathematica-mpr.com/	academic
NARIC National Rehabilitation Information Center	The National Institute on Disability and Rehabilitation Research (NIDRR) Tools Collection, is a new web site that supports NIDRR's commitment to the widespread dissemination of the scientific and technological information generated by grantees' research,	http://www.naric.com/	advocacy
National Association of State Directors of Developmental Disabilities Services (NASDDDS)			advocacy
National Center of Health Statistics	National Center for Health Statistics' website, a rich source of information about America's health. Principal health statistics agency, we compile statistical information to guide actions and policies to improve the health of our people. We are a unique	http://www.cdc.gov/nchs/nhis.htm	federal
National Collaborative on Workforce and Disability (NCWD)	NCWD/Youth is your source for information about employment and youth with disabilities. Our partners — experts in disability, education, employment, and workforce development — strive to ensure you will be provided with the highest quality, most relevant	http://www.ncwd-youth.info/index.html	advocacy
National Council on Disability	The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The purpose of NCD is to promote policies, programs, practices, and procedures that	www.ncd.gov	federal
National Council on Disability, One Stop Tool Kit	Welcome to the One-Stop toolkit website, a technical assistance product developed by DTI Associates, Inc. on behalf of Disability Program Navigator Grantees. This website provides accessible and comprehensive tools and information to grantees who provide	http://www.onestoptoolkit.org/	federal
National Council on Independent Living	The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of organizations and individuals including: Centers fo	http://www.ncil.org/	advocacy
National Disability Rights Network	The National Disability Rights Network (NDRN) is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the P&A/CAP netwo	http://www.ndrn.org/index.htm	advocacy
National Dissemination Center for Children with Disabilities (NICHCY)	Center provides information to the nation on: disabilities in children and youth; programs and services for infants, children, and youth with disabilities; IDEA, the nation's special education law; No Child Left Behind, the nation's general education law; Maag, Elaine. (2006, April). A Guide to Disability Statistics from National Health Interview Survey – Disability Supplement. Rehabilitation Research and Training Center on Disability Demographics and Statistics, Cornell University, Ithaca, NY. The Nationa	http://www.nichcy.org/Pages/Home.aspx	advocacy
National Health Interview Survey – Disability Supplement (NHIS-D)	Maag, Elaine. (2006, April). A Guide to Disability Statistics from National Health Interview Survey – Disability Supplement. Rehabilitation Research and Training Center on Disability Demographics and Statistics, Cornell University, Ithaca, NY. The Nationa	http://digitalcommons.ilr.cornell.edu/edicollect/1206/	academic
National Health Interview Survey (NHIS) User Guide	Harris, B.H., Hendershot, G., & Stapleton, D.C. (2005, October). A Guide to Disability Statistics from the National Health Interview Survey. Rehabilitation Research and Training Center on Disability Demographics and Statistics, Cornell University, Ithaca,	http://digitalcommons.ilr.cornell.edu/edicollect/186/	academic
National Healthcare Quality & Disparities Reports, Agency for Healthcare Research and Quality	For the fifth year in a row, the Agency for Healthcare Research and Quality (AHRQ) has produced the National Healthcare Quality Report (NHQR) and the National Healthcare Disparities Report (NHDR). These reports measure trends in effectiveness of care, pat	http://www.ahrq.gov/qual/qrd07.htm	federal
National Institute on Disability and Rehabilitation Research (NIDRR)	The National Institute on Disability and Rehabilitation Research (NIDRR) provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. All of our programmatic efforts are aimed at i	http://www.ed.gov/about/offices/list/osers/nidrr/index.html	federal

New Horizons Independent Living Center	New Horizons Independent Living Center Inc. is a non-profit, consumer driven 501(c)(3) corporation providing services and advocacy which empower and enable people with disabilities to self-determine the goals and activities of their lives in family, home,	http://www.newhorizonsilc.org/	advocacy
Northern Arizona University, Institute for Human Development	The underlying premise for University Centers on Disabilities is on the active, reciprocal exchange of information and resources between communities and institutions of higher education would benefit persons with disabilities through improved systems of s	http://www.nau.edu/ihd/	academic
Opening Doors: A Housing Initiative for the Disability Community	Opening Doors is a housing initiative designed to provide information and technical assistance on affordable housing issues to people with disabilities, their families, advocates, and service providers across the United States. Includes: Opening Doors, a	http://www.c-c-d.org/task_forces/housing/intro_page.htm	advocacy
PACER Center (Parent Advocacy Coalition for Educational Rights)	The mission of PACER Center (Parent Advocacy Coalition for Educational Rights) is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents. W	http://www.pacer.org	advocacy
Partners in Policymaking, Pilot Parents of Southern Arizona	Since 1987, Partners programs have been implemented nationally and internationally. More than 15,000 Partners graduates are part of a growing national and international network of community leaders serving on policy making committees, commissions, and boa	http://www.partnersinpolicymaking.com/index.html	advocacy
PAS Center for Personal Assistance Services	PAS - also known as personal attendant services, attendant care services and personal care services (PCS) - include "people or devices that assist a person with a physical, sensory, mental, or cognitive disability with tasks that the person would perform	http://www.pascenter.org/home/index.php	academic/advocacy
Pilot Parents of Southern Arizona	Pilot Parents of Southern Arizona is a support organization for parents of children with special needs. It is one of two designated Parents Training and Information Centers in the State of Arizona and provides service in Cochise, Gila, Graham, Greenlee, L	www.pilotparents.org	advocacy
Pima Council on Developmental Disabilities	The purpose of this web site is to provide information that will give people with developmental disabilities and their families the knowledge to access training, educational programs and other activities that will help define their goals, understand the s	www.disabilitydepotaz.org	state
Raising Special Kids	Raising Special Kids is one of 100 Parent Training and Information centers in the United States, providing information, resources, and support to families of children with disabilities.	www.raisingpecialkids.org	advocacy
SMILE	S.M.I.L.E., Services Maximizing Independent Living and Empowerment, is a Yuma, Arizona based non-profit organization. Since 1998 S.M.I.L.E. has been serving the disabled citizens of Yuma.	www.nelaw.com/smile/	
Special Education Program for Teachers and Administrators (SEPTA)	State/regional organization, works to develop and implement a comprehensive Special Education training program that enhances the professional development of Bureau of Indian Affairs (BIA) and BIA grant school personnel.	http://www.septa.arizona.edu/	Academic
State of Arizona Legislature	The official site of the Arizona State Legislature.	www.azleg.state.az.us	
State of Arizona: Population Brief	Author(s): Don E. Albrecht. Sponsoring organization: Western Rural Development Center. Baseline information for the advancement of rural development that examines population changes and characteristics within Arizona. Date: 2008	http://wrdc.usu.edu/files/uploads/Population/Arizona_WEB.pdf	
SOUTHWEST AUTISM RESEARCH AND RESOURCE CENTER (SARRC)	The Southwest Autism Research and Resource Center's (SARRC) mission is to advance research and provide a lifetime of support for individuals with autism and their families. SARRC's research brings together many methods and scientists in an effort to gain a greater understanding of possible causes of autism, identify better treatments, learn how to prevent it and ultimately find a cure for those affected by autism spectrum disorders. SARRC provides clinical services, school-based services, and vocational services. Southwest Human Development (SWHD) provides services to children and adults with disabilities and other special needs, and support to their families. The Assistive Technology and Resource Center offers workshops and training, evaluations, support groups, and has a lending library. The early intervention program offers occupational, speech, and physical therapy, and service coordination. The infant toddler feeding program provides comprehensive assessments; consultation and medical record review, and follow up by a developmental pediatrician.	www.autismcenter.org/	advocacy/service
SOUTHWEST HUMAN DEVELOPMENT	Southwest Institute for Families and Children (SWI) is a non-profit research and development organization focusing of children's health and education.	http://www.swhd.org/	advocacy/service
Southwest Institute or Families and Children		http://www.swifamilies.org	advocacy
TASH	TASH is an international grassroots leader in advancing inclusive communities through research, education and advocacy. Founded in 1975, organization advocates for human rights and inclusion for people with the most significant disabilities and support n	http://www.tash.org/index.html	advocacy
The Alliance for Technology Access	The Alliance for Technology Access (ATA) is a network of community-based resource centers dedicated to providing information and support services to children and adults with disabilities, and increasing their use of standard, assistive, and information te	http://www.ataccess.org/	advocacy

The American Association on Intellectual and Developmental Disabilities (AAIDD)	The professional association run by and for professionals who support people with intellectual and developmental disabilities. AAIDD, (formerly AAMR -- American Association of developmental disability) is the oldest and largest interdisciplinary organization of	http://www.aaidd.org	
The Arc of the United States	The Arc is the world's largest community based organization of and for people with intellectual and developmental disabilities. It provides an array of services and support for families and individuals and includes over 140,000 members affiliated through	www.thearc.org	advocacy
The Center for Mental Health Services (CMHS), SAMHSA	The Substance Abuse and Mental Health Services Administration (SAMHSA), an agency of the U.S. Department of Health and Human Services (HHS), was created to develop and focus attention on programs and funding for improving the lives of people with or at ri	http://mentalhealth.samhsa.gov/cmhs/	federal
The Design Linc	On-line resources and information specifically geared toward people with disabilities and special design needs, as well as those involved in their care. Over 15 years of experience and extensive research in accessible design. Latest information on where to	www.designlinc.com	advocacy
The International Center for Disability Resources on the Internet	Founded in 1998, The International Center for Disability Resources on the Internet (ICDRI) is a non-profit center based in the United States and designated as a 501 (c)(3) entity. Overarching vision: the equalization of opportunities for persons with disab	http://www.icdri.org/	advocacy
The National Center on Physical Activity and Disability	NCPAD is an information center concerned with physical activity and disability. Being physically active is good for every body. That's a message you will find many times on this site. Being active is an important part of getting and staying healthy.	http://www.ncpad.org/	advocacy
The National Collaborative on Workforce and Disability for Youth (NCWD/Youth)	The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) assists state and local workforce development systems to better serve all youth, including youth with disabilities and other vulnerable youth. The NCWD/Youth, created in 2001, i	http://www.ncwd-youth.info/resources_&Publications/disability_Legislation/all_legislation.shtml	advocacy
United Cerebral Palsy	United Cerebral Palsy (UCP) was founded more than 60 years ago – in 1949 – by parents of children with cerebral palsy. Today, UCP is a leading service provider and advocate for children and adults with disabilities. Since its inception, UCP has been committed to change and progress for persons with disabilities and strives to ensure the inclusion into every facet of society – from the web to the workplace, from the classroom to the community – to ensure a life without limits for people with disabilities.	http://www.ucp.org/	advocacy/service
United Cerebral Palsy of Central Arizona	United Cerebral Palsy of Central Arizona (UCP) is committed to creating possibilities and nurturing opportunities for those with disabilities. UCP is a leader in providing therapies, independent living services, inclusive and integrated educational based programs, innovative social programs, and basic research. Programs are dedicated to advancing the independence, productivity, and self-sufficiency of each individual.	http://www.ucpsa.org/	advocacy/service
U.S. Census Bureau	The Census Bureau serves as the leading source of quality data about the nation's people and economy.	http://www.census.gov/	
U.S. Department of Education, Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration	The Rehabilitation Services Administration (RSA) oversees grant programs that help individuals with physical or mental disabilities to obtain employment and live more independently through the provision of such supports as counseling, medical and psycholo	http://www.ed.gov/about/offices/list/osers/rsa/index.html	federal
U.S. Department of Health and Human Services, Office of Disability, Aging, and Long-Term Care Policy	The Office of Disability, Aging, and Long-Term Care Policy (DALTCP) is charged with developing, analyzing, evaluating, and coordinating HHS policies and programs which support the independence, productivity, health, and long-term care needs of children, w	http://aspe.hhs.gov/_office_specific/daltcp.cfm	federal
U.S. Department of Health and Human Services-Office on Disability	The Department of Health and Human Services (HHS) is the United States government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves.	http://www.hhs.gov/	federal
U.S. Department of Justice Americans with Disabilities Act	Information and technical assistance on the Americans with Disabilities Act.	http://www.usdoj.gov/crt/ada/adahom1.htm	federal
U.S. Department of Transportation, Federal Transit Administration	Information on federal transportation programs related to individuals with disabilities. Federal Transit Administration, Region 9 serves Arizona, California, Hawaii and Nevada, as well as the territories of Guam, American Samoa, and the Northern Mariana Is	http://www.fta.dot.gov	federal
U.S. Department of Veterans Affairs	Vocational Rehabilitation and Employment, 2004 Task Force Report to the Secretary. www.va.gov/opp/vre_report.htm	http://www.va.gov/	federal
University of Arizona Mel and Enid Zuckerman College of Public Health	Academic/Research, a nationally accredited college of public health. An integral part of their mission is to promote health equality and respond to health disparities.	http://www.publichealth.arizona.edu/default.aspx	academic
University of California, San Francisco (UCSF) Disability Statistics Center	The Disability Statistics Center produces and disseminates policy-relevant statistical information on the demographics and status of people with disabilities in American society. The Center's work focuses on how that status is changing over time with rega	http://dsc.ucsf.edu/main.php	academic

ARIZONA STATE AND LOCAL DEVELOPMENTAL DISABILITIES SELF-ADVOCACY ORGANIZATIONS

Organization Name	Mission/Description	Contact Information	Geographic Scope	Not-For-Profit Status	Primarily DD Oriented?
African-American Autism Support Services of Arizona	To connect, support, educate and equip the African American community in becoming involved in the advocacy, education and research efforts pertaining to Autism and the Autism Spectrum locally and nationally	www.Africanamericanautismofaz.org/index.php	Maricopa County	No	YES
Arizona Association for the Deaf	This organization shall be organized and operated exclusively to promote the welfare of deaf and hard of hearing residents of the state of Arizona in education, economic, security, social equality, and just rights and privileges as citizens	http://www.azadinc.org/	State	501(c)(3)	NO
Arizona Autism Coalition	The Arizona Autism Coalition improves the lives of individuals with Autism Spectrum Disorder and their families in Arizona by sharing resources and affecting autism systems reform through state-wide collaboration and advocacy.	www.azautism.org	State	501(c)(3)	YES
Arizona Autism Spectrum, Support, Information, and Strategies for Transitions. AZ-ASSIST	Our mission is to provide education, strategies, and support related to transition into the community after high school to parents of teens and young adults on the autism spectrum and to provide transition education and create opportunities for social skill development for teens and young adults on the Autism Spectrum.	http://azassist.wetp.com	Maricopa and Pinal Counties	?	YES
Arizona Bridge to Independent Living (ABIL)	ABIL and all other Centers for Independent Living are involved in changing systems to make them more "user" friendly and responsive to our needs. Independent Living & Self-determination philosophy stresses the importance of people with disabilities being in decision-making roles about programs that are for their benefit. We provide monthly advocacy-related workshops where people can learn together self-advocacy skills and how the various systems work. We usually provide two advocacy related workshops each month.	www.abil.org	Maricopa County	501(c)(3)	NO
Arizona Commission for the Deaf and Hard of Hearing	ACDHH aspires to be a national leader in communication access, support services and community empowerment throughout the state.	http://acdhh.org/	State	?	NO
Arizona Council for Exceptional Children	CEC is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted. CEC advocates for appropriate governmental policies, sets professional standards, provides continual professional development, advocates for newly and historically underserved individuals with exceptionalities, and helps professionals obtain conditions and resources necessary for effective professional practice.	www.azcec.org/	State	501(c)(3)	NO
Arizona Council of the Blind	Statewide affiliate of the American Council of the Blind, Inc. organization made up of blind, visually impaired, and sighted Arizonans, with a broad diversity of occupations and professions. Primary focus is on blindness-related issues - especially on dealing effectively with the challenges of daily living	http://aztec.asu.edu/azcb/	State	501(c)(3)	NO
Arizona Disability Advocacy Coalition	The mission of AzDAC is to act as a catalyst to engage individuals with disabilities, their families and organizations that serve them in advocacy efforts that promote public policy which enhances the choice, dignity, rights and responsibilities of people with disabilities.	http://www.azdac.org/	State	501(c)(3)	NO

ASSIST! To Independence	Helping American Indians with differing disabilities live in harmony	www.assisttoindependence.org	Northeastern Arizona			NO
Autism Society Greater Phoenix and Autism Society Greater Tucson, Autism Society of America, Northern Arizona Chapter (nazasa)	The Autism Society, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. We do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy	www.tucsonautism.org www.phxautism.org	State	501(c)(3)		YES
Autistic Self-Advocacy Network (ASAN)	A nonprofit organization run by and for people on the autism spectrum, whose leadership is made up entirely of self-advocates on the autism spectrum. Includes links to autism reporting in the news as well as a list of chapters and affiliates and a resource library. Arizona chapter	http://www.autisticadvocacy.org/	State & National	501(c)(3)		YES
Best Buddies Arizona	Best Buddies® is a nonprofit 501(c)(3) organization dedicated to enhancing the lives of people with intellectual disabilities by providing opportunities for one-to-one friendships and integrated employment.	www.bestbuddiesarizona.org	State	501(c)(3)		NO
DIRECT Center for Independence	DIRECT Center for Independence, Inc. is a consumer-directed, community-based advocacy organization, that promotes independent living and offers a variety of programs for all people with disabilities which encourages them to achieve their full potential and to participate in the community	www.directilc.org	Pima County	501(c)(3)		NO
Down Syndrome Connection	To support and inspire individuals with Down Syndrome including their families and our community. We provide information, resources, and connections to people who share the joys and unique challenges of loving someone with Down Syndrome	http://www.dsconnection.com/	Pima County			YES
Down Syndrome Network Arizona	Our mission at DSNetwork is to educate, support and advocate for those in our community impacted by Down syndrome. DSNetwork will achieve this goal through an open, supportive and collaborative network that will connect individuals and families with needed resources and information.	http://www.dsnetworkaz.org/index.html	State	501(c)(3)		YES
Kids With Autism Can	Mission Statement: To help kids with Autism (and other spectrum disorders) work towards independence through therapy and education. Kids With Autism Can will encourage parents to work with their children to foster skills of independence by focusing on their strengths	http://kidswithautismcan.org	State	501(c)(3)		YES
Mental Health Association of Arizona	The Mental Health Association of Arizona promotes good mental health and works on behalf of all people living with mental illness by advocating, educating and shaping public policy.	http://www.mhaarizona.org/	State	501(c)(3)		NO
National Alliance on Mental Illness (NAMI) Arizona	A 501(c)(3) representing Arizona families affected by serious mental illness	http://nami.org	State & National	501(c)(3)		NO
New Horizons Independent Living Center	To provide services and advocacy which empower and enable people with disabilities to self-determine the goals and activities of their lives	www.newhorizonsilc.org	Yavapai County	501(c)(3)		NO
People First Arizona	A statewide self-advocacy organization comprised primarily of people with developmental disabilities, families, and advocates	http://cpes.com/advocacyresources/selfadvocacy/peoplefirst.htm	State	501(c)(3)		YES
Pilot Parents of Southern Arizona	Parent information and training center for families. Collects, organize and distribute useful information to support families in advocating for their needs. Runs Partners in PolicyMaking Program.	www.pilotparents.org	Pima County	501(c)(3)		YES

Raising Special Kids	Parent Information and Training Center. Provides training, information and referral and advocacy and support. Programs include health care training and information, special education training, and family support groups.	www.raisingpecialkids.org	State	501(c)(3)	YES
S.M.I.L.E. - Survives Maximizing Independent Living Empowerment	To provide the catalyst for community change and life altering experiences and thereby empower individuals with significant disabilities, throughout Yuma and La Paz Counties:	http://www.snap211.com/org/1482438.html	Yuma County	501(c)(3)	NO
Santa Cruz Parents Love Connection	We help Parents who have Special Needs Children learn what is available for them. We teach IDEA,FAPE,504C,and the ADA laws to help parents in their IEP Meetings with their child's school, so that they better know what is available by law for their child.	none	Santa Cruz County	?	NO
Self Advocacy Coalition of Arizona	The Self-Advocacy Coalition of Arizona is a statewide organization that enhances the rights and responsibilities of individuals with disabilities	http://sacofaz.org/	State	501(c)(3)	YES
Sharing Down Syndrome Arizona	The SDSA vision is to educate and empower parents to be the best advocate for their child.	http://sharingds.org/	State	501(c)(3)	YES
Southern Arizona Network for Down Syndrome (SANDS)	Welcome to Southern Arizona Network for Down Syndrome (SANDS), our mission: To improve and enrich the lives of individuals with Down syndrome and to promote public awareness.	http://www.sandsaz.org/	Pima County	501(c)(3)	YES
Speak-Up Arizona	This is the home page for epilepsy advocates in Arizona! Join us in our effort to find a cure, stop discrimination and improve access to care and treatment.	http://epilepsyfoundation.ning.com/group/speakuparizona	State	501(c)(3)	NO
The ARC of Arizona	Arc sponsored conferences and workshops, resource information and advocacy, for children and adults with cognitive and other developmental disabilities. The Arc of Arizona currently works with 15 organized self advocacy groups with over 500 active members with DD.	www.arcarizona.org	State & Local	501(c)(3)	YES
The Extreme Parents Family Caregiver Group	Are you caring for, planning with, and dreaming along with someone who is an older teen, a young adult or an adult with a disability? If so, the Extreme Parent/Family Caregiver Group would like you to become involved. This group is led by family caregivers and meets weekly as long as there is a need. Sponsored by Pilot Parents of Southern Arizona and the Sonoran UCEDD	none or Pilot Parents	Pima County	No	YES
Tucson Alliance for Autism	To promote community awareness and provide diagnostic and therapeutic services for individuals with an Autism Spectrum Disorder (ASD)	http://www.tucsonallianceforautism.org	Pima County	501(c)(3)	YES
Youth Action Council of Arizona (YAC-AZ)	The mission of the group is to empower youth by taking personal responsibility in an effort to improve the quality of their lives, as well as the quality of lives of others	www.yakkit.org	Maricopa County	?	NO

Developmental Disabilities Planning Council/Review of State Services and Supports
Contract #: ISA DDPC 01-04-2010

Approximately 30,815 people with developmental disabilities (DD) are served by the Arizona Department of Economic Security's Division of Developmental Disabilities (DES/DDD) on the basis of four diagnostic categories (cognitive disability, autism, cerebral palsy and epilepsy) and substantial functional limitations.¹ Certain at risk infants, toddlers and young children may also be eligible. Service distribution is roughly proportional to the overall distribution of population within Arizona's six districts. In terms of ethnicity and race, the numbers are also reflective of the general population patterns in Arizona.²

The DDD data indicate that 26,719 (87%) individuals with developmental disabilities in Arizona reside with a family caregiver or spouse or have their own households, while 2,455 (8%) live in a developmental disability group home and another 842 (3%) live in what DDD calls an adult developmental home.

There are other important demographic trends affecting the DD services and supports landscape. Between 1980 and 2006, Arizona's Hispanic population increased from 444,000 to 1.3 million, a remarkable 192% increase.³ There are twenty-one federally recognized Native American tribes in Arizona, each with its own unique culture and internal governmental structure. In the tribal communities, health and social services are available but limited in scope. Potential barriers to services include second language issues and cultural beliefs about health and disability.

Demand for developmental disability (DD) services and supports at both the state level and national level continues to grow, encouraged by demographic, legal, and political forces.⁴ At the same time, Arizona's budget crisis has resulted in unprecedented reductions in funding and services across health, education and human service agencies.

AGENCIES AND ORGANIZATIONS PROVIDING SERVICES TO PEOPLE WITH DD

Department of Economic Security (DES)

Agency: The Division of Developmental Disabilities (DDD)

Eligibility: A child from birth through age five with a developmental disability or significant delay in one or more areas of development (language, cognitive, social, physical, self-help) that could lead to a developmental disability; or a condition that is likely to result in a developmental disability without services. Children age six and over must have cerebral palsy, epilepsy, autism, or a cognitive disability which is identified before age 18, likely to continue indefinitely, and causes substantial limitations in three or more of the following life functions: receptive and expressive language, learning, self-direction, self-care, mobility, capacity for independent living, and economic self-sufficiency.

Services: Attendant care, day treatment and training, employment supports and services, rehabilitation, home health aide, home modification, home nursing, housekeeping, intermediate care

¹ Based upon Division data shared with the Sonoran UCEDD in August of 2010.

² U.S. Census Bureau, *State and County Quickfacts*, 2009. Retrieved from <http://quickfacts.census.gov/qfd/states/04000.html>

³ Albecht, D. E. (2008). *The State of Arizona. Population Brief: Trends in the Western U.S.* Logan, UT: Western Rural Development Center. Retrieved from http://wrdc.usu.edu/files/uploads/Population/Arizona_WEB.pdf.

⁴ Braddock, D., Hemp, R., & Rizzolo, M. C. (2008). *The State of the State in Developmental Disabilities* (Seventh Edition). Boulder: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry.

facilities for cognitive/intellectual disability, medical services, nursing facilities, respiratory therapy, respite, therapies - occupational, physical and speech, transportation (non-emergency).

Barriers: Budget cuts have required DDD to terminate some home and community based services for 300 children and 400 adults with DD who are not eligible for services funded through the state's Title XIX Medicaid program. These services were paid entirely out of state funds.

Department of Economic Security (DES)

Agency: Division of Children, Youth, and Families/Temporary Assistance to Needy Families (TANF)

Eligibility: Single parent families, with a strict time limit and work requirement. Some individuals with DD are eligible if they fall within the categories.

Services: Financial assistance to eligible families; assistance in training and finding work; and some child-care assistance if the parent is working.

Barriers: Persons with DD may need more assistance with work. Parents of children with DD often have difficulty working and need day care for special needs. An estimated 10,000 people are losing eligibility for temporary cash assistance as the time limit for assistance is cut back to 36 months from 60.⁵

Department of Economic Security (DES)

Agency: Arizona Early Intervention Program (AzEIP)

Eligibility: Children from birth until age three who have a developmental delay in which the child has not reached 50 percent of the developmental milestones expected at his or her chronological age, in one or more of the following domains: Physical, cognitive, language/communication, social/emotional, and adaptive self-help.

Services: Assistive technology, audiology, family training, counseling and in home visits, health services, medical services only for diagnostic or evaluation purposes, nursing services, nutrition, occupational therapy, physical therapy, psychological services, service coordination, social work, special instruction, speech-language therapy, vision services, and transportation (to enable the child and family to participate in early intervention services).

Barriers: Reports of lack of sufficient early intervention service providers in rural areas and too few qualified professionals who can diagnose autism across the state. Fees for early intervention services based on family income and family size. ALTCS, Indian Tribes, and less than 199% poverty level don't have to pay.

Department of Economic Security (DES)

Agency: Rehabilitative Services Administration/Vocational Rehabilitation (RSA/VR)

Eligibility: Disability must be a barrier to obtaining or retaining employment and the provision of vocational rehabilitation services allows the individual to become independently employed.

Services provided: Education, training and job development services may include assistive technology or services that may be needed to obtain or retain employment, job coaching, and re-training or education to secure and/or keep employment.

Barriers: RSA/VR is operating under an Order of Selection under which, depending on budget issues, either all categories are closed or only Priority Group One clients (eligible individuals with

⁵ Center on Budget and Policy Priorities, "An Update on State Budget Cuts At Least 46 States Have Imposed Cuts That Hurt Vulnerable Residents and the Economy." Retrieved from: <http://www.cbpp.org/cms/?fa=view&id=1214>

the most significant disabilities) get services. Most DD clients fall under Priority Group One. As of March 12, there are 2,118 individuals in Priority Group One on the waiting list, with some releases expected in coming weeks and a goal of all individuals in Priority Group One released from the waiting list by June. Some DD individuals will not be found eligible for VR because they are considered unable to become competitively employed.

Department of Economic Security (DES)

Agency: Division of Aging and Adult Services

Eligibility: Individuals 55 and older as well as adults with disabilities. While not DD specific services, older individuals with DD and their parents would be eligible.

Services: Independent Living Supports that provide a range of services and supports to older adults and eligible persons with disabilities. Programs include AZ Links, the Family Caregiver Support Program, Home and Community Living Supports, and Nutrition Services.

Barriers: The FY 2010 and FY 2011 state budgets have seen reduced funding for aging and adult services, including cuts to Independent Living Supports and in-home assistance for 700 older Arizonans that allows them to remain in their home instead of moving to a nursing home.

Department of Health Services (DHS)

Agency: Office for Children with Special Health Care Needs (OCSHCN)

Eligibility:⁶ Children who have or are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Services: OCSHCN provides medical and related services through clinics to children who are at risk for developmental delay, metabolic/genetic disorders, or hearing impairment.

Barriers: Only AHCCCS eligible children are receiving services. 19% of children with special health care needs in Arizona are reported to have at least one unmet health care need during the last 12 months. This rate is 2.5 times higher than the rate for other children. Proposed cuts federally to Maternal Child Health Title V may affect services.

Department of Health Services (DHS)

Division of Behavioral Health Services (DBHS)

Agency: Tribal and Regional Behavioral Health Authorities (RBHA's)

Eligibility: People who are Title XIX (AHCCCS) or Title XXI Children's Health Insurance Program (CHIP-Federal) (Kids Care-Arizona) eligible and have certain behavioral health conditions that can benefit from medically necessary behavioral health services. Others identified as having a serious mental illness may also be eligible. ADHS/DBHS has Intergovernmental Agreements (IGAs) with some of Arizona's American Indian Tribes to deliver behavioral health services to persons living on the reservation.

Services: Prevention services provide information and skill building techniques to help clients lead a happy life. Evaluations help determine what individual issues may be and what to do about them. Treatment includes such things as counseling, crisis response, medications, and in-home supports.

⁶ Much of the data for this section and following sections was taken from the recently released *Maternal Child Health Assessment* report issued by the Maternal Child Health and Children with Special Health Care Needs programs.

Barriers: State budget cuts have meant substantial reductions to the behavioral health services that are provided to non-Title XIX (state-only) populations. Greater needs are being reported in Tucson following the January 8, 2011 shootings.

Agency: Arizona Health Care Cost Containment System (AHCCCS)

Eligibility: Arizona's Medicaid agency provides payment for health care for people who are very low income (100% poverty level or below), including people with developmental disabilities on SSI.

Services: Coverage includes Acute Care Services. Doctor's visits, immunizations, prescription coverage if no Medicaid, lab and x-rays, specialist care, hospital services, transportation to doctor, emergency care, pregnancy care, surgery services, physical exams, behavioral health, family planning, and dialysis.

Barriers: AHCCCS is only available to people at the very bottom of the economic stratum: generally monthly income cannot exceed \$903 for one person or \$1,215 (100% of the federal poverty level) for two people. Many individuals who are not eligible for or able to afford employer related health insurance still make too much money to qualify for AHCCCS. Services have also been cut recently for AHCCCS participants. In addition, proposed budget cuts would reduce eligibility, cutting an estimated 280,000 people currently on AHCCCS. While these cuts will not affect DDD clients who are eligible for Title XIX support, it could have an impact on low-income people who meet the federal definition of developmental disability but whose income exceeds the proposed new AHCCCS limits.

Agency: Arizona Long-Term Care System (ALTCS), part of AHCCCS

Eligibility: Individuals who are elderly, physically disabled or developmentally disabled must meet functional and income requirements, and be at risk of institutionalization.

Services: Long-term care and case management, in home services, habilitation (if DD) and a broad range of other services including day treatment and job supports. It also pays for nursing home if institutionalized.

Barriers: Effective October 1, 2010, AHCCCS benefit changes eliminated a wide range of acute care medical services previously available to ALTCS members, including most dental care and services, well doctor visits, bone anchored hearing aids and cochlear implants, and more. Other potential cuts include the Freedom to Work program which helps individuals with disabilities between 16 and 65 who want to work but are worried about losing medical and Social Security benefits.

Arizona Department of Education

Agency: Special Education, Exceptional Students Division

Eligibility: Age 3-5, pre-school and up to age 22 - children who need special education and/or related service in order to obtain free, appropriate public education.

Services: Specialized designed instruction and related services, including transition.

Barriers: In resource limited environments it may be more difficult for schools to provide inclusion and other services to children with DD and decreased state funding for education overall.

Agency: Arizona Department of Corrections

Eligibility: Incarcerated people with DD under age 22 are eligible for special education.

Services: Special education services including specialized instruction and related services pursuant to an IEP.

Barriers: Lack of identification or knowledge of the extent and characteristics of the DD population in prison.

Agency: Arizona Department of Juvenile Corrections

Eligibility: Youth with DD are eligible for educational services under an IEP, as well as a variety of counseling and rehabilitation services.

Services: The ADJC has policies and procedures in place to provide programs and related services for students who are eligible under the Individuals with Disabilities Education Act (IDEA).

Barriers: HB2376, pending in the State Senate as of March 26, 2011, would retain the Department of Juvenile Corrections until July 1, 2012. Legislation in 2010 established the Commission on Juvenile Corrections Reform to make recommendations regarding the juvenile corrections system.

Federal Programs

Social Security Administration

Agency: Supplemental Security Income (SSI)

Eligibility: Adults or children who are disabled or blind, have limited income and resources, meet living arrangement requirements, and are otherwise eligible. Also children, birth to 18, who are seriously disabled and have little or no income and resources.

Services: The monthly payment varies up to the maximum federal benefit rate, which may be supplemented by the State or decreased by countable income and resources. The monthly maximum Federal amounts for 2011 are \$674 for an eligible individual and \$1,011 for an eligible individual with an eligible spouse.

Barriers: In up to half the cases, individuals are initially denied SSI and only through the appeals process are found to be eligible. Reconsiderations and appeals can take up to two years. Eventually, if found eligible, the applicant will receive all back benefits.

Agency: Social Security Disability Insurance (SSDI)

Eligibility: Worker must earn sufficient credits based on taxable work to be "insured" for Social Security purposes. Disability benefits are payable to blind or disabled workers, widow(er)s, or adults disabled since childhood, (based on the credits of a disabled worker who is deceased) or are otherwise eligible. SSDI pays benefits to people who cannot work because they have a medical condition that is expected to last at least one year or result in death. SSDI does not give money to people with partial disability or short-term disability.

Services: The amount of the monthly disability benefit is based on the Social Security earnings record of the insured worker.

Barriers: Most individuals who are developmentally disabled would not be eligible for SSDI because of limited work history unless they are eligible through a parent. They are usually eligible for SSI if they have limited income and resources.

The *Work Opportunity Tax Credit* is a federal tax credit incentive that Congress provides to private-sector businesses for hiring individuals from twelve target groups who have consistently faced significant barriers to employment, including people with disabilities who are referred by Vocational Rehabilitation. The main objective of this program is to enable the targeted employees to gradually move from economic dependency into self-sufficiency as they earn a steady income and become contributing taxpayers, while the

participating employers are compensated by being able to reduce their federal income tax liability.

Advocacy/Non-Profit Organizations/Academic/Other (sampling – many others in State)

The Arizona Center for Disability Law, Arizona Developmental Disabilities Planning Council, Sonoran UCEDD, and Institute for Human Development are partner organizations that together form the Arizona Developmental Disabilities Network.

Arizona Center for Disability Law serves as the state's designated protection and advocacy system for individuals with disabilities, and provides legal and advocacy services, training, information and referral in priority areas, which include special education, employment, access to health care services, and abuse and neglect prevention/investigation.

Arizona Developmental Disabilities Planning Council engages in advocacy, capacity building and systemic change to increase inclusion and involvement in the community, and strives to achieve the essence of the Developmental Disabilities Act by promoting self-determination, independence, productivity and integration to support persons with developmental disabilities and their families in all facets of community life.

University Centers for Excellence in Developmental Disability Education, Research, and Service

Sonoran UCEDD (University of Arizona) has programs and projects that assist individuals with developmental disabilities in navigating life transitions, and promotes services and supports in Hispanic communities along the Arizona/Mexico border. It provides services to diverse linguistic and ethnic populations, and develops and implements family support projects.

Institute for Human Development (Northern Arizona University) provides support and services to individuals with disabilities and families across northern Arizona, including Native American tribes and families. It administers family support and self-determination projects, as well as early intervention services to young children and families across the State.

Arizona Disability Advocacy Coalition acts as a catalyst to engage individuals with disabilities, their families and organizations that serve them in advocacy efforts that promote public policy which enhances the choice, dignity, rights and responsibilities of people with disabilities.

Arizona Technology Access Project provides the following to people with disabilities, their family members, and service providers: equipment demonstrations, short-term equipment loans, equipment reutilization, alternative financing, and public awareness,

training and technical assistance including transition services and interagency coordination/ collaboration.

Autism Society chapters in Tucson, Phoenix and Flagstaff reach out to individuals with autism and their families with information, support, and encouragement.

Epilepsy Foundation of Arizona works to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through research, education, advocacy and services.

Linkages works as the liaison between area businesses with employment openings and participating rehabilitation providers with qualified people ready to work, seeking to ensure that all people are given the opportunity to perform and be valued.

Partners in Policymaking is an innovative, competency based leadership training program for adults with developmental disabilities and parents of young children with disabilities designed to teach best practices in disability, and to teach the competencies of influencing and communication.

People First of Arizona is part of a self-advocacy movement by and for people with disabilities offering experience through participation.

Pilot Parents of Southern Arizona is committed to providing encouragement and support to families who have children with special needs so that their children can reach their maximum potential within the family and society.

Raising Special Kids provides training and information to parents with children and youth with special health care needs, as well as the professionals who serve them.

Self Advocacy Coalition of Arizona enhances the rights and responsibilities of individuals with disabilities by establishing and maintaining working partnerships with individuals and advocacy groups.

Southwest Autism Research and Resource Center sets forth, promotes and facilitates best practices for early intervention and the long-term care of individuals with autism spectrum disorders through integrative research, educational outreach, model programs and collaborative initiatives.














Statewide Independent Living Council provides the following to individuals with disabilities: independent living, home modification, travel training, person care attendants, advocacy, and employment services. There are five Centers for Independent Living in Arizona: *ABIL - Arizona Bridge to Independent Living* in Phoenix, *ASSIST! to Independence* in Tuba City, *DIRECT Center for Independence, Inc.* in Tucson, *New Horizons Independent Living Center* in Prescott Valley and *S.M.I.L.E. - Services Maximizing Independent Living Empowerment* in Yuma.

The Arc of Arizona advocates for the rights and full community participation of all people with intellectual and developmental disabilities, working to improve systems of supports and services, connect families, inspire communication and influence public policy.




Tucson Alliance for Autism promotes community awareness and provides diagnostic and therapeutic services for individuals with an Autism Spectrum Disorder (ASD), educates and supports professionals and families on ASD-related issues, and supports and provides resources for families.

United Cerebral Palsy affiliates in Phoenix and Tucson provide support groups for people with disabilities and their family members and friends, share important information and services across the developmental disability community, and advocate for improved services.

1. I currently participate in the following activities: (please check all that apply to yourself as a person with a developmental disability or your family member with a developmental disability)

		Response Percent	Response Count
Day program for persons with developmental disabilities		16.2%	12
Go out to eat		77.0%	57
Go on vacation		51.4%	38
Go shopping		74.3%	55
Go to religious and/or spiritual services		56.8%	42
Recreation		32.4%	24
Volunteer in the community		23.0%	17
Social club		12.2%	9
Sports (including Special Olympics)		21.6%	16
Paid employment		17.6%	13
Exercise program		12.2%	9
School		58.1%	43
Other (please specify)		10.8%	8
		answered question	74
		skipped question	6

2. Does your medical practitioner understand and respect your disability and health care needs?

		Response Percent	Response Count
Yes		76.0%	57
No		2.7%	2
Not sure		21.3%	16

If you said "no" please explain why: 4

answered question	75
skipped question	5




3. In your opinion, how important are each of the following to a medical practitioner's ability to provide quality care to persons with developmental disabilities?

	Very Important	Important	Somewhat Important	Not Very Important	Response Count
Medical knowledge and expertise	89.2% (66)	10.8% (8)	0.0% (0)	0.0% (0)	74
Compassion and respect for all patients	85.3% (64)	14.7% (11)	0.0% (0)	0.0% (0)	75
Dedication to their patients	81.3% (61)	18.7% (14)	0.0% (0)	0.0% (0)	75
Understanding of disability-related health needs	84.7% (61)	12.5% (9)	2.8% (2)	0.0% (0)	72
Communicates clearly	89.3% (67)	10.7% (8)	0.0% (0)	0.0% (0)	75
Asks about my health-care goals	64.0% (48)	29.3% (22)	6.7% (5)	0.0% (0)	75



Other (please specify) 6

answered question	75
skipped question	5







4. Are you satisfied with the condition of your teeth and mouth?

		Response Percent	Response Count
Yes		61.6%	45
No		31.5%	23
Other (please specify)		6.8%	5
		answered question	73
		skipped question	7




5. Have you had a dental exam in the past year?

		Response Percent	Response Count
Yes		63.5%	47
No		36.5%	27
		answered question	74
		skipped question	6






6. If you have not had a dental exam in the past year which of the following explains why? (please check all that apply)

		Response Percent	Response Count
I have had an exam in the past year		43.8%	21
Cannot afford the cost		29.2%	14
Cannot find a dentist close enough to where I live		0.0%	0
Cannot find a dentist who accepts patients with special needs		14.6%	7
Had a problem with transportation that kept me from getting to the dentists office		6.3%	3
Nearby dentists do not accept my health payment plan		8.3%	4
Other (please specify)		25.0%	12
answered question			48
skipped question			32





7. Are there adequate opportunities for recreation in your community for persons with developmental disabilities?

		Response Percent	Response Count
Yes		17.6%	13
No		58.1%	43
Don't Know		24.3%	18
answered question			74
skipped question			6






8. If you answered with NO, what is the reason? (please check all that apply)

		Response Percent	Response Count
Recreational opportunities exist, but they are difficult to get to		24.5%	13
Recreational opportunities for persons with developmental or other disabilities do not exist in my area		17.0%	9
There are not enough recreational opportunities for persons with developmental or other disabilities		67.9%	36
I answered Yes to the last question		9.4%	5
Other (please specify)		32.1%	17
		answered question	53
		skipped question	27





9. I would like to have more recreational opportunities available for people with developmental disabilities in my community.

		Response Percent	Response Count
Strongly agree		59.5%	44
Agree		29.7%	22
Neither agree nor disagree		9.5%	7
Disagree		1.4%	1
Strongly disagree		0.0%	0
		answered question	74
		skipped question	6




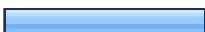

10. If you are answering on behalf of a child, what does your child do during the average day? (please check all that apply)

		Response Percent	Response Count
Day care		3.2%	2
Head Start		0.0%	0
Pre-school		9.5%	6
School		61.9%	39
Not applicable		17.5%	11
Other (please specify)		25.4%	16
		answered question	63
		skipped question	17





11. Self-advocacy, or the ability to speak up for myself, helps me live the life I want to live.

		Response Percent	Response Count
Strongly agree		58.9%	43
Agree		21.9%	16
Neither agree nor disagree		16.4%	12
Disagree		2.7%	2
Strongly disagree		0.0%	0
		answered question	73
		skipped question	7








12. A sufficient number of self-advocacy training opportunities exist in my area.

		Response Percent	Response Count
Strongly agree		5.4%	4
Agree		12.2%	9
Neither agree nor disagree		39.2%	29
Disagree		29.7%	22
Strongly disagree		13.5%	10
answered question			74
skipped question			6

















13. If your family relies on public transportation including para-transit, is it adequate to get you to the places you need to be in your community?

		Response Percent	Response Count
Always		8.5%	4
Often		17.0%	8
Sometimes		51.1%	24
Never		23.4%	11
answered question			47
skipped question			33




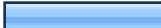

14. If finding adequate transportation is difficult, what is the reason? (please check all that apply)

		Response Percent	Response Count
I do not have difficulty finding adequate transportation		34.0%	18
It is inconvenient		32.1%	17
It is not accessible		9.4%	5
It is not available where I live		20.8%	11
It is too expensive		3.8%	2
It is too slow		26.4%	14
Other (please specify)		22.6%	12
		answered question	53
		skipped question	27







15. Which of the following services and supports do you currently use? (please choose all that apply)

		Response Percent	Response Count
ABS Therapy		1.4%	1
Music therapy		13.7%	10
Attendant care		13.7%	10
Behavioral health		26.0%	19
Day program		13.7%	10
Early intervention/early childhood		5.5%	4
Employment services		9.6%	7
Habilitation		43.8%	32
Housing		9.6%	7
Occupational therapy		32.9%	24
Respite		42.5%	31
Special education and related services		52.1%	38
Speech therapy		45.2%	33
Paratransit		11.0%	8
x - None of the above		8.2%	6
Other (please specify)		21.9%	16
answered question			73
skipped question			7

16. Sufficient supports exist to help persons with developmental disabilities transition from high school and to plan for life after high school, including work or post secondary education.

		Response Percent	Response Count
Strongly agree		1.4%	1
Agree		8.2%	6
Neither agree nor disagree		31.5%	23
Disagree		23.3%	17
Strongly disagree		35.6%	26
answered question			73
skipped question			7

17. Do you have health insurance to help you pay for health care costs?





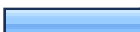

		Response Percent	Response Count
ALTCS (Arizona Long-Term Care System)		39.2%	29
AHCCCS (Arizona Health Care Cost Containment System) health plan		27.0%	20
Employer sponsored private insurance		21.6%	16
Individually purchased private insurance		5.4%	4
No health insurance		1.4%	1
Other (please specify)		5.4%	4
answered question			74
skipped question			6

18. The mission of the DDPC is to represent the interests and needs of persons with developmental disabilities as defined in the federal Developmental Disabilities Act as – a disability that occurred prior to the age of 22, is lifelong, and affects three or more major life activities. Please tell us how important each of the items below to the DDPC's mission.






	Very Important	Important	Somewhat Important	Not Very Important	Rating Average	Response Count
Aging services	47.3% (35)	32.4% (24)	16.2% (12)	4.1% (3)	1.00	74
Special education	71.2% (52)	21.9% (16)	4.1% (3)	2.7% (2)	1.00	73
Caregiver support and education	61.3% (46)	33.3% (25)	5.3% (4)	0.0% (0)	1.00	75
Child care-related initiatives and activities	45.9% (34)	32.4% (24)	13.5% (10)	8.1% (6)	1.00	74
Dental care-related initiatives and activities	58.7% (44)	33.3% (25)	5.3% (4)	2.7% (2)	1.00	75
Early intervention	60.8% (45)	27.0% (20)	8.1% (6)	4.1% (3)	1.00	74
Education K-12 initiatives and activities	59.5% (44)	33.8% (25)	2.7% (2)	4.1% (3)	1.00	74
Employment-related initiatives and activities	67.6% (50)	23.0% (17)	6.8% (5)	2.7% (2)	1.00	74
Health service-related initiatives and activities	68.0% (51)	30.7% (23)	1.3% (1)	0.0% (0)	1.00	75
Housing-related initiatives and activities	62.2% (46)	28.4% (21)	8.1% (6)	1.4% (1)	1.00	74
Post-secondary options for young people with developmental disabilities	76.7% (56)	17.8% (13)	4.1% (3)	1.4% (1)	1.00	73
Advocacy initiatives and activities that ensure the excellence of services and supports	73.7% (56)	25.0% (19)	1.3% (1)	0.0% (0)	1.00	76
Recreation-related initiatives and activities	61.3% (46)	30.7% (23)	8.0% (6)	0.0% (0)	1.00	75
Training of direct service providers	69.3% (52)	26.7% (20)	2.7% (2)	1.3% (1)	1.00	75
Transportation-related activities	60.0% (45)	28.0% (21)	10.7% (8)	1.3% (1)	1.00	75
Other services available or offered						

to individuals in a community including formal and informal community supports that affect quality of life.	68.0% (51)	25.3% (19)	5.3% (4)	1.3% (1)	1.00	75
answered question						76
skipped question						4

19. How satisfied are you with school-based special education services?

		Response Percent	Response Count
I have no experience with school-based special education or related services		9.3%	7
Very satisfied		14.7%	11
Somewhat satisfied		30.7%	23
Neither satisfied nor dissatisfied		10.7%	8
Somewhat dissatisfied		20.0%	15
Very Dissatisfied		13.3%	10
answered question			75
skipped question			5




20. What do you like about the special education services you or your family member receives? (please check all that apply)

		Response Percent	Response Count
I have no experience with school-based special education or related services		15.2%	10
The services have helped me progress in life and meet goals and expectations		42.4%	28
The services meet my individual educational needs		15.2%	10
The staff responds to my concerns and treat me with respect		42.4%	28
Other (please specify)		24.2%	16
		answered question	66
		skipped question	14







21. If you ARE NOT satisfied with special education services, please tell us what you would like to see changed?

	Response Count
	39
answered question	39
skipped question	41






22. Whether schools should be able to place students in seclusion or restraints and under what conditions, is a topic being discussed at a state and national level. Have you been subject to restraint or seclusion at school or are you aware of instances where an individual with DD has been restrained or secluded while at school?

		Response Percent	Response Count
Yes		41.9%	31
No		43.2%	32
Don't know		16.2%	12
answered question			74
skipped question			6

23. How satisfied are you with the early intervention or the early childhood service system?

		Response Percent	Response Count
I have no experience with early intervention or the early childhood service system?		24.0%	18
Very satisfied		21.3%	16
Somewhat satisfied		20.0%	15
Neither satisfied nor dissatisfied		12.0%	9
Somewhat dissatisfied		13.3%	10
Very Dissatisfied		8.0%	6
answered question			75
skipped question			5

24. What do you like about the early intervention or the early childhood service system? (please check all that apply)

		Response Percent	Response Count
I have no experience with early intervention or early childhood services		40.0%	28
The services have directly improved my child's quality of life		32.9%	23
The services meet my child's individual needs		20.0%	14
The staff responds to my concerns and treats my child with respect		28.6%	20
Other (please specify)		17.1%	12
		answered question	70
		skipped question	10


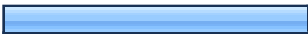




25. If you ARE NOT satisfied with the early intervention or the early childhood service system, please tell us how you think it could be improved?

	Response Count
	17
answered question	17
skipped question	63

26. How satisfied are you with the services provided by the Division of Developmental Disabilities (DDD)?

		Response Percent	Response Count
I have no experience with the Division of Developmental Disabilities		12.0%	9
Very satisfied		24.0%	18
Somewhat satisfied		40.0%	30
Neither satisfied nor dissatisfied		4.0%	3
Somewhat dissatisfied		9.3%	7
Very Dissatisfied		10.7%	8
answered question			75
skipped question			5







27. What do you value about DDD services? (please check all that apply)

		Response Percent	Response Count
I have no experience with DDD services		14.7%	10
Services address my individual needs		45.6%	31
The staff responds to my concerns and treats me with respect		55.9%	38
The services have directly improved my quality of life		41.2%	28
The services have helped me progress in life and meet goals and expectations		41.2%	28
Other (please specify)		17.6%	12
		answered question	68
		skipped question	12


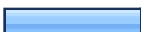



28. If you ARE NOT satisfied with DDD services, please tell us what you would like to see changed?

	Response Count
	27
answered question	27
skipped question	53

29. How satisfied are you with behavioral health (psychological, psychiatric, or behavior management) services?

		Response Percent	Response Count
I have no experience with behavioral health services		39.4%	28
Very satisfied		9.9%	7
Somewhat satisfied		19.7%	14
Neither satisfied nor dissatisfied		5.6%	4
Somewhat dissatisfied		14.1%	10
Very Dissatisfied		9.9%	7
		answered question	71
		skipped question	9







30. What has behavioral health services done well? (please check all that apply)

		Response Percent	Response Count
I have no experience with behavioral health services		47.5%	28
Services address my individual needs		20.3%	12
The staff responds to my concerns and treats me with respect		25.4%	15
The services have directly improved my quality of life		20.3%	12
Other (please specify)		16.9%	10
		answered question	59
		skipped question	21






31. If you ARE NOT satisfied with behavioral health services, please tell us how you think it could be improved?

	Response Count
	22
answered question	22
skipped question	58

32. How satisfied are you with rehabilitative services?

		Response Percent	Response Count
I have no experience with rehabilitative services		52.2%	36
Very satisfied		15.9%	11
Somewhat satisfied		17.4%	12
Neither satisfied nor dissatisfied		2.9%	2
Somewhat dissatisfied		5.8%	4
Very Dissatisfied		5.8%	4
		answered question	69
		skipped question	11




33. What does rehabilitative services do well? (please check all that apply)

		Response Percent	Response Count
I have no experience with rehabilitative services		48.3%	28
The services have directly improved my quality of life		31.0%	18
The services meet my individual needs		25.9%	15
The staff responds to my concerns and treat me with respect		29.3%	17
Other (please specify)		12.1%	7
		answered question	58
		skipped question	22



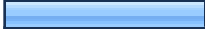

34. If you ARE NOT satisfied with rehabilitative services, please tell us how you think it could be improved?

	Response Count
	14
answered question	14
skipped question	66

35. Are you/your family member with a developmental disability working in a job where you receive minimum wage or above?

		Response Percent	Response Count
Yes		20.0%	14
No		31.4%	22
Not working		48.6%	34
answered question			70
skipped question			10


36. What is your age/age of the person with a developmental disability you are assisting in filling out this survey?

		Response Percent	Response Count
0-3		2.9%	2
4-21		64.3%	45
21-55		30.0%	21
Over 55		2.9%	2
answered question			70
skipped question			10



37. If you are a person with a developmental disability currently living with an adult family member, what is the adult family member's age?

	Adult 1	Adult 2 (if applicable)	Adult 3 (if applicable)	Response Count
25-45	80.0% (20)	60.0% (15)	8.0% (2)	25
46-60	73.9% (17)	69.6% (16)	4.3% (1)	23
61-70	71.4% (5)	57.1% (4)	0.0% (0)	7
71-80	0.0% (0)	0.0% (0)	0.0% (0)	0
Over 80	100.0% (2)	50.0% (1)	0.0% (0)	2
I am not living with an adult family member care-giver	100.0% (10)	0.0% (0)	0.0% (0)	10
answered question				59
skipped question				21








38. What is the zip code where you live?

		Response Percent	Response Count
ZIP:		100.0%	71
answered question			71
skipped question			9







39. What is your gender?

		Response Percent	Response Count
Female		42.9%	30
Male		57.1%	40
answered question			70
skipped question			10







40. What county do you live in?

		Response Percent	Response Count
Cochise		0.0%	0
Santa Cruz		1.4%	1
Pima		39.4%	28
Yuma		0.0%	0
Pinal		7.0%	5
Graham		1.4%	1
Greenlee		0.0%	0
Maricopa		43.7%	31
Gila		0.0%	0
La Paz		0.0%	0
Apache		0.0%	0
Navajo		0.0%	0
Coconino		5.6%	4
Yavapai		0.0%	0
Mohave		1.4%	1
answered question			71
skipped question			9

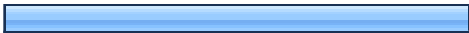

41. How do you define your racial/ethnic identity? (Choose all that apply)

		Response Percent	Response Count
American Indian or Alaska Native		1.4%	1
Asian		2.8%	2
Black or African American		8.3%	6
Hispanic or Latino		15.3%	11
Native Hawaiian or Other Pacific Islander		1.4%	1
White		79.2%	57
	Other (please specify)		2
answered question			72
skipped question			8

42. Where do you currently live?

		Response Percent	Response Count
Foster care or host home		4.1%	3
Group Home or Adult Developmental Home		8.2%	6
I share a house or apartment		4.1%	3
Nursing facility		0.0%	0
With your family		63.0%	46
Your own house or apartment		17.8%	13
Other (please specify)		2.7%	2
		answered question	73
		skipped question	7

43. Do you access the Internet on a regular basis?

		Response Percent	Response Count
Yes		69.9%	51
No		30.1%	22
		answered question	73
		skipped question	7

44. Is there anything we did not ask you about that you think is important to share with us?

**Response
Count**

30

answered question

30

skipped question

50

DD Planning Council Provider, Advocate, and Professional Survey




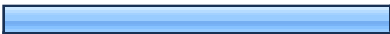




1. Are persons with developmental disabilities typically able to see a dentist on a regular basis?

		Response Percent	Response Count
Yes		16.7%	31
No		55.4%	103
Don't know		28.0%	52
	Comment		63
answered question			186
skipped question			0

2. Do persons with developmental disabilities typically have access to a dentist in a timely fashion?

		Response Percent	Response Count
Yes		17.7%	33
No		50.5%	94
Don't Know		31.7%	59
	Comment		35
answered question			186
skipped question			0





3. If you answered NO to question two, which of the following explains why? (please check all that apply)

		Response Percent	Response Count
Cannot find a dentist close enough to where the person lives		19.0%	19
Cannot find a dentist who accepts persons with special needs		58.0%	58
Had a problem with transportation that kept the person from getting to the dentist's office		20.0%	20
Nearby dentists do not accept health payment plan		31.0%	31
The cost is not affordable.		78.0%	78
Other (please specify)		22.0%	22
		answered question	100
		skipped question	86







4. In your opinion, how important are each of the following to a medical practitioner's ability to provide quality care to persons with developmental disabilities?

	Very Important	Important	Somewhat Important	Not Very Important	Rating Average	Response Count
Medical knowledge and expertise	87.2% (156)	12.3% (22)	0.0% (0)	0.6% (1)	1.00	179
Compassion and respect for all patients	92.2% (166)	7.2% (13)	0.0% (0)	0.6% (1)	1.00	180
Dedication to their patients	79.9% (143)	18.4% (33)	1.1% (2)	0.6% (1)	1.00	179
Understanding of disability-related health needs	91.1% (164)	7.8% (14)	0.0% (0)	1.1% (2)	1.00	180
Communicates clearly	90.6% (164)	8.8% (16)	0.0% (0)	0.6% (1)	1.00	181
Asks about health care goals	53.8% (98)	34.1% (62)	10.4% (19)	1.6% (3)	1.00	182
				Other (please specify)		29
answered question						185
skipped question						1




5. To what degree is public transportation including para-transit available to persons with developmental disabilities?

		Response Percent	Response Count
Always		6.7%	12
Often		34.8%	62
Sometimes		53.4%	95
Never		5.1%	9
answered question			178
skipped question			8




6. If finding adequate transportation is difficult, what is the reason? (please check all that apply)

		Response Percent	Response Count
It is not accessible		28.3%	45
It is not available where I live		42.8%	68
It is too slow		42.1%	67
It is inconvenient		49.1%	78
It is too expensive		28.3%	45
Other (please specify)		28.9%	46
answered question			159
skipped question			27




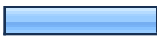

7. Are there adequate opportunities for recreation in the community for persons with developmental disabilities?

		Response Percent	Response Count
Yes		30.4%	56
No		52.7%	97
Don't Know		16.8%	31
Comment			39
answered question			184
skipped question			2






8. If you answered with NO, what is the reason?

		Response Percent	Response Count
Recreational opportunities exist, but they are difficult to get to.		13.3%	13
Recreational opportunities for persons with developmental disabilities do not exist.		13.3%	13
There are not enough recreational opportunities for persons with developmental disabilities.		73.5%	72
	Comment		20
answered question			98
skipped question			88

9. In my contact with persons with developmental disabilities and their families, I believe that they are capable of representing themselves as advocates on issues critical to their quality of life.

		Response Percent	Response Count
Strongly agree		13.5%	25
Agree		33.5%	62
Neither agree nor disagree		24.9%	46
Disagree		22.7%	42
Strongly disagree		5.4%	10
answered question			185
skipped question			1

10. A sufficient number of self-advocacy training opportunities exist in my area.

		Response Percent	Response Count
Strongly agree		1.6%	3
Agree		20.1%	37
Neither agree nor disagree		34.8%	64
Disagree		37.0%	68
Strongly disagree		6.5%	12
answered question			184
skipped question			2

11. The mission of the DDPC is to represent the interests and needs of persons with developmental disabilities as defined in the federal Developmental Disabilities Act as – a disability that occurred prior to the age of 22, is lifelong, and affects three or more major life activities. Please tell us how important each of the items below are to the DDPC's mission.






	Very Important	Important	Somewhat Important	Not Very Important	Rating Average	Response Count
Aging services	58.2% (103)	35.6% (63)	5.1% (9)	1.1% (2)	1.00	177
Special education	62.5% (110)	31.3% (55)	5.1% (9)	1.1% (2)	1.00	176
Caregiver support and education	69.8% (125)	27.9% (50)	1.7% (3)	0.6% (1)	1.00	179
Child care-related initiatives and activities	50.6% (91)	36.7% (66)	10.6% (19)	2.2% (4)	1.00	180
Dental care-related initiatives and activities	55.1% (98)	37.1% (66)	6.7% (12)	1.1% (2)	1.00	178
Early intervention	80.4% (144)	16.2% (29)	2.8% (5)	0.6% (1)	1.00	179
Education K-12 initiatives and activities	64.2% (115)	30.7% (55)	4.5% (8)	0.6% (1)	1.00	179
Employment-related initiatives and activities	69.1% (123)	27.0% (48)	3.4% (6)	0.6% (1)	1.00	178
Health service-related initiatives and activities	68.2% (122)	28.5% (51)	2.8% (5)	0.6% (1)	1.00	179
Housing-related initiatives and activities	62.2% (112)	32.2% (58)	5.0% (9)	0.6% (1)	1.00	180
Post-secondary options for young people with developmental disabilities	55.6% (99)	36.0% (64)	7.9% (14)	0.6% (1)	1.00	178
Advocacy initiatives and activities that ensure the excellence of services and supports	73.4% (135)	24.5% (45)	1.1% (2)	1.1% (2)	1.00	184
Recreation-related initiatives and activities	46.3% (82)	41.2% (73)	10.7% (19)	1.7% (3)	1.00	177
Training of direct service providers	71.0% (125)	25.0% (44)	2.8% (5)	1.1% (2)	1.00	176
Transportation-related activities	55.4% (98)	36.7% (65)	7.3% (13)	0.6% (1)	1.00	177
x - Other services available or						

offered to individuals in a community including formal and informal community supports that affect quality of life.	59.3% (80)	33.3% (45)	5.9% (8)	1.5% (2)	1.00	135
						Other (please specify) 27
						answered question 186
						skipped question 0







12. Please rate the following items in terms their importance for maintaining the maximum inclusion of persons with developmental disabilities in all facets of daily life.

	Very Important	Important	Somewhat Important	Not Very Important	Rating Average	Response Count
Being around other people	79.0% (139)	18.8% (33)	2.3% (4)	0.0% (0)	1.00	176
Being part of a community	79.7% (141)	17.5% (31)	2.8% (5)	0.0% (0)	1.00	177
Being treated with respect	92.7% (164)	7.3% (13)	0.0% (0)	0.0% (0)	1.00	177
Having a job, going to school, or engaging in meaningful activities	84.9% (152)	14.5% (26)	0.6% (1)	0.0% (0)	1.00	179
Liking one's neighborhood	40.6% (71)	43.4% (76)	14.9% (26)	1.1% (2)	1.00	175
Making one's own choices	75.0% (132)	22.2% (39)	2.8% (5)	0.0% (0)	1.00	176
Not feeling lonely	72.9% (97)	24.1% (32)	3.0% (4)	0.0% (0)	1.00	133
Not feeling lonely	72.0% (126)	25.7% (45)	2.3% (4)	0.0% (0)	1.00	175
						Other (please specify) 14
						answered question 183
						skipped question 3






13. High school transition planning is effective in preparing students with developmental disabilities for adult living including employment.

		Response Percent	Response Count
Strongly agree		35.3%	65
Agree		20.1%	37
Neither agree nor disagree		16.8%	31
Disagree		17.4%	32
Strongly disagree		10.3%	19
answered question			184
skipped question			2

14. How satisfied are you with school-based special education services?

		Response Percent	Response Count
I have no experience with school-based special education and related services		12.0%	22
Very satisfied		8.7%	16
Somewhat satisfied		29.0%	53
Neither satisfied nor dissatisfied		10.4%	19
Somewhat dissatisfied		26.8%	49
Very Dissatisfied		13.1%	24
answered question			183
skipped question			3




15. What do you think works well with special education services? (please check all that apply)

		Response Percent	Response Count
The services meet individual educational needs		51.5%	87
The staff responds to concerns and treat people with respect		45.0%	76
The services have helped people progress in life and meet goals and expectations		42.6%	72
I have no experience with school-based special education or related services		15.4%	26
Other (please specify)		20.1%	34
		answered question	169
		skipped question	17







16. If you ARE NOT satisfied with special education services, please tell us what you would like to see changed.

	Response Count
	89
answered question	89
skipped question	97






17. Whether schools should be able to place students in seclusion or restraints and under what conditions, is a topic being discussed at a state and national level. Are you aware of instances where an individual with DD has been restrained or secluded while at school?

		Response Percent	Response Count
Yes		45.9%	84
No		37.7%	69
Don't know		16.4%	30
answered question			183
skipped question			3

18. How satisfied are you with early intervention or the early childhood service system?

		Response Percent	Response Count
I have no experience with early intervention or early childhood services		23.4%	43
Very satisfied		17.9%	33
Somewhat satisfied		29.3%	54
Neither satisfied nor dissatisfied		12.0%	22
Somewhat dissatisfied		12.5%	23
Very Dissatisfied		4.3%	8
answered question			184
skipped question			2

19. What do you think works well with early intervention or the early childhood service system? (please check all that apply)

		Response Percent	Response Count
I have no experience with early intervention and/or early childhood services		29.9%	52
The services meet individual needs		45.4%	79
The services have directly improved people's quality of life		51.1%	89
The staff is responsive and respectful		50.6%	88
Other (please specify)		12.6%	22
answered question			174
skipped question			12

20. If you ARE NOT satisfied with early intervention or early childhood services, please tell us what you would like to see changed.

	Response Count
	44
answered question	44
skipped question	142







21. How satisfied are you with the services provided by the Division of Developmental Disabilities (DDD)?

		Response Percent	Response Count
I have no experience with the Division of Developmental Disabilities		1.7%	3
Very satisfied		14.6%	26
Somewhat satisfied		50.0%	89
Neither satisfied nor dissatisfied		11.2%	20
Somewhat dissatisfied		16.9%	30
Very Dissatisfied		5.6%	10
		answered question	178
		skipped question	8






22. What stands out when you reflect on your experience with DDD services? (Please select all that apply)

		Response Percent	Response Count
I have no experience with DDD services		2.3%	4
Services effectively address individual needs		35.8%	62
The services have directly improved people's quality of life		54.3%	94
The services have helped people progress in life and meet goals and expectations		57.2%	99
The staff responds to concerns, and treat people with respect		52.6%	91
Other (please specify)		32.9%	57
		answered question	173
		skipped question	13

23. How satisfied are you with the behavioral health services provided to people with developmental disabilities in Arizona?

		Response Percent	Response Count
I have no experience with behavioral health services		16.2%	30
Very satisfied		3.8%	7
Somewhat satisfied		36.2%	67
Neither satisfied nor dissatisfied		10.3%	19
Somewhat dissatisfied		22.7%	42
Very Dissatisfied		10.8%	20
answered question			185
skipped question			1







24. What has behavioral health done well? (please check all that apply)

		Response Percent	Response Count
I have no experience with behavioral health services		18.8%	28
Services address people's individual needs		35.6%	53
The staff is supportive, respond to concerns, and treat people with respect		40.9%	61
The services have directly improved people's quality of life		36.9%	55
Other (please specify)		24.2%	36
answered question			149
skipped question			37






25. If you ARE NOT satisfied with behavioral health services, please tell us what you would like to see changed.

	Response Count
	71
answered question	71
skipped question	115

26. How satisfied are you with rehabilitative services provided to persons with developmental disabilities in Arizona?

		Response Percent	Response Count
I have no experience with vocational rehabilitation services		22.0%	40
Very satisfied		10.4%	19
Somewhat satisfied		33.0%	60
Neither satisfied nor dissatisfied		15.4%	28
Somewhat dissatisfied		12.6%	23
Very Dissatisfied		6.6%	12
		answered question	182
		skipped question	4


27. What do you like about rehabilitative services? (please check all that apply)

		Response Percent	Response Count
I have no experience with rehabilitative services		23.0%	35
The services meet people's individual needs		34.9%	53
The services have directly improved people's quality of life		46.7%	71
The staff responds to concerns and treat people with respect		43.4%	66
Other (please specify)		17.1%	26
		answered question	152
		skipped question	34

28. If you ARE NOT satisfied with rehabilitative services, please tell us what you would like to see changed.

	Response Count
	47
answered question	47
skipped question	139



29. What is the zip code where you live?

		Response Percent	Response Count
ZIP:		100.0%	179
		answered question	179
		skipped question	7

30. What county do you live in?

		Response Percent	Response Count
Cochise		2.8%	5
Santa Cruz		2.8%	5
Pima		59.1%	107
Yuma		1.1%	2
Pinal		1.1%	2
Graham		0.0%	0
Greenlee		0.0%	0
Maricopa		22.1%	40
Gila		0.0%	0
La Paz		0.0%	0
Apache		0.6%	1
Navajo		0.6%	1
Coconino		7.2%	13
Yavapai		1.1%	2
Mohave		1.7%	3
answered question			181
skipped question			5

31. What is your gender?

		Response Percent	Response Count
Female		78.1%	143
Male		21.9%	40
answered question			183
skipped question			3

32. How do you define your racial/ethnic identity? (Check all that apply)

		Response Percent	Response Count
American Indian or Alaska Native	<input type="checkbox"/>	3.3%	6
Asian	<input type="checkbox"/>	1.1%	2
Black or African American	<input type="checkbox"/>	1.6%	3
Hispanic or Latino	<input type="checkbox"/>	16.8%	31
Native Hawaiian or Other Pacific Islander	<input type="checkbox"/>	0.5%	1
White	<input type="checkbox"/>	76.6%	141
Other (please specify)	<input type="checkbox"/>	2.7%	5
answered question			184
skipped question			2