

**ADVISORY COUNCIL  
ON  
DEVELOPMENTAL DISABILITIES**

**2004-2005 QUALITY OF LIFE  
SURVEY**

State of Arizona  
Maricopa County

### ACKNOWLEDGEMENT

The Advisory Council on Developmental Disabilities sincerely appreciates the individuals and families who gave their personal time to participate in the survey, and the caregivers and staff who assisted the families. We extend our thanks to the Division of Developmental Disabilities, District I serving Maricopa County, for the printing and mailing of the survey. We also want to thank the Public Relations and Marketing Committee, Chaired by Dr. Jim Adams in the development of the survey and are especially grateful to Hilary W. Cummings for her analysis and preparation of the graphics.

The Governor's Council on Developmental Disabilities provides funding for the Advisory Council on Developmental Disabilities, Serving Maricopa County.

# 2004-2005 QUALITY OF LIFE SURVEY

*Promoting Self-determination,  
Independence,  
Productivity, and  
Integration and  
Inclusion in All  
Facets of Community Life*

July 2005  
Prepared by the

Advisory Council  
On  
Developmental Disabilities

Dr. Ray Rafford, President  
Margaret "Midge" White, Ex. Director



ARIZONA DEPARTMENT OF ECONOMIC SECURITY

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December 15, 2005

Margaret "Midge" White, M. Ed.  
Executive Director, Maricopa Advisory Council on Developmental Disabilities  
1102 East University Dr., Suite #3  
Mesa, AZ 85203

Dear Ms. White:

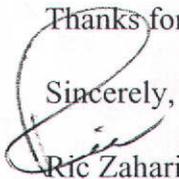
Thank you for sharing your 2004-2005 *Quality of Life Survey* with the Division. We were happy to support you by disseminating the survey to our families last year. A return of over 2,000 surveys makes this a legitimate source of information for us, with other data points, to extrapolate system needs.

The report validates a number of our findings from internal surveys and wait list data:

- The number extrapolated from your data who are waiting and receiving no services is probably higher than our percentages show statewide, but it wouldn't be surprising to have a higher response rate among these folks, since they are the most likely to be unhappy with the current state of affairs; nonetheless, our practice is to serve state only folks on the basis of 'one in, one out', with children getting priority, so this does reflect the legitimate unmet needs of over a thousand people;
- Respite is clearly our most sought after service because it gives the family the breathing space they need to continue long term home-based care; Utah has dedicated state only dollars to respite for families waiting for services;
- Availability of workers to serve those with developmental disabilities is a well established problem and is getting worse; it stems from a basic structural shortage of workers in the market place and from the relatively low wages paid in our field;
- The number of our clients with developmental disabilities who are employed is a low 16% of the total adult population we serve; consequently we have set a goal of moving that percentage to 25% (closer to the national average) by getting those who want to work into the workplace; our recent reengineering of supported work services and rates should help;
- Your findings about the high satisfaction rate with acute care services and the low satisfaction rate with behavioral health services mirror our own data;

Thanks for your advocacy. Don't hesitate contacting me for clarification.

Sincerely,

  
Ric Zaharia, Ph.D.  
Assistant Director

c Jami Snyder

## Quality of Life Survey

### Executive Summary

The Advisory Council on Developmental Disabilities developed the "Quality of Life Survey" to review services for people with developmental disabilities as a follow-up to the 1990 Report done by the Governor's Council.

The surveys were mailed to over 12,000 individuals in Maricopa County and 2076 were completed and returned to the Advisory Council. The response rate of 17.3% validated the survey results as representative of the population. Copy of the actual survey can be found at Appendix C and included general questions in areas of: geographic location, disability, age, survey responder, and state only funded or Arizona Long Term Care System (ALTCS) eligible. The "state only" and ALTCS" funded pie chart shows that, 50% of the respondents, are served by the ALTCS program and 18% are receiving state only funding. An additional 10% receive both and 22% are enrolled in the program but receive no service.

Specific service questions included areas of: The Division of Developmental Disabilities (Division) services, Level of Division Services, Availability of Division Providers, Education, Recreation, Employment, Transportation, and Medical and Behavioral Health.

Respondents ranked the level of service from the Division adequate, between 67% to 11% in areas ranging from respite to assisted living. Families ranked therapies as high need and yet the level of service ranked 36% to 60% of meeting their therapy needs. Attendant care was checked as a service used by 604 individuals and yet 36% ranked no service. Adequate service totaled 52% and 9% checked that attendant care service was too low. Day care, after school, housekeeping, summer programs and group homes all had more checks for no service than for adequate. Of the 410 people that needed housekeeping (because of severe disability) 72% checked no service. One of the major problems of lack of services seems to be a shortage of qualified providers. The percentage of qualified providers always available was from 60% to 27%.

Over 1000 respondents were of school age and ranked their special education plans either good or very good in 67% and 62% of the time. Availability of therapies was ranked at only 9% for very good and 28% for good.

An average of 1320 people answered the three questions on recreational opportunities showing a high need for these services. However, just over a third of the respondents checked good or very good for availability of either integrated or stand alone programs for people with disabilities.

Employment services ranked close to 50% for good or very good for job training, job coaches and sheltered workshop employment. However, job availability was only 13% for very good and 15 % for good.

Transportation was ranked the lowest area for poor and fair from 57% to 40% for areas of dial a ride, buses, on time and wait time. Buses ranked 39% for good and very good compared to dial a ride at 25%.

The lowest rankings in the medical area were for psychiatric care, behavioral health care and knowledge of disability of health care providers. We failed to ask a question about dental care, but many comments from families indicated lack of dental care for adults with disabilities was a major problem.

**Recommendations:**

- Increase funding for “state only” eligible individuals. This program has increased very little since the Federal Medicaid Program started in 1988 since most new money goes for matching dollars for the ALTCS program.
- Study barriers to availability of qualified providers. Review progress of a certificate program for attendant care, respite and habilitation providers. Make recommendations and advocate for solutions to increase the number of qualified providers.
- Develop and establish incentives for speech therapists, physical and occupational therapists and music therapists to work with people with developmental disabilities.
- Support the qualified vendor program, by funding the published rate for Division providers of services, at 100% of the established cost of services and approve a system of keeping these rates up with prevailing costs.
- Collaborate through public-private partnerships to establish adequate day care, after school and summer programs for individuals with developmental disabilities.
- Fully fund special education, according to the most recent Cost Study, to more adequately meet the needs of students with disabilities for all schools.
- Advocate for social recreational programs for people with developmental disabilities, both integrated programs, with typical peers and separate programs.
- Advocate for the full state match to draw down 100% of the Federal allocation to improve and increase the numbers served by employment programs through Vocational Rehabilitation.
- Monitor the new transportation initiative implementation in Maricopa County to increase and improve transit services for people with disabilities.
- Advocate for appropriate programs for people with dual diagnosis of developmental disability and behavioral health issues through the Division and Value Options.
- Develop a pilot program for people with autism to test various behavioral programs.

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Appendix A: Overview –Division of Developmental Disabilities (1990 Report)

Appendix B: Survey Respondent Comments

Appendix C: Copy of the Survey Mailed to Clients in Maricopa Co.

Advisory Council on Developmental Disabilities  
Serving Maricopa County

Quality of Life Survey

**Introduction**

In 2002 the Advisory Council on Developmental Disabilities (Advisory Council), Serving Maricopa County, began discussing ways to conduct a follow-up to the 1990 Report to the Congress, which was conducted by the Arizona Governor's Council on Developmental Disabilities. The Advisory Council is part of a state-wide network of six Advisory Councils funded by the Governor's Council. The 1990 Report served as a "blue-print for charting a course of action to bring about a changed and improved future for citizens with developmental disabilities" (1990 Report, Executive Summary).

The target population of the 1990 Report included individuals with developmental disabilities according to the broad federal functional definition, (P.L. 100-146). The Advisory Council completed a six-page consumer satisfaction survey titled "Quality of Life Survey" in September of 2003. The 1990 Report had three components, including 500 face-to-face interviews with consumers on satisfaction of services, review and analysis of all existing state and federal programs serving people with developmental disabilities, and the identification of major policy issues facing the state as well as recommendations for needed changes. The target population of the new consumer satisfaction survey includes only individuals and families receiving services from the Arizona Department of Economic Security's Division of Developmental Disabilities (Division) within Maricopa County. The eligibility criteria for services from the State of Arizona, uses a categorical definition, which includes individuals with mental retardation, cerebral palsy, epilepsy and autism. Children under six years of age can become eligible for services if they are developmentally delayed. (See Appendix A) The Division mailed 12,000 surveys to all of the people that were enrolled in services in Maricopa County, in the fall of 2003. The Advisory Council is pleased to have had 2076 surveys returned from all across Maricopa County, which totals a 17.3% response rate, and validates the survey results as representative of the population.

**Vision of the Future**

The 1990 Report Executive Summary stated that, "The Governor's Council has a powerful, positive vision of the future for Arizona's children and adults with developmental disabilities and their families. It envisions:

- Families will receive the services and supports they need to care for family members in their homes, and to help them realize their full developmental potential;
- Children will attend community schools in regular classrooms with their peers;

- Supports will be provided which meet children’s individual needs helping them to live in society participating to their fullest potential;
- Adults will live independently and receive the assistance and support they need to lead productive lives;
- Adults will work and contribute to their maximum potential, making positive contributions to their communities;
- All Arizonans with developmental disabilities, and their families, will be able to choose what they need and not merely receive what services are available.

**PUBLIC POLICY WILL NEED TO CHANGE TO MEET THESE CHALLENGES”**

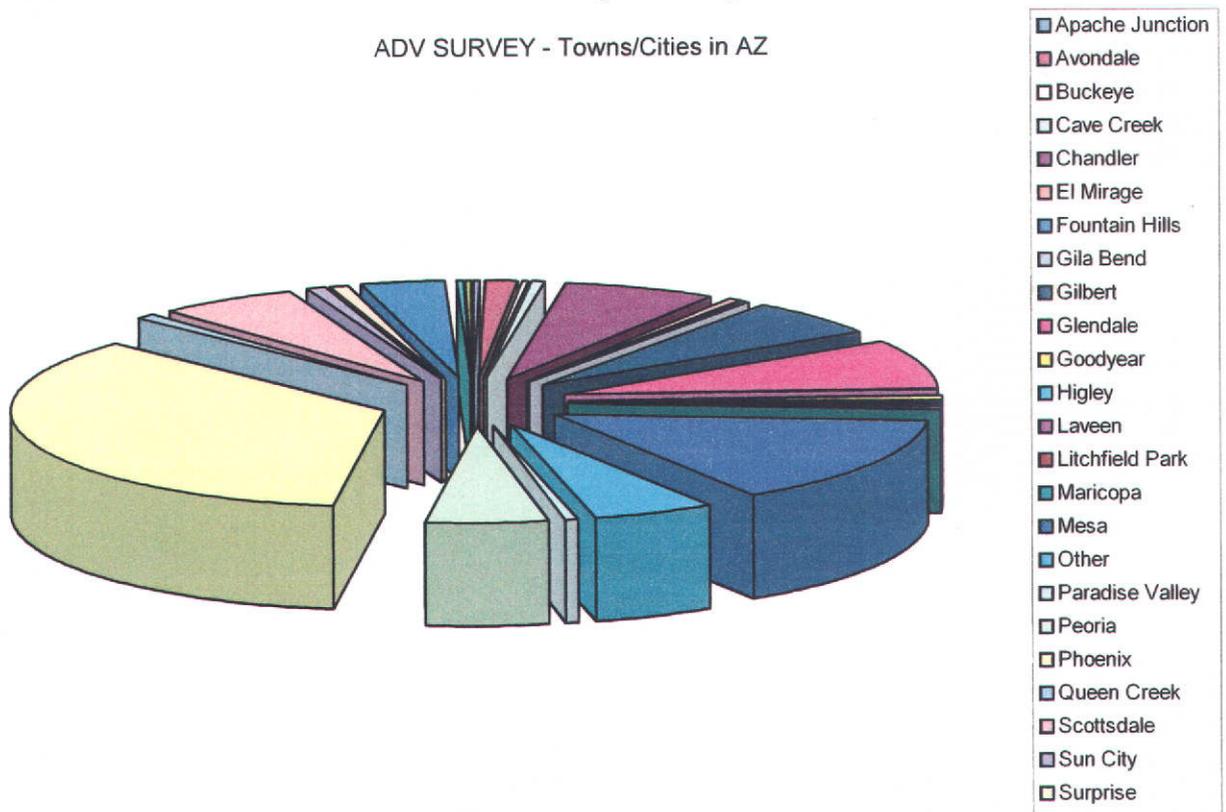
We have made progress in the decade of the 1990’s and beyond. We will try to capture consumer needs and their satisfaction with services in this report from the Quality of Life Survey of 2004.

**Survey Results**

**Geographic Distribution**

**Figure 1: Cities and Towns of Residence in Maricopa County**

ADV SURVEY - Towns/Cities in AZ



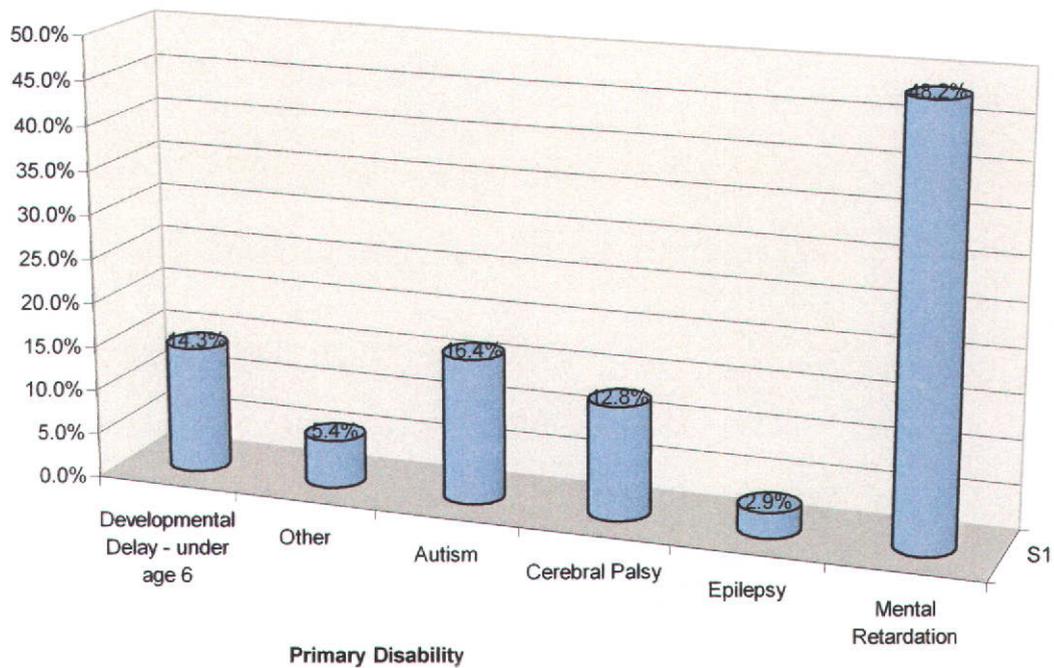
The survey was sent to people living in Maricopa County and enrolled with the Division of Developmental Disabilities for services. Most of the 2076 people that responded to the

survey listed the city or town of residence. **Figure 1, “Cities and Towns of Residence in Maricopa County”** lists the cities and towns of residence and shows the percentage of survey respondents residing in each.

Primary Disability

The survey asked for primary and secondary disabilities to be filled in on a blank space. We have merged the various disabilities into the broad categories of 1) mental retardation, 2) cerebral palsy, 3) epilepsy and 4) autism, because these are the categories of eligibility through the Division. For those respondents who did not fit into one of the four categories we have assumed they qualified under the developmental delay criteria for children up to age six. Secondary disabilities include many disabling conditions and we have not isolated these percentages because we are most interested in the primary disability as the qualifying factor for services for the Division.

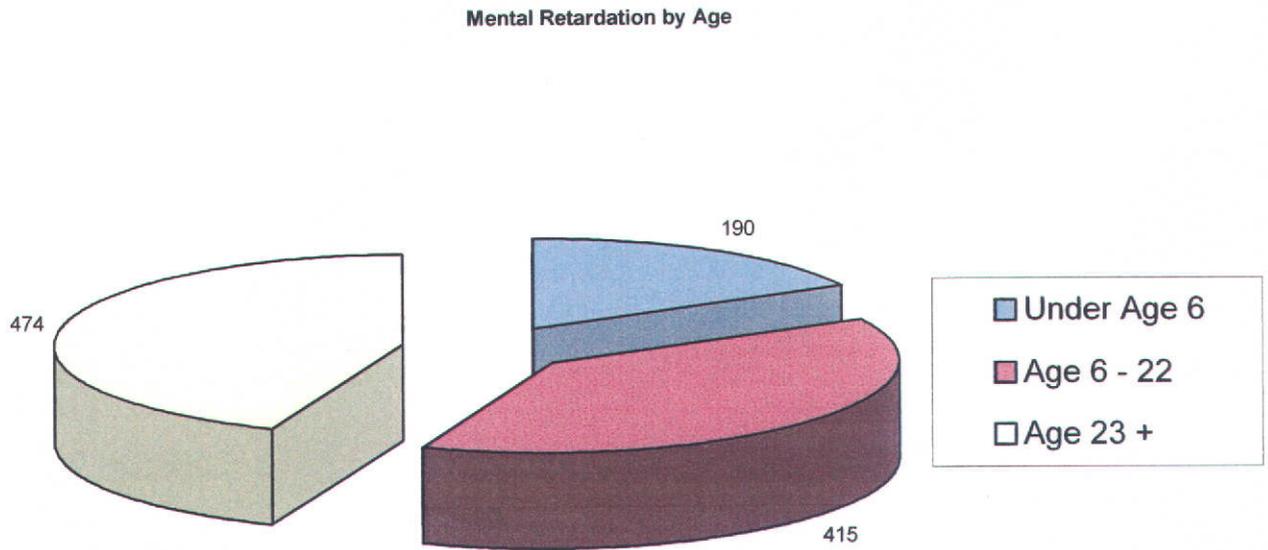
**Figure 2: Primary Disability**



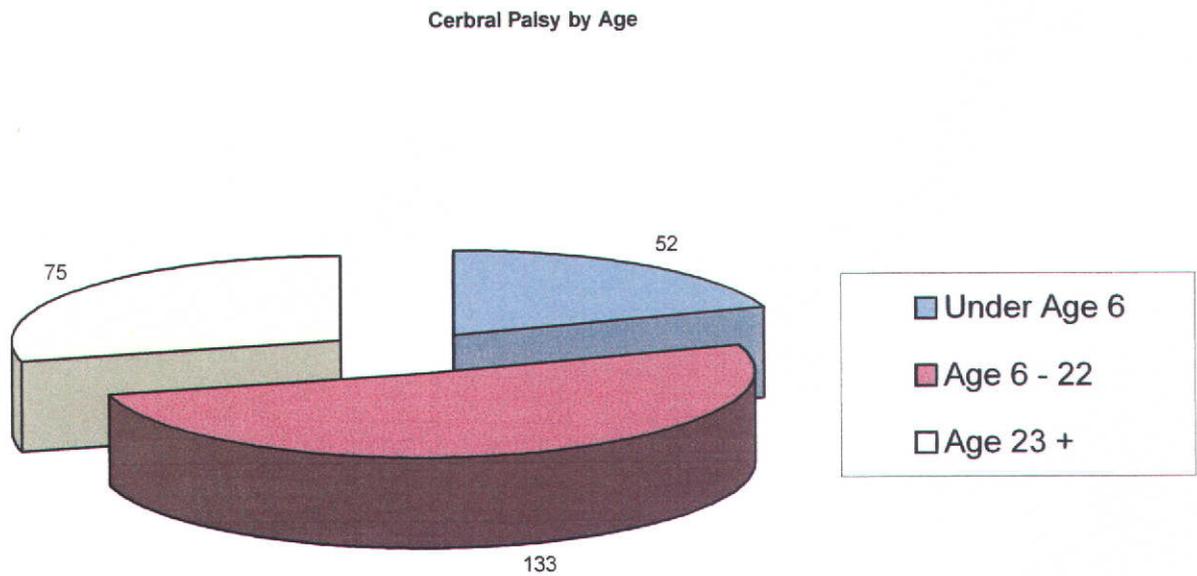
Age by Category of Disability

The following figures show the age of individuals in the four disability categorical areas including: those under age six, those who are school age from age six through twenty-two, and those who are adults of age twenty-three and older.

**Figure 3: Mental Retardation by Age (Total Number= 1079)**

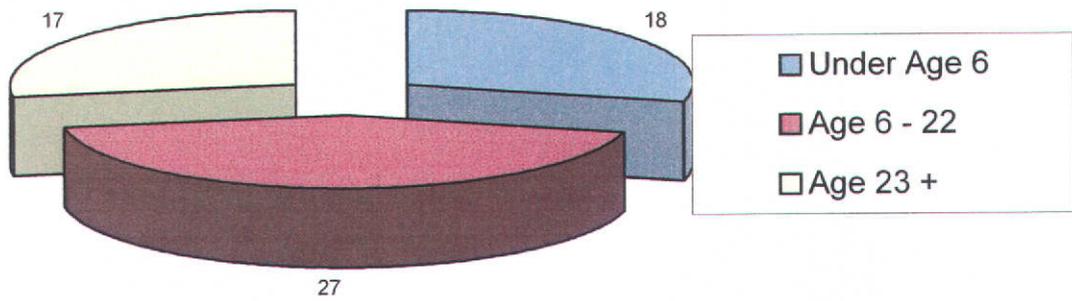


**Figure 4: Cerebral Palsy by Age (Total Number = 280)**



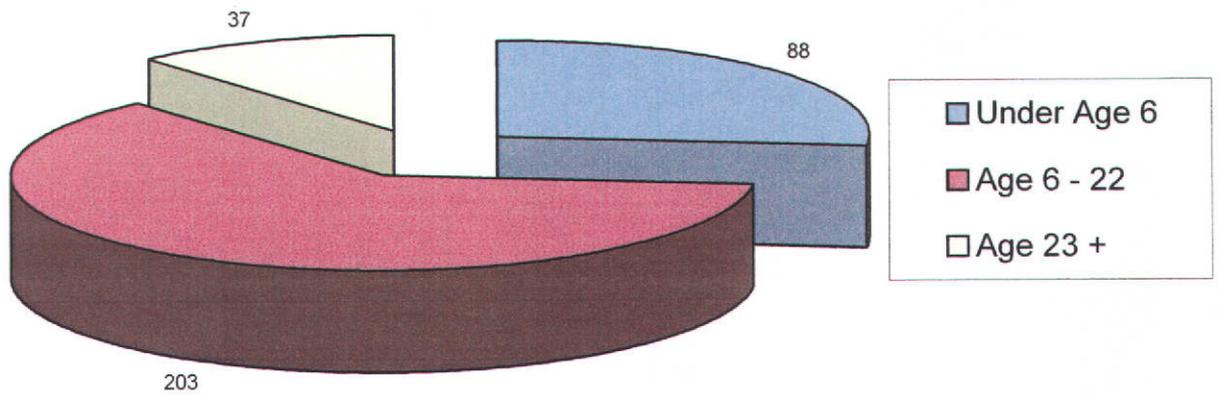
**Figure 5: Epilepsy by Age (Total Number = 62)**

**Epilepsy By Age**



**Figure 6: Autism by Age (Total Number = 328)**

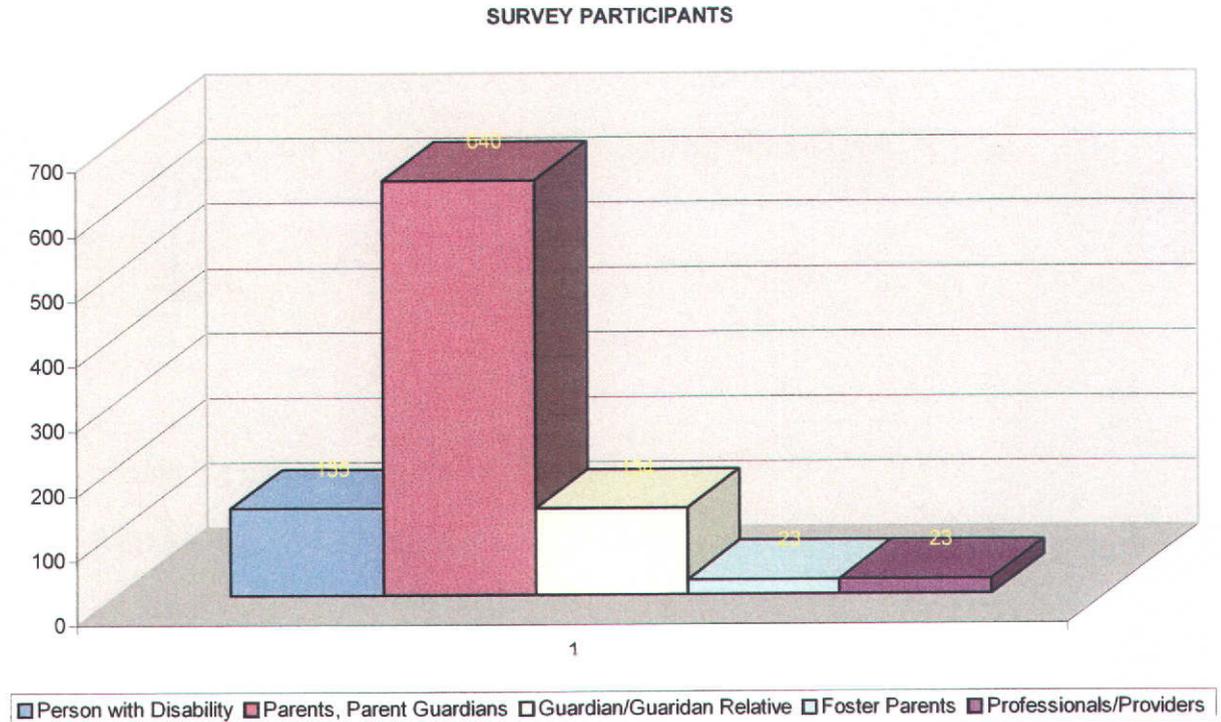
**AUTISM BY AGE**



## Survey Participants

Figure 7 is a graph of five categories of people who actually filled out the survey. We can see that the large majority of 640 respondents out of the total of 955 who filled in this question were parents or guardians. It is interesting that approximately the same number of consumers that filled out the survey themselves equaled the number of guardians or relatives other than parents who responded to this question. A small number of surveys were filled out by foster parents or professionals/providers.

**Figure 7: Survey Participants**



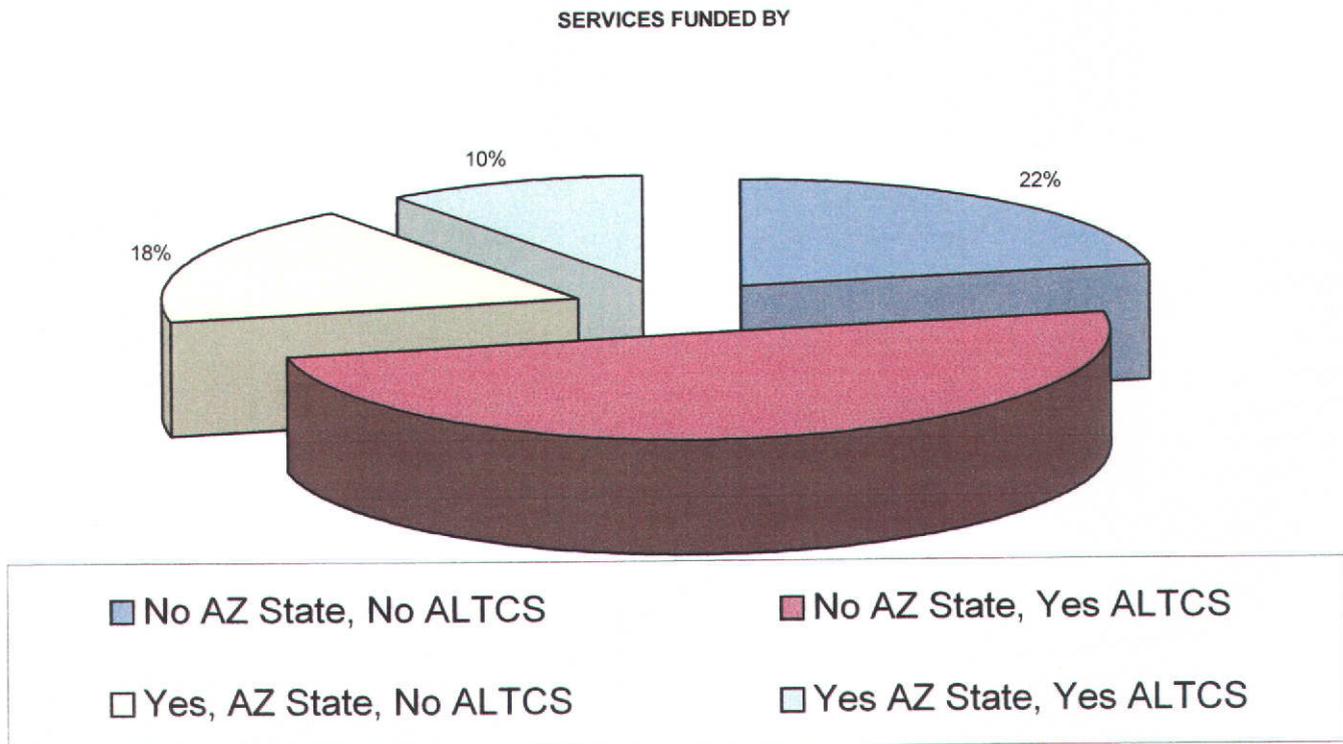
## State Only Funded or AZ Long Term Care System (ALTCS)

The State of Arizona has a two-tier system according to the funding source of care: *state only* eligible or *Arizona long term care* eligible. One of the eligibility categories mentioned above need to be met by all people to receive services through the Division. Those who are deemed lower functioning may qualify for the federal Medicaid program from Title XIX of the Social Security Act. The Arizona Long Term Care System (ALTCS) program, Medicaid and Title XIX are all interchangeable terms for the same program, which is funded through state funds and matching federal funds from the federal Medicare/Medicaid program. The ALTCS program was started in Arizona in 1988 for people with developmental disabilities, as well as the elderly and the physically disabled. Most all of the increased state funding since 1988 for people with developmental disabilities has gone for the match dollars required for the federal

program. The State of Arizona has been able to increase services for many people, because of these federal dollars. The State match is approximately 32% to draw down a 68% federal dollar. Individuals who are higher functioning who do not qualify for the ALTCS program are eligible for state only funded services. Unfortunately, these individuals are often on a waiting list because there has been very little additional state only funding for over seventeen years.

Currently this means there are no State only funded services for children age three through six unless they are ALTCS eligible. Families of school age children need services beyond the scope of the school district's responsibility such as respite, habilitation and attendant care. It also means there are waiting lists for day programs and employment services for adults. Parents who have kept their children with disabilities at home all of their lives cannot get transition or emergency services when the parents are failing. Figure 8 below shows the number of people who responded to the survey who are *state only* eligible or ALTCS eligible. Figure 8 shows that 50 % of respondents, are receiving services from the federally funded ALTCS program. An additional 10% get funding from the ALTCS program as well as some dollars from the *state only funds*. The figure shows that 18 % are receiving services from *state only* funding and that 22% are enrolled in the program but getting no services. In some cases people choose not to get services for a time. However, it is mostly due to no services or appropriate service available.

**Figure 8: Eligibility for State Only Funding or ALTCS**



### Importance of Division Services

Figure 9 shows a ranking of low, medium and high importance of services generally offered by the Division as judged by survey respondents. The percentages in the N/A (not applicable) column meant those consumers and family members did not need that particular service. Therapies were ranked as the very highest with habilitation and respite next. Summer programs and day programs were the third highest. The number of respondents is greatest in respite and speech services. This is not surprising, as parents and guardians need a break as caregivers. We know from other sources that speech therapy is not readily available and is sought after for many who are in need of it. (There is a margin of error of 1% -2% with the following percentages.)

**Figure 9:** Division of Developmental (DDD/Division) Services:  
Please rank importance of services you are interested in below.

|                       | N/A | Low | Moderate | High | Total Respondents |
|-----------------------|-----|-----|----------|------|-------------------|
| Respite               | 16% | 9%  | 15%      | 60%  | 1604              |
| Habilitation          | 21% | 7%  | 11%      | 61%  | 1509              |
| Attendant care        | 38% | 16% | 10%      | 36%  | 1375              |
| Speech therapy        | 6%  | 6%  | 8%       | 70%  | 1596              |
| Occupational therapy  | 3%  | 8%  | 14%      | 75%  | 1342              |
| Physical therapy      | 8%  | 12% | 14%      | 66%  | 1223              |
| Music therapy         | 1%  | 16% | 24%      | 59%  | 1125              |
| Housekeeping          | 48% | 18% | 14%      | 20%  | 1326              |
| Day programs          | 29% | 12% | 12%      | 47%  | 1485              |
| Day care              | 47% | 15% | 10%      | 28%  | 1328              |
| After school programs | 39% | 11% | 12%      | 30%  | 1365              |
| Summer programs       | 26% | 7%  | 13%      | 54%  | 1468              |
| Group homes           | 54% | 15% | 9%       | 22%  | 1334              |
| Assisted living       | 57% | 14% | 8%       | 21%  | 1311              |

### Level of Division Services

The level of satisfaction in Figure 10 shows a wide range of satisfaction for the various services. The 1990 Report collected data on satisfaction by disability groups and not by specific services. The overall level of satisfaction with Division services was 73% (1990 Report Executive Summary page 8). The question below of "Does the level of service from DDD/Division meet your needs?" is much more pointed than "are you satisfied with the Division services". We have also had tremendous population growth in Maricopa County since 1990 and comparable growth in the DD population. In addition, the Federal Medicaid/ALTCS program had just started in Arizona in December of 1988 for people with developmental disabilities. Although the ALTCS program has served many more people than were served in 1990, it has also left behind those not eligible for long term care or ALTCS. Over 50% of the respondents checked by program that they

had no service in almost half of the categories listed. Many of these are probably state only eligible and therefore have no funding which results in no service.

Of the three hundred fifty five people who needed group home service only 20% checked adequate. However, of those that received services 62.5% indicated the service was adequate. In addition, 8% checked that the service was too low to meet their needs, 4% got case management only and 68% checked no service. These may be the individuals who have lived at home all their lives and their parents are elderly or dying. There are not enough funds for these emergencies, let alone money for transition planning for new living arrangements for when the parents die.

**Figure 10: DDD Services:**  
**Does the level of service from DDD meet your needs? (Check ONLY those services you are using)**

|                       | Total # | No Service | Case Manag. Only | Too Low | Adequate |
|-----------------------|---------|------------|------------------|---------|----------|
| Respite               | 1155    | 7%         | 12%              | 14%     | 67%      |
| Habilitation          | 986     | 21%        | 4%               | 13%     | 62%      |
| Attendant care        | 604     | 36%        | 3%               | 9%      | 52%      |
| Speech therapy        | 1073    | 27%        | 3%               | 18%     | 52%      |
| Occupational therapy  | 1019    | 21%        | 4%               | 15%     | 60%      |
| Physical therapy      | 848     | 29%        | 3%               | 11%     | 57%      |
| Music therapy         | 688     | 50%        | 2%               | 12%     | 36%      |
| Housekeeping          | 410     | 72%        | 3%               | 8%      | 17%      |
| Day programs          | 617     | 43%        | 4%               | 10%     | 43%      |
| Day care              | 408     | 60%        | 3%               | 12%     | 17%      |
| After school programs | 485     | 59%        | 2%               | 17%     | 22%      |
| Summer programs       | 658     | 41%        | 2%               | 23%     | 34%      |
| Group homes           | 355     | 68%        | 4%               | 8%      | 20%      |
| Assisted living       | 301     | 80%        | 4%               | 5%      | 11%      |

(See Appendix B for Comment from this area of the survey.)

#### Availability of Division Providers

One of the major problems in getting service is that there are no providers available. In a good economic climate jobs are readily available. Some people would say it is a lot easier to work at McDonald's than to provide respite or attendant care for people with disabilities. The flipping burgers job probably has a higher salary with less training needed. In Figure 11 the only service listed at over 50% adequate is Day Programs at 60%. The range is from 60% to 27% of people who can always depend on a qualified provider for the various services. The average is only 31% for providers always being available for authorized service needs. The table average for frequently qualified providers is 17%. Providers available in sometimes, rarely and never categories are from 6% to 43% of the time.

**Figure 11: DDD Services:  
Are Qualified Providers available for your authorized service needs? (Check ONLY those you need)**

|                      | Total | Never | Rarely | Sometimes | Frequently | Always |
|----------------------|-------|-------|--------|-----------|------------|--------|
| Respite              | 1053  | 7%    | 14%    | 22%       | 21%        | 36%    |
| Habilitation         | 810   | 10%   | 13%    | 20%       | 20%        | 37%    |
| Attendant care       | 406   | 10%   | 9%     | 11%       | 18%        | 52%    |
| Speech               | 961   | 20%   | 12%    | 13%       | 18%        | 37%    |
| Occupational therapy | 898   | 13%   | 10%    | 12%       | 22%        | 43%    |
| Physical therapy     | 710   | 14%   | 7%     | 11%       | 21%        | 47%    |
| Music therapy        | 489   | 14%   | 13%    | 10%       | 17%        | 46%    |
| Housekeeping         | 168   | 43%   | 10%    | 11%       | 9%         | 27%    |
| Day programs         | 412   | 4%    | 9%     | 11%       | 16%        | 60%    |
| Summer programs      | 481   | 20%   | 16%    | 19%       | 18%        | 27%    |
| Group homes          | 159   | 32%   | 9%     | 6%        | 19%        | 34%    |
| Assisted living      | 107   | 43%   | 10%    | 6%        | 10%        | 31%    |

### Education Services

Over 1000 of the 2076 respondents ranked their school on the items in figure 12. From these numbers we can assume that approximately one-half of the respondents were of school age. In education the individual education plan (IEP), which is a plan of goals and objectives, drives the system. That means if the IEP team has agreed on an appropriate plan for the education and training of the special education student then the local school is required to implement the plan. In the *development of the IEP* the respondents checked “good” or “very good” in 67% of the time. For *implementation of IEP plans* they checked “good” or “very good” in 62% of the time. The majority of respondents reported that the system works well. However, 19% checked average and 14% and 18% respectively checked either fair or poor in regard to IEP development and implementation.

Of the total respondents, about half, or 528 ranked the area of vocational training and 777 ranked extended school year services. Students generally need to be over 14 years of age to get vocational services and students need to have retention or other learning problems to qualify for extended school year services. These services are generally offered during summer vacation. Respondents checked *vocational training* as the lowest for services, followed by *aid training*, *aid availability* and *availability of therapies*. Only 43% ranked vocational training to be “good” or “very good”. This lack of transition services from school to work shows up in students in special education when they graduate from high school as adults at usually age 21. Special education is available for up to age 22 and many students take advantage of the additional time to help prepare them for life.

Teacher training was ranked at 65% for “good” or “very good”. No Child Left Behind should help in the area where teacher training was ranked 18% for “fair” or “poor”. Studies show that the teacher is the most positive influence in learning.

**Figure 12: Education**

**Please rank your school system in the following areas:**

|   | Total | Poor | Fair            | Average     | Good        | Very Good    |
|---|-------|------|-----------------|-------------|-------------|--------------|
| Development of IEP Plans  | 1107  | 6%   | 8%              | 19%         | 32%         | 35%          |
| Implementation of IEP plans   | 1126  | 8%   | 10%             | 20%         | 31%         | 31%          |
| Teacher training  | 1115  | 9%   | 9%              | 15%         | 28%         | 37%          |
| Aide training   | 1065  | 13%  | 12%             | 17%         | 28%         | 29%          |
| Aide availability   | 1045  | 14%  | 12%             | 18%         | 27%         | 28%          |
| Availability of therapies   | 1071  | 14%  | 13%             | 20%         | 28%         | 9%           |
| Transportation options  | 1020  | 7%   | 7%              | 16%         | 33%         | 37%          |
| Vocational training   | 528   | 19%  | 13%             | 21%         | 23%         | 23%          |
| Extended school year:   |       |      |                 |             |             |              |
| Availability  | 777   | 21%  | 10%             | 18%         | 24%         | 26%          |
| Appropriateness of options  | 754   | 24%  | 13%             | 19%         | 22%         | 21%          |
| Fairness of qualifying criteria   | 777   | 20%  | 12%             | 19%         | 27%         | 32%          |
| Extent of discrimination at school due to disability:<br>Number of respondents = 1011 |       |      | Frequent<br>10% | Some<br>20% | Rare<br>27% | Never<br>43% |

Recreation Services

Figure 13 shows the importance of recreation with large numbers filling in this section of the survey. The availability and adequacy of recreation areas below show more responses for “poor” than “very good” in every case. Other checks are fairly evenly divided from the range of “poor” to “very good”. Obviously the responses show there is a real need for recreational opportunities for people with developmental disabilities served by the State of Arizona.

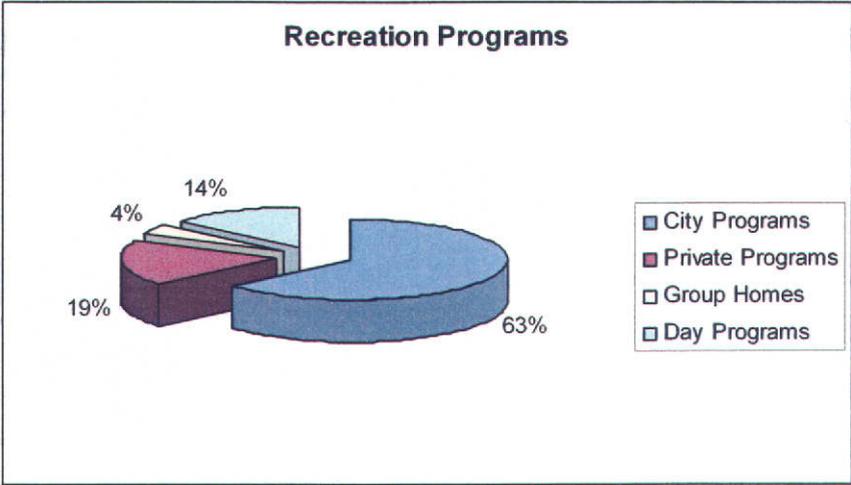
**Figure 13: Recreation**

**Please rank recreational opportunities:**

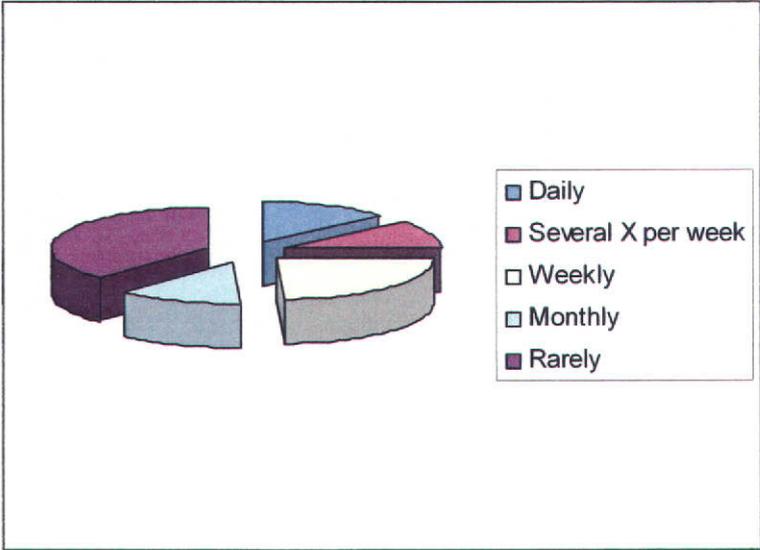
|   | Poor | Fair | Average | Good | Very Good |
|---|------|------|---------|------|-----------|
| Variety of options available  | 7%   | 20%  | 20%     | 20%  | 14%       |
| Adequate opportunities for interaction with typical peers   | 26%  | 19%  | 19%     | 21%  | 15%       |
| Adequate programs solely for people with special needs (i.e., special Olympics, special needs softball teams, etc.) | 27%  | 17%  | 20%     | 19%  | 16%       |

**Totals:** Variety = 1220, Adequate Peer Interaction = 1416, Adequate Programs = 1325

The pie charts below show a break out of where individuals obtain recreation services and how frequently they participate in programs or activities.



How frequently do you participate in programs or activities?



### Employment Services

The greatest barrier to employment, according to the respondents would seem to be job availability. Over half of the people ranked "poor" or "fair" for *job availability* with 40% checking the poor category. The numbers were very low that use employment services. We have estimated above that about half of the respondents are school age so that would account for part of the low numbers. The other reason may be that there are large waiting lists for vocational services as documented in other sources. The other percentages were very similar and fairly evenly distributed from "poor" to "very good" for *job training, job coaches and sheltered employment*.

**Figure 14: Employment/ Work: Please rank services you use.**

|  | Total | Poor | Fair | Average         | Good        | Very Good   |              |
|--|-------|------|------|-----------------|-------------|-------------|--------------|
| Job training   | 210   | 20%  | 14%  | 15%             | 25%         | 24%         |              |
| Job coaches  | 206   | 22%  | 13%  | 18%             | 20%         | 25%         |              |
| Job availability   | 198   | 40%  | 16%  | 14%             | 15%         | 13%         |              |
| Sheltered workshop availability  | 191   | 23%  | 11%  | 14%             | 28%         | 21%         |              |
| Adequate accommodations for people with special needs?                             | 247   | 19%  | 16%  | 19%             | 22%         | 22%         |              |
| Extent of discrimination at work due to disability?<br>Number of respondents = 315 |       |      |      | Frequent<br>15% | Some<br>17% | Rare<br>14% | Never<br>52% |

### Transportation

It is not surprising that the lowest ranked area of service was transportation. Arizona is getting better, but has been slow in establishing transit programs. We were surprised that *ADA dial-a-ride*, which is supposed to be a higher level of specialized service, for people who qualify was checked as "poor" by 44% of respondents. Actually it was also 44% for "poor" for the regular *dial-a-ride*. In other transportation areas of *public busses, service on time* and *wait time* the "very good" rankings were also far below the rankings for "poor". Figure 15 below shows the specific percentage rankings of each category.

**Figure 15: Transportation**

**Please check and rank public transportation services you rely on:**

|                 | Total | Poor | Fair | Average | Good | Very Good |
|-----------------|-------|------|------|---------|------|-----------|
| ADA Dial A Ride | 209   | 44%  | 10%  | 14%     | 20%  | 11%       |
| Dial A Ride     | 248   | 44%  | 13%  | 18%     | 15%  | 10%       |
| Public Busses   | 340   | 25%  | 15%  | 19%     | 23%  | 16%       |
| Service on Time | 341   | 30%  | 15%  | 18%     | 22%  | 14%       |
| Wait Time       | 307   | 40%  | 17%  | 18%     | 16%  | 8%        |

## Medical

Almost three-fourths (1455) of the respondents apparently use the Arizona Health Care Cost Containment (AHCCCS) system for their *health care provider*. A total of 74% checked "good" or "very good" for this service. Only 11% checked "poor" or "fair". When Arizona started the Federal Medicaid Program, called the Arizona Long Term Care System (ALTCS) in 1988 it was bundled with the acute health care program for people with developmental disabilities who qualify. AHCCCS, the Division of Developmental Disabilities, advocates and families have worked very hard for a number of years to improve the services so we are glad to see the high rankings in *health care providers*. Even *choice of health care providers* is high with 64% ranking "good" and "very good" and only 7% ranking poor.

The percentages of satisfaction were not nearly so high in the behavioral health area, however. The numbers show that we have a long way to go in this area including the *knowledge of dual diagnosis of developmental disability and behavioral health*.

As we analyze this data we are sorry we did not collect information on dental care. The Advisory Council is aware of problems of getting dental care for adults with developmental disabilities. Dental care is covered for children through the ALTCS program, but there is no coverage for adults with developmental disabilities in the State of Arizona through the Medicaid program. Adult dental care for people served through ALTCS could be a selected service to be covered in the future.

**Figure 16: Medical**  
**Please rank services you use:**

|  | Total | Poor | Fair | Average | Good | Very Good |
|--|-------|------|------|---------|------|-----------|
| AHCCCS health care provider  | 1455  | 4%   | 7%   | 15%     | 35%  | 39%       |
| Choice of health care provider   | 1350  | 7%   | 9%   | 16%     | 33%  | 34%       |
| Adequate number of health care Providers?                                      | 1325  | 11%  | 10%  | 19%     | 34%  | 26%       |
| Level of knowledge of disability of health care provider?                      | 1346  | 11%  | 12%  | 18%     | 28%  | 21%       |
| Psychiatric care   | 581   | 17%  | 13%  | 17%     | 29%  | 21%       |
| Behavioral health care   | 570   | 21%  | 14%  | 18%     | 29%  | 21%       |
| Knowledge of dual diagnosis of Developmental disability and Behavioral health? | 751   | 20%  | 12%  | 18%     | 26%  | 23%       |
| Adequate Review of Medications?  | 966   | 9%   | 10%  | 15%     | 30%  | 30%       |

### Development of a Pilot Program for Individuals with Autism

Over 500 people responded to the section and ranked interest in a pilot program to be developed by the Division on Developmental Disabilities on autism and behavior.

APPENDIX A

# 1990 SUMMARY REPORT

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## OVERVIEW OF THE SERVICE SYSTEM

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### Division of Developmental Disabilities

The Division of Developmental Disabilities (DDD), within the Department of Economic Security, is the primary agency in Arizona which provides individual and family support to people with developmental disabilities. The Division provides program services to children and adults with developmental disabilities who live in a variety of settings including group homes, family homes, relative or guardian homes, or in independent living situations. State law requires, and Division policy affirms, the right of each person with developmental disabilities to be in the least restrictive environment for receiving services.

In defining its target service group the DDD follows the Arizona statute in its definition of developmental disabilities, which is more restrictive than the federal definition. Arizona statute requires one of four disabilities to be eligible to receive services: mental retardation, cerebral palsy, epilepsy or autism. Substantial functional limitations in three or more of the following areas of major life activity also must occur: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.

Eligible individuals must also be a resident of the state of Arizona and the disability must have occurred before the age of 18. Individuals who have a primary hearing, vision, or physical disability, or who have a serious emotional or mental illness are not eligible for the Division's services under the state definition.

Eligibility requirements are more flexible for infants and young children under the age of 37 months. These individuals can receive services if it is determined there is a significant risk that they may become developmentally disabled, based upon an observed significant delay in one or more areas of development, or if there is the likelihood that without services they will become developmentally disabled. Children 37 months to school age are eligible if it is determined they are experiencing a significant delay in one or more areas of development and there is a probability of becoming developmentally disabled without services.

Services provided by the Division of Developmental Disabilities include case management, adult residential and support services, and programs for children and families. Adult services include a variety of day programs which range from rehabilitation instructional services and adult day care to supported employment. Residential programs include state institutions, foster care, community based group homes, and various semi-independent living arrangements. Children's programs include family-based services such as developmental day training and summer programs. Support to individuals and their families includes physical therapy, occupational therapy, speech therapy, respite care, counseling, medical assistance, transportation, community living support, and recreation and socialization programs. All children and adults receiving services have an individual program plan (IPP) that specifies services to be provided. This program is initiated and monitored by the case manager.

APPENDIX B

# 2004-2005 Quality of Life Survey

## Comments

### Does the level of DD service meet your needs?

We are able to work around

Speech therapist resigned from company. Difficult to find a replacement

Therapies are 30 min to & from home. I spend as much time driving as she gets service. Music at school. There are not a lot of people available - so I have gone long periods of time without respite/habilitation

Do not receive any services listed

Summer program - nothing appropriate for my child. He has qualified but I can't find a program that has children like him in it.

Music therapy - just starting

Quite a lot - no respite or habilitation services in immediate area (Ahwatukee)

I live in a rural area, and I have too many limitations for providers. I feel discriminated against just because I live 8 miles from the center of our little tow. People aren't willing to come and help me

I have the DD "hours" for service do not have the providers

There is a great deal of turnover with workers

Two years ago PT was prescribed have never seen despite PCs to office (DD). I am at the point where I will have to file a grievance

Not able to be gone long enough!

We use Hope Group - shortage of providers on West Side of town

Speech therapy - on waiting list. A sick hab worker is distressful for a working mom.

Although I receive adequate hours for respite , hab and attendant care I cannot find anyone to provide the service.

Not eligible for services due to more than \$2000 in named account

We get no services none were explained case managed only.

No impact.

Music Therapy: Just starting on waiting list 2 1/2 years

No services

When therapist is not available we receive no services

Cont. 2: Needs

An extra nurse for respite might help us in our case.

Hard to find qualified providers

Impossible to get a therapist, so I gave up.

I only hear from our case manager when a new one is assigned

DI program unable to work with family. Second EI program has taken more than 3 months to contact patient to resume services.

Having parents sign "time-card" for therapists might promote less cancellations.

The only problem we have encountered is complaints by our attendance care person that checks for payment are continually late or lost and she is paid only after numerous calls to DDD

The main summer program we used for years - Gilbert Parks & Rec Summer Playground Program, was cancelled this year, purportedly due to "funding problems."

We may not be able to take as long a vacation as we would like to.

Not impacting services

The visits are usually made up if therapist misses.

None as no PT/OT/Speech or Staff or Contract to service

We have not been able to receive services for over a year now. I know other parents with "higher functioning" children who are? Have spoken with many different people from DDD & ALTCS about this.

You have been unable to help me find appropriate program or service in my area.

You have been unable to help me find appropriate program or service in my area.

No problem

\_\_\_\_\_ gets sick all the time because he had R.S.F. when he 2 months old. Now he has Bronchitis always bother him.

He has received speech, OT, Summer Programs in the past. His school now provides Speech, OT, Music therapy.

Need assistance in finding a home for \_\_\_\_\_.

Not at all.

Looking for new O.T.

Each therapist should have an alternate so that the appointments can go on and therapy is not interrupted.

Number of staff is sometimes not adequate.

APPENDIX C

# Quality of Life Survey

**Please fill in the following information:**

Are you a person with a developmental disability? Yes \_\_\_\_\_ No \_\_\_\_\_  
 If no, Please check (X) your relationship to a person with a developmental disability:  
 Parent \_\_\_\_\_ Guardian \_\_\_\_\_ Relative \_\_\_\_\_ Professional \_\_\_\_\_ Other \_\_\_\_\_  
 Person's Primary Developmental Disability: \_\_\_\_\_  
 Secondary Disability if there is one: \_\_\_\_\_  
 Person's age \_\_\_\_\_ Sex: M \_\_\_\_\_ F \_\_\_\_\_ National Origin \_\_\_\_\_  
 Place of Residence: (city) \_\_\_\_\_ # of Years in Arizona \_\_\_\_\_  
 Name (optional) \_\_\_\_\_  
 Mailing Address (optional – we will send you a summary of the survey results): \_\_\_\_\_

E-mail (optional – we will send you a summary of the survey results if listed): \_\_\_\_\_

Telephone (Optional) We will keep you informed of events and issues: \_\_\_\_\_

**PLEASE CHECK BOX for Programs this individual is eligible for:**

AZ State Only  ALTCS/Title XIX (19)/LTCare/Medicaid

**Division of Developmental (DDD/Division) Services:**

**Please rank importance of services you are interested in below.**

|                       | N/A | Low | Moderate | High | Very High |
|-----------------------|-----|-----|----------|------|-----------|
| Respite               |     |     |          |      |           |
| Habilitation          |     |     |          |      |           |
| Attendant care        |     |     |          |      |           |
| Speech                |     |     |          |      |           |
| Occupational therapy  |     |     |          |      |           |
| Physical therapy      |     |     |          |      |           |
| Music therapy         |     |     |          |      |           |
| Housekeeping          |     |     |          |      |           |
| Day programs          |     |     |          |      |           |
| Day care              |     |     |          |      |           |
| After school programs |     |     |          |      |           |
| Summer programs       |     |     |          |      |           |
| Group homes           |     |     |          |      |           |
| Assisted living       |     |     |          |      |           |

Comments: (Continue on back if desired)

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**DDD Services:**

**Does the level of service from DDD meet your needs? (Check ONLY those services you are using)**

|                       | N/A | No Service | Case Manag. only | Too Low | Adequate |
|-----------------------|-----|------------|------------------|---------|----------|
| Respite               |     |            |                  |         |          |
| Habilitation          |     |            |                  |         |          |
| Attendant care        |     |            |                  |         |          |
| Speech therapy        |     |            |                  |         |          |
| Occupational therapy  |     |            |                  |         |          |
| Physical therapy      |     |            |                  |         |          |
| Music therapy         |     |            |                  |         |          |
| Housekeeping          |     |            |                  |         |          |
| Day programs          |     |            |                  |         |          |
| Day care              |     |            |                  |         |          |
| After school programs |     |            |                  |         |          |
| Summer programs       |     |            |                  |         |          |
| Group homes           |     |            |                  |         |          |
| Assisted living       |     |            |                  |         |          |

|  |
|--|
| How are absences or vacations impacting your services? |
|  |
| Comments:  |
|  |

**DDD Services:**

**Are Qualified Providers available for your authorized service needs? (Check ONLY those you need)**

|                      | N/A | Never | Rarely | Sometimes | Frequently | Always |
|----------------------|-----|-------|--------|-----------|------------|--------|
| Respite              |     |       |        |           |            |        |
| Habilitation         |     |       |        |           |            |        |
| Attendant care       |     |       |        |           |            |        |
| Speech               |     |       |        |           |            |        |
| Occupational therapy |     |       |        |           |            |        |
| Physical therapy     |     |       |        |           |            |        |
| Music therapy        |     |       |        |           |            |        |
| Housekeeping         |     |       |        |           |            |        |
| Day programs         |     |       |        |           |            |        |
| Summer programs      |     |       |        |           |            |        |
| Group homes          |     |       |        |           |            |        |
| Assisted living      |     |       |        |           |            |        |

|                           |
|---------------------------|
| Comments on DDD services: |
|                           |
|                           |

**DDD Services: DDD or Independent Providers**

If you have a problem finding qualified providers, please check the major reason(s)?

|                            | Never | Sometimes | Always |
|----------------------------|-------|-----------|--------|
| Location                   |       |           |        |
| Low salary                 |       |           |        |
| Providers lack training    |       |           |        |
| Cannot afford to advertise |       |           |        |
| Other                      |       |           |        |

**Education: Please list your school district \_\_\_\_\_**

Please rank your school system in the following areas:

|   | N/A | Poor | Fair | Average  | Good | Very Good |       |
|---|-----|------|------|----------|------|-----------|-------|
| Development of IEP Plans                              |     |      |      |          |      |           |       |
| Implementation of IEP plans                           |     |      |      |          |      |           |       |
| Teacher training                                      |     |      |      |          |      |           |       |
| Aide training   |     |      |      |          |      |           |       |
| Aide availability                                     |     |      |      |          |      |           |       |
| Availability of therapies                             |     |      |      |          |      |           |       |
| Transportation options                                |     |      |      |          |      |           |       |
| Vocational training                                   |     |      |      |          |      |           |       |
| Extended school year:                                 |     |      |      |          |      |           |       |
| Availability  |     |      |      |          |      |           |       |
| Appropriateness of options                            |     |      |      |          |      |           |       |
| Fairness of qualifying criteria                       |     |      |      |          |      |           |       |
| Extent of discrimination at school due to disability: |     |      |      | Frequent | Some | Rare      | Never |
| Comments:   |     |      |      |          |      |           |       |
|   |     |      |      |          |      |           |       |
|   |     |      |      |          |      |           |       |
|   |     |      |      |          |      |           |       |

**Recreation:**

Please rank recreational opportunities:

|   | Poor | Fair | Average | Good | Very Good |
|---|------|------|---------|------|-----------|
| Variety of options available  |      |      |         |      |           |
| Adequate opportunities for interaction with typical peers   |      |      |         |      |           |
| Adequate programs solely for people with special needs (i.e., special Olympics, special needs softball teams, etc.) |      |      |         |      |           |

**Please Check the following areas:**

Do you primarily rely on recreational programs from:

\_\_\_ city programs \_\_\_ private programs \_\_\_ group homes \_\_\_ day programs

How frequently do you participate in programs or activities?

\_\_\_ Daily \_\_\_ Several times/week \_\_\_ weekly \_\_\_ monthly \_\_\_ rarely

|           |
|-----------|
| Comments: |
|           |
|           |
|           |

**Employment/ Work: Please rank services you use.**

|  | None | Poor | Fair     | Average | Good | Very Good |
|--|------|------|----------|---------|------|-----------|
| Job training   |      |      |          |         |      |           |
| Job coaches  |      |      |          |         |      |           |
| Job availability                                       |      |      |          |         |      |           |
| Sheltered workshop availability                        |      |      |          |         |      |           |
| Adequate accommodations for people with special needs? |      |      |          |         |      |           |
| Extent of discrimination at work due to disability?    |      |      | Frequent | Some    | Rare | Never     |

|           |
|-----------|
| Comments: |
|           |
|           |
|           |
|           |

**Transportation:**

**Please check and rank public transportation services you rely on:**

|                 | Poor | Fair | Average | Good | Very Good |
|-----------------|------|------|---------|------|-----------|
| ADA Dial A Ride |      |      |         |      |           |
| Dial A Ride     |      |      |         |      |           |
| Public Busses   |      |      |         |      |           |
| Service on Time |      |      |         |      |           |
| Wait Time       |      |      |         |      |           |

**Medical:**

**Please rank services you use:**

|  | None | Poor | Fair | Average | Good | Very Good |
|--|------|------|------|---------|------|-----------|
| AHCCCS health care provider  |      |      |      |         |      |           |
| Choice of health care provider   |      |      |      |         |      |           |
| Adequate number of health care Providers?                                      |      |      |      |         |      |           |
| Level of knowledge of disability of health care provider?                      |      |      |      |         |      |           |
| Psychiatric care   |      |      |      |         |      |           |
| Behavioral health care   |      |      |      |         |      |           |
| Knowledge of dual diagnosis of Developmental disability and Behavioral health? |      |      |      |         |      |           |
| Adequate Review of Medications?  |      |      |      |         |      |           |

**Please List Any Barriers to use of AHCCCS Providers.**

Number of providers: \_\_\_\_\_  
 Location of providers: \_\_\_\_\_  
 Quality of service: \_\_\_\_\_  
 Other: \_\_\_\_\_

**Development of a Pilot Program: Autism Only**

DDD is considering a Pilot Program to allow families to hire skilled consultants to help them with Applied Behavior Analysis (ABA) and Positive Behavior Support (PBS) programs. This Pilot Program would include help with:

- 1) Development of an ABA/PBS program (lists of activities, drills, etc.)
  - 2) Training of Respite/Habilitation providers for the ABA/PBS program
- Continuing oversight of respite/habilitation providers via regular meetings with the program team.

|  | None | Minor | Moderate | High | Very High |
|--|------|-------|----------|------|-----------|
| <b>Please rank the importance of or your interest in such a Pilot Program for People with Autism</b> |      |       |          |      |           |

Please Return Survey To:

PLEASE RETURN BY NOVEMBER 20<sup>TH</sup>, 2003

Advisory Council on Developmental Disabilities  
 Serving Maricopa County  
 1102 East University, Suite 3  
 Mesa, Arizona, 85203

# Advisory Council On Developmental Disabilities



An affiliate of the Governor's Council  
on Developmental Disabilities

Getting The Job Done

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