

**DEPARTMENT OF ECONOMIC SECURITY  
DIVISION OF DEVELOPMENTAL DISABILITIES**

**FAMILY SUPPORT  
ANNUAL REPORT**

July 1, 2007 - June 30, 2008



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DEPARTMENT OF ECONOMIC SECURITY

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*Your Partner For A Stronger Arizona*

## **DIVISION OF DEVELOPMENTAL DISABILITIES**

### **MISSION**

To support the choices of individuals with disabilities and their families by promoting and providing within communities, flexible, quality, consumer-driven services and supports.

### **VISION**

Individuals with developmental disabilities are valued members of their communities and are involved and participating based on their own choices.

### **VALUES**

We Value:

1. Healthy relationships with people;
2. Individual and family priorities and choices;
3. Equal access to quality services and supports for all individuals and families;
4. Partnerships and ongoing communication with individuals, family members, advocates, providers, and community members;
5. Developmental approaches – changing conditions that affect people rather than changing people who are affected by conditions;
6. Individual freedom from abuse, neglect and exploitation with a balance between the right to make choices and experience life and individual safety;
7. A diverse workforce that is motivated, skilled and knowledgeable of and uses the most effective practices known;
8. An environment rich in diversity in which each person is respected and has the opportunity to reach their optimal potential;
9. An individual's right to choose to participate in and contribute to all aspects of home and community life; and
10. A system of services and supports which are:
  - Responsive – timely and flexible responses to internal and external customers;
  - Strength based – recognizing people's strengths, promoting self-reliance, enhancing confidence and building on community assets;
  - Effective – ongoing identification of effective methods and practices and incorporation of those practices into operations; and
  - Accountable – to our customers and to the taxpayers.

**THE KEY TO OUR SUCCESS  
EXCEEDING THE EXPECTATIONS OF OUR CUSTOMERS**

## **I. Introduction**

In 1993, Family Support Legislation (A.R.S. § 36-596.51 et seq.) was passed that defined a family support program in Arizona for people with developmental disabilities and their families, subject to funding appropriations. This legislation was a result of collaboration with families, advocacy organizations, providers of services, and the Department of Economic Security, Division of Developmental Disabilities (Division), in recognition of the significance of family support as a national initiative. While there is no appropriated funding for a family support program in Arizona, the Division integrates the philosophy of the legislation into its activities as indicated in the Mission, Vision, and Values. This Annual Report highlights initiatives and systems that the Division and many collaborators have successfully implemented. It also describes the number of people served and the ways in which they are supported.

Family support is defined as services, supports and other assistance that are provided to families with members who have a developmental disability and are designed to:

- Strengthen the family's role as a primary caregiver;
- Prevent inappropriate out-of-home placement;
- Maintain family unity;
- Reunite families with members who have been placed out of home;
- Include respite care, assistive technology, appropriate personal assistance services, parent training and counseling, vehicular and home modifications and assistance with extraordinary expenses associated with the needs of a person with a developmental disability; and
- Integrate consumers into the community.

## **II. Overview of the Division of Developmental Disabilities**

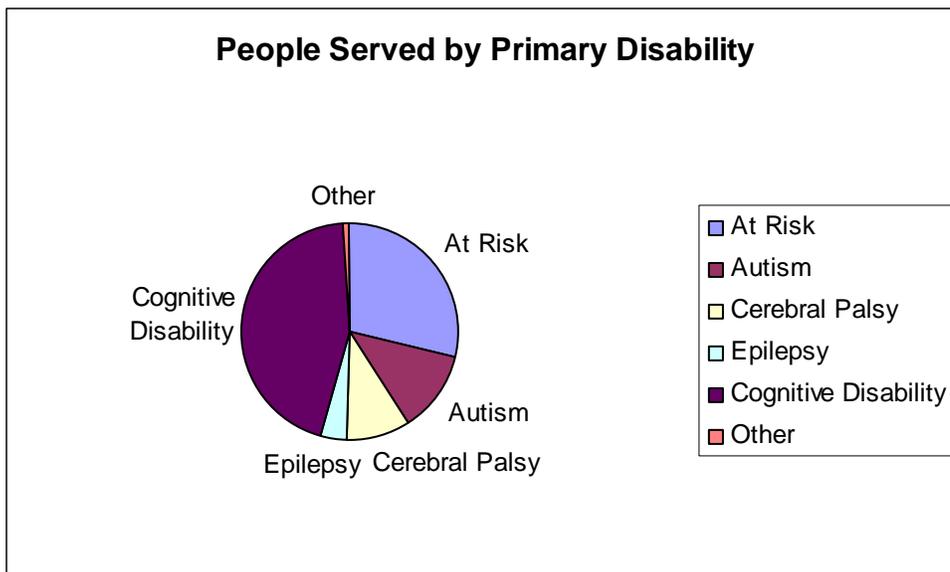
The Division of Developmental Disabilities within the Arizona Department of Economic Security provides services and programs to 29,192 people with developmental disabilities and their families as of June 30, 2008. The Division believes that people can best be supported in integrated community settings and the majority of the Division's programs and services are tailored to meet the individual needs of people with developmental disabilities and their families at home and in community-based settings.

The Division coordinates services and resources through central administrative offices, six district offices and fifty-three local offices located in communities throughout Arizona. These district and local offices promote the use of existing community resources and program flexibility to meet the needs of individuals with developmental disabilities and their families. While some services are delivered directly by the state, most services and supports are delivered through a network of individual and agency providers throughout Arizona.

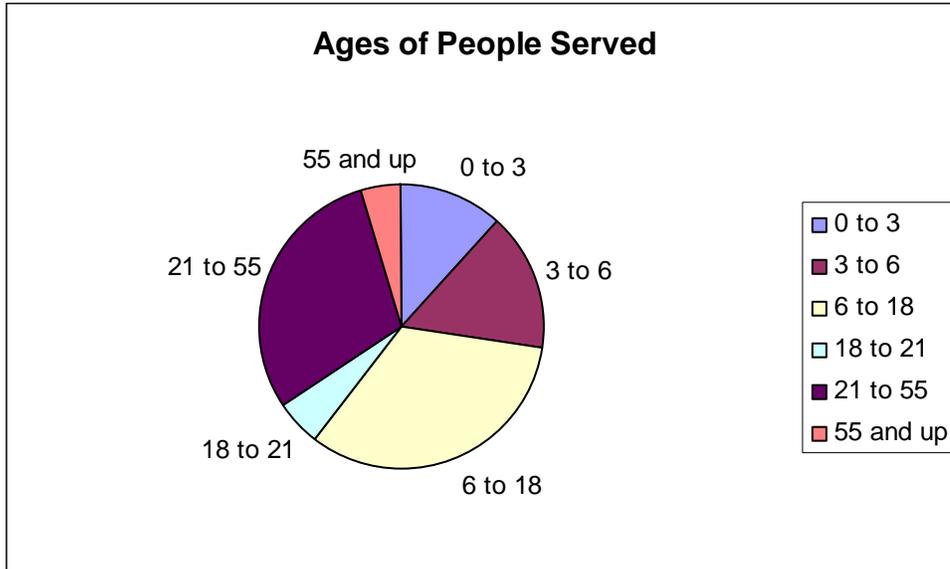
To be eligible for Division services a person must be an Arizona resident and have a chronic disability, which is attributable to a cognitive disability, cerebral palsy, epilepsy or autism that is manifested before the age of 18. The disability must also result in substantial functional limitations in three or more of the following areas of major life activities:

- Self care: needing help with eating, hygiene, etc.
- Receptive and expressive language: needing help with communicating with others
- Learning: needing help with acquiring and processing new information
- Mobility: needing help with moving from place to place
- Self direction: needing help with managing personal finances or making decisions
- Capacity for independent living: needing supervision or assistance on a daily basis
- Economically self sufficient: not being financially independent

Infants and toddlers under the age of six years may be eligible for services if they exhibit a significant delay in one or more areas of development or, for children under the age of three, are determined to be at risk without services. The following graph shows the eligible individuals served by primary disability:



The Division supports people of all ages. The following graph shows the ages of people served:

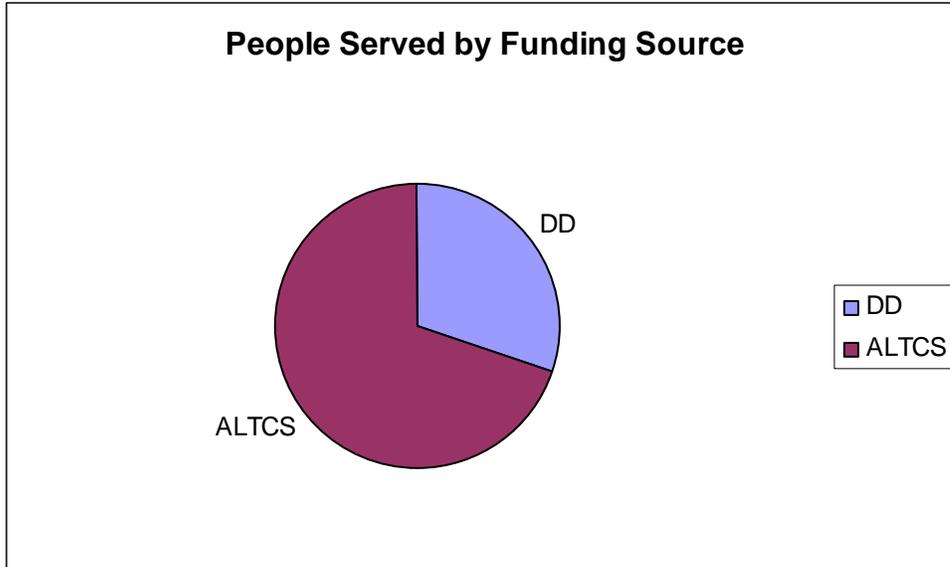


The Division provides services through two primary funding systems: the state funded program and the Arizona Long Term Care System.

The state funded program covers individuals who meet the statutory criteria described above. Under the state funded program, services can only be provided to individuals with developmental disabilities up to the Division's legislative budget appropriation. There is often a waiting list to receive these services. The types of services provided are described in Section III of this report.

Individuals with developmental disabilities who are eligible for services through the Division may also be eligible for services through the Arizona Long Term Care System. The Arizona Health Care Cost Containment System (AHCCCS) determines eligibility for Long Term Care Services through a review of the person's service needs and financial eligibility. The Arizona Long Term Care System is the Medicaid Title XIX program for persons with developmental disabilities who meet the Arizona Long Term Care System (ALTCS) eligibility criteria. The Arizona Long Term Care System provides long term and acute care services to individuals with developmental disabilities who are at risk of institutionalization. It is a research and demonstration program approved through the Federal Centers for Medicare and Medicaid Services and is intended to illustrate that home and community-based services and a managed care approach are more cost effective than institutionalization. Long term and acute care services are bundled under a single system of support coordination in order to coordinate and enhance service delivery. These services are based on assessed needs.

The following graph shows eligible individuals served by funding source:



The Division provides most of its service through a statewide network of profit and non - profit agencies (Qualified Vendors) and individual providers. Services are provided based on the person's identified needs, state and/or federal guidelines and, when applicable, the availability of funds.

### III. Services and Supports

Services generally fall into broad categories as follows:

- Case management (support coordination)

People receive assistance from a support coordinator (case manager) in determining eligibility, assessing needs and obtaining services and supports. Case managers:

- Gather information to help determine eligibility
- Develop, with ideas and suggestions from the person and their family, an Individual Service/Support Plan that identifies the supports and services needed
- Assist the person and family in obtaining the needed services and supports
- Monitor the provision and effectiveness of services
- Provide information about services available from other state and community agencies as well as from private organizations

Targeted Support Coordination is an option for people who are eligible for health care through the Arizona Health Care Cost Containment System and behavioral health services through the contracted Regional Behavioral Health Authority, but are not eligible for ALTCS. This option allows the individual/responsible person to determine the frequency and type of contact he/she wants from the support coordinator. This program does not provide for the other services covered by Long Term Care such as respite, habilitation, etc., but helps connect people with other community services. People who are eligible for Medicaid (Title XIX) are eligible for Targeted Support Coordination.

Many services are available to both people who are eligible for the Arizona Long Term Care System and to people who only qualify for the state funded developmental disability services. The state funded program offers essentially the same services as does the Arizona Long Term Care program except for acute and behavioral health services. An asterisk (\*) below indicates services that are for Arizona Long Term Care members only.

- Augmentative Communication Devices (devices that help a person communicate like a notebook, communication board, or computer system. Each device is individualized to a person's specific needs and strengths)
- Attendant Care (help with personal care and housekeeping)
- Day Services - Day treatment and training (training, supervision, therapeutic activities and support to promote skill development in independent living, self care, communication and social relationships. Services can be provided in both congregate and individual community settings.)
- Early Periodic Screening, Diagnosis and Treatment Services (EPSDT)\*
- Employment Services - Supported work programs
- Environmental modifications and repairs (building modifications and repairs to allow an individual to function as independently as possible in their own home)
- Habilitation - Habilitation uses a variety of methods to help people learn (interventions such as habilitative therapies, special developmental skills, behavioral intervention, sensory-motor development designed to increase the person's skills and functioning)
- Habilitative Therapy (occupational therapy, physical therapy and speech)
- Health Plan Services (acute care) \*
- Homemaker (help with housekeeping)
- Home Health Aide (health maintenance, continued treatment or monitoring of a health condition and supportive care with activities of daily living)\*
- Home Health Nurse (skilled nursing services)\*
- Hospice (care for individuals who are terminally ill)\*
- Behavioral Health (care and treatment for people with behavioral health needs such as crisis services, evaluation and diagnosis, counseling, behavioral health rehabilitation, transportation, respite, medication, psychiatric medication adjustment and monitoring, psychiatric medication adjustment and monitoring or in patient hospital services)\*

- Residential Services (see discussion below)
- Transportation
- Respite Care (short term care and supervision to provide relief to the caregiver)

#### **IV. Residential Options**

The Division provides services in a variety of living environments, of which the vast majority are community based. Over 88 percent of individuals the Division serves live in their own or their family's home. Opportunities are provided for people to choose a place to live, with necessary supports, within their home communities such as receiving services to live within the family home, living in one's own home or apartment, living in an adult developmental or child developmental home or residing in a small group home.

*Individually Designed Living Arrangement* - This service provides for an alternative, non-licensed residential living situation for consumers to choose where and with whom he/she will live and assume all responsibility for his/her residence. Generally, one or more consumers reside together in a private residence that is leased or owned by the consumer(s) and/or the consumer(s) representative(s). The focus of this service is to provide teaching supports (habilitation) to individuals based on the collective need for support to eligible consumers who have chosen to reside together and share their resources.

*Adult Developmental Home* - A residential setting for adults that is licensed to provide space room, board, supervision and teaching (habilitation) for up to three people.

*Child Developmental Foster Home* - A residential setting for up to three children that is licensed to provide supervision, teaching (habilitation) and room and board for children who have been adjudicated dependent by the court. The long-term goal is to move the children out of foster care into a permanent home. There are also children, not involved in the foster care system, that receive residential foster home services outside of their family home.

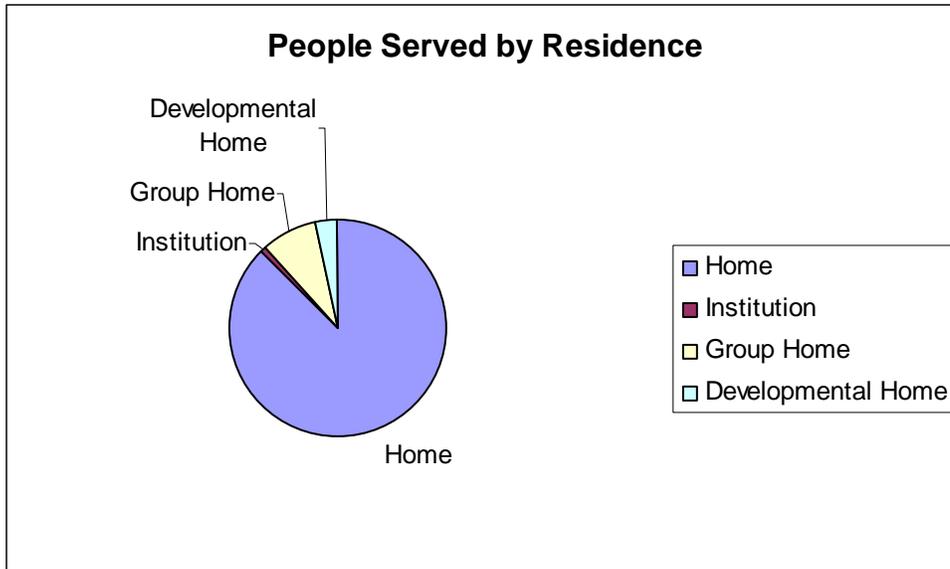
*Group Home* - A community residential setting for up to six people that provides supervision, habilitation, room and board. The group home provides a safe and homelike atmosphere, which meets the needs of individuals who cannot physically or functionally live independently in the community.

Rarely, a person needs a more intensive residential setting. For those individuals, the following facilities may be accessed:

*Nursing Facility* - A Medicaid certified facility, which provides inpatient room, board and nursing services to individuals who need them on a continuous basis but do not require hospital care or direct daily care from a physician.

*Intermediate Care Facility for the Mentally Retarded*: A facility whose primary purpose is to provide health, habilitative and rehabilitative services to people who require them on a continuous basis.

The following graph shows eligible individuals by residence.



## V. Provider Network

The Division provides most of its service through a statewide network of profit and non-profit agencies (Qualified Vendors) and individual providers.

<u>Home &amp; Community-Based Providers</u>	<u># of Contracts</u>
Agencies (Qualified Vendors)	790
Adult Developmental Homes	433
Child Developmental Homes	326
Individual Providers (approx.)	3272

## VI. Additional Services for Children

Children from birth to three years of age, who have a developmental delay and who are eligible for services through the Division, may also be eligible for services through the Arizona Early Intervention Program and through the Arizona Long Term Care System. The plan developed includes the necessary outcomes to enhance the child's development and the capacity of the family and service providers to meet the specific support needs of the child. Division funded services may include developmental special instruction, therapies and other early intervention services based on needs.

## **VII. Acute Care Health Plan Services**

The Division currently holds contracts with four Health Plans that together provide services to Arizona Long Term Care Systems members with developmental disabilities residing in every Arizona county. The Health Plans are responsible to assign or allow choice of a primary care provider to each person who is enrolled. The Health Plans are:

- Arizona Physicians Independent Physician Association
- Mercy Care
- Capstone
- Care First

The Division also coordinates with Indian Health Services for children and adults who are tribal members.

## **VIII. Other Division Activities that Support Arizona's Families**

In addition to the supports and services noted above, the Division strives to provide other supports to consumers and families. Some of these are as follows:

- The Division's website is constantly updated to provide information to consumers and families. It provides information about the Qualified Vendor program (how the Division contracts for services), the Fiscal Intermediary program (the fiscal agent for families who select independent providers) and how to work with providers. It also contains Division laws, rules, policies and forms. Many of the Division's publications are available on the website such as *Navigating the System* (a handbook for consumers and families), the *ALTCS Member Handbook*, *DDD Working with You and others*. The website also has a referral feature for people who would like to apply for eligibility determination.
- The Division supports Councils and family groups. Some of these groups are the Developmental Disabilities Advisory Council (a Governor appointed Council that is advisory to the Assistant Director of the Division of Developmental Disabilities), the Self-Determination Advisory Council (a consumer advisory group to the Division), FACT groups (Families Actively Communicating Together – a parent driven group that provides support and learning opportunities) and specialized groups for autism, Down syndrome and groups for families who speak Spanish.
- The Division has a policy review group that provides input on all policy revisions. These revisions are then presented to the Developmental Disabilities Advisory Council, the Self-Determination Advisory Council, as well as families, consumers, and advocacy groups so they can provide input in policy development and/or revision.

- All new support coordinators go through a three week training course known as Core Training. Trainers include consumers, families, and state staff. This training teaches support coordinators the philosophy of the Division and provides the foundation for further on-the-job training. The training provides information on person centered and family centered care as well as family support systems.
- The Division provides support to Human Rights Committees throughout the state. These committees are composed of local volunteers who provide independent oversight in matters related to the rights of people with developmental disabilities such as incidents of abuse, neglect or exploitation. The volunteers include family members of people with developmental disabilities.
- The Division provides support to Program Review Committees across the state. These volunteer committees review every proposed behavior treatment plan to make sure the programs include positive strategies and do not violate people's rights.
- The Division's quality management system includes the Risk Incident Management System which is an automated system for incident reporting. Incident management assists in promoting the health, safety, and welfare of people with developmental disabilities through active reporting, investigating, tracking and trending of incidents and the implementation of both individual-specific and systemic corrective actions and prevention strategies. It also includes residential monitoring of roughly 1,000 group homes every six months for compliance with programmatic standards. The Consumer Resolution Tracking System is an automated system used to track family and consumer concerns and complaints and to describe the resolution of the issue. Staff is able to look for patterns of concerns so there can be systemic resolution. Consumer satisfaction is a component of the quality system. The system includes comprehensive trending and tracking of acute and long term care systems and opportunities for improvement.

## **IX. A Snapshot of 2008 Accomplishments**

In partnership with consumers, families, and community stakeholders, the Division continues to support innovations and improvements. Some of achievements are as follows:

- The National United Cerebral Palsy Association, one of the nation's leading organizations serving and advocating for people with developmental disabilities, conducted a study on Medicaid programs in the fifty (50) states and the District of Columbia to determine how inclusive each state's support system is for people with developmental disabilities. Arizona ranked 1<sup>st</sup> in providing supports and services to consumers in their homes and communities for the second year in a row.

- The Division received a three year grant from the Centers for Medicare and Medicaid Services to prepare youth who are in transition from school to adult living to exercise choice, promote the use of informal and community supports and to make knowledgeable decisions on their living arrangements, work, social networks and services. Michael Smull, a nationally known expert on supporting people with developmental disabilities, presented a two day workshop on Person Centered Thinking that served as a foundation for everyone involved in supporting people with significant disabilities. Implementation of Person Centered Plans is more likely when staff and other people in someone's life have gone through this training.
- Twenty-one people with developmental disabilities and family members graduated from Partners in Policymaking, an innovative leadership training program that teaches people to be community leaders and to affect systems and policy change at the local state and national levels. Participation in the program requires a concerted effort on the part of the graduates over a seven month period. Partners in Policymaking graduates gain the ability to teach policymakers a new way of thinking about people with developmental disabilities and their families.
- The Division partners with the Sonoran University Center of Excellence in Developmental Disabilities (UCEDD) on a project to describe and address barriers to effective late life transitions for aging family caregivers of adults with developmental disabilities. The project also promotes effective late life transitions for people with developmental disabilities as well as improving aging related and end of life care for people with developmental disabilities.
- The Self-Determination Advisory Council, a Division sponsored group of self advocates, meets quarterly to review policy and provide feedback to the Division. The Council is working on recruiting new members, creating a budget and engaging in fundraising to support Council activities. The Council is very concerned about transportation issues and will be inviting a guest speaker to address this concern.
- The Division is a partner in Arizona's Aging and Disability Resource Center whose goal is to create a coordinated system of information, assistance and access for all people seeking long term care services. This system, known as AzLinks, includes a web site ([www.azlinks.gov](http://www.azlinks.gov)) that provides links to many federal, state, and other agencies integrating resources on a variety of relevant topics. AzLinks also has a reference manual for people who do not have access to the internet.
- The Division continues to participate in the national Core Indicators Project a project that measures the satisfaction with supports and services provided to people with developmental disabilities and their families. Preliminary data for fiscal year 2008 show a consistent level of satisfaction since 2000. Based on the information generated by this survey, the Division chooses an area to work

on. Last year, the Division focused on enhancing self-advocacy for consumers. Currently, the Division is focusing on alleviating loneliness through increasing self-advocacy. Each District has a Consumer Advisory Council which will advise the District on ways to assist consumers in becoming self-determined advocates.

- The Division is working with public and private partners to promote and sustain a professional, well-trained direct support workforce. Last fall, the Division sponsored its fourth annual Direct Support Professional Recognition event that provided an avenue for families and consumers to nominate outstanding caregivers with whom they work. In February, the Division co-sponsored a conference for state and contracted agencies to focus on recruitment and retention strategies for direct support for direct support professionals.

#### **X. Success Statistics:**

The Division's Strategic Plan measures how well the Division is following its mission. In fiscal year 2008:

- 82 foster children with special needs were adopted.
- 414 people participated in the dental pilot program. The Division received funding for adults with developmental disabilities who had no access to dental care. Through this pilot, people were able to have dental care at the Arizona School of Dentistry and Oral Health.
- 369 habilitation workers received training and certification to provide services to children with autism. These workers have learned special techniques to more effectively teach these children.
- 100 percent of families were satisfied with Applied Behavioral Analysis services based on quarterly surveys. Applied Behavioral Analysis is structured teaching taking what is known about a person's behavior and uses it to bring about a positive change.
- 4,485 people participated in a day program or sheltered workshop and 1,018 people were in individual or group supported employment programs.
- 2,546 people selected an individual provider of their choice and participated in the fiscal intermediary program. This allows people to use a combination of individual providers or individual providers and agencies.
- 194 families used Cooperatives, Microboards or Support Brokerage models; a 94 percent increase as compared to last fiscal year. These are different options for choosing and arranging supports and services. Cooperatives are a group of consumers and families who come together to manage their services and supports. A Microboard is an individual family that incorporates to manage their

family member's supports and services. A Support Broker assists an individual to be more self-directed in their supports and services.

- 219 physical therapists provide services to people with developmental disabilities; a 13 percent increase and 314 speech therapists provide services to people with developmental disabilities; a 15 percent increase over last fiscal year. The Division continues to expand its cadre of therapists to try to meet unmet needs and provide for increased choice. Therapies are available for both children and adults, based on need.
- 1,323 individuals/families chose to use contracted support coordinators; a 9 percent increase as compared to fiscal year 2007. Consumers and families can choose between state staff or contracted support coordinators.
- Satisfaction with a Division support coordinator is at 99 percent; a 1 percent improvement over last fiscal year.
- 91 percent of consumers live with their family or in their own home; a 2 percent increase over fiscal year 2007.

## **XI. Conclusion**

The Division of Developmental Disabilities is proud to be a leader for its support of individuals and families and continuously seeks to improve its system of supports for consumers and families. The Division will continue to recruit additional therapists through advertising in state and national trade journals. This year, the Qualified Vendor system will update its service specifications (service descriptions) and expectations of the services. The Division will engage consumers and families to provide valuable ideas on how services should look. With the Developmental Disabilities Advisory Council, the Division will explore new ways to receive input from people with developmental disabilities and their families on how to improve the service delivery system. The Self-Determination Advisory Council is recruiting new members to expand the breadth of input to the Division. The Division will actively pursue additional employment opportunities for people with developmental disabilities.

The Division looks forward to collaborating with the community, stakeholders and other entities to continue providing quality supports and services in the most inclusive ways and settings.