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

**FAMILY SUPPORT
ANNUAL REPORT**

July 1, 2003 - June 30, 2004

I. Background

In 1993, Family Support Legislation was passed that defined a family support program, subject to funding appropriations. This legislation was a result of collaboration with families, advocacy organizations, providers of service and the Division of Developmental Disabilities (Division) in recognition of the significance of family support as a national initiative. While there was no appropriated funding for a family support program, the Division integrated the philosophy of the legislation. This report highlights initiatives and systems the Division and many collaborators have successfully implemented.

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

In 1993, a Statewide Family Support Steering Committee was established to provide guidance to the Division in making the philosophy of family support central to all functions of the Division. The Family Support Steering Committee was comprised of family members, people eligible for services from the Division, providers and Division staff. This group, from across the state, represented the diversity of Arizona and the diversity within the Division's service delivery system.

The following are guiding principles adopted by the Statewide Family Support Steering Committee and the Division which help guide the Division in implementing programs, services and supports which are helpful to individuals and families:

Family Empowerment - defined as greater family control and responsibility in decision making.

Family Integrity - defined as services that promote and enhance family units, competence and independence while minimizing dependency.

Family Needs - defined as services that must be based on issues identified by families and that are flexible enough to meet unique needs.

Family Values - defined as services that support the family as the best caregiver to its family member with a developmental disability.

Community Development - defined as state governments that alone cannot meet the needs. Schools, churches, local organizations, neighbors and friends must help.

As recommended by the Statewide Family Support Steering Committee, a diverse group of twenty-one people from across the state were invited to develop a vision for the system. This Vision, created in February 1997, is the cornerstone by which we evaluate and measure our effectiveness on behalf of families:

Families and Individuals have a Vision...

...of a System that:

- *Begins with the families and individuals and respects their preferences, interests, needs, cultures, languages and belief systems.*
- *Provides adequate information and training to assist families and individuals in making informed decisions and choices.*
- *Provides opportunities for Family Networks that work in collaboration with the service system.*
- *Provides a continuum of service options that support the expectations and agreements established through the person/family centered planning process.*
- *Integrates access to non-Division services available throughout the community and across the state.*

- *Allows families and individuals to identify their role in interacting with the service system.*
- *Bases service delivery on the needs of the individual/family, regardless of geographic location, disability, availability of service options or funding.*
- *Provides families and individuals with flexible and creative service delivery options, e.g., cash subsidies, non-traditional providers, vouchers, debit cards, etc.*
- *Provides coordination across all facets of the service system in order to maximize the efficient use of resources and minimize the negative impact on families and individuals.*

For this evaluation period, the evaluation is assessed against the statements contained within the Vision.

II. Outcomes

The Division of Developmental Disabilities supports the Vision developed by families and individuals served. Family Support is not a separate program, however, the Division incorporates the philosophy contained in the legislation in all activities. The Division is committed to the ongoing support of individuals and families and recognizes the need for continued improvement of Division systems and practices in order to improve processes that support individuals and families.

Vision Statement

Begins with the families and individuals and respects their preferences, interests, needs, cultures, languages and belief systems.

The Division:

- posts a periodic newsletter to the Division's website as a means to share important information from the Division that may impact or be of interest to consumers, families and other Division stakeholders
- provides staff support to the Developmental Disabilities Advisory Council at their regularly scheduled meetings and

public forums. This volunteer Council is charged with making recommendations to the Assistant Director regarding policy, budget, the health, safety, welfare and legal rights of people with developmental disabilities. This Council also oversees and approves expenditures from the Client Services Trust Fund.

- provides staff support to the Self-Determination Advisory Council. This Council is comprised primarily of self-advocates who receive supports and services through the Division. This Council works with the Division to identify and develop policies, procedures and rules that support and promote individuals having control over their lives. The Council will also work to promote the development of supports and services which nourish community relationships and opportunities for individuals with developmental disabilities.
- has culturally diverse staff and staff who speak other languages
- provides a variety of interpreter services
- seeks out providers who respond to the diverse needs of the community. The Division monitors needs for supports and services through a network development plan. This assists the Division in identifying areas of the state where concentrated recruitment efforts of additional providers are needed.
- provides training and technical assistance to families, in their native language, in their homes to assist families in meeting the needs of their family member who has a disability while taking into account cultural considerations. This training and technical assistance could include such things as behavioral support or modeling teaching techniques for skill acquisition.
- supports Spanish-speaking family groups by providing staff support and leadership development so families better understand the system and can become better advocates
- translated Division forms and other publications into Spanish
- in conjunction with the Developmental Disabilities Advisory Council, hosts public forums throughout the state as a means to solicit input from families, consumers and other stakeholders regarding the quality of supports and services provided through the Division

Vision Statement

Provides adequate information and training to assist families and individuals in making informed decisions and choices.

The Division:

- has a web site which includes information about the Division, events, policies, rules and activities. The site also includes links to other sites of interest. The site is located at <http://www.azdes.gov/ddd> and is updated regularly.
- developed a web based referral system which generated 16 referrals from 420 visits to the site in June, 2004
- supports numerous family groups statewide
- provides information and welcome packets to individuals and families at intake
- developed a “Tool Box” for consumers and families who use independent providers to assist them in their role as “Employer”
- held statewide meetings and a teleconference to provide the over 3,500 consumers and families who use independent providers with information about the new fiscal intermediary service
- developed “Frequently Asked Questions and Answers” about the fiscal intermediary service
- contracts with two agencies who provide peer support and with one agency that provides “Partners in Policymaking” which is a nationally recognized training program that helps individuals and families to learn about multi-systems including how to have a direct effect on public policy

Vision Statement

Provides opportunities for Family Networks that work in collaboration with the service system.

The Division:

- provides support to family networks throughout the state by providing staff support based on the needs and desires of the family networks. This could include leadership development activities, scheduling speakers, sending out meeting notices and general support.
- provides support to nine Human Rights Committees statewide who are charged with safeguarding the rights of individuals and families. This support includes gathering information for review, following up on questions, responding to calls and general support.
- is working with families to develop a service cooperative. This cooperative will be run by families and will provide an alternative to traditional service delivery.
- participates as a member of the Governor's Council on Developmental Disabilities

Vision Statement

Provides a continuum of service options that support the expectations and agreements established through the person/family centered planning process.

The Division:

- provided early intervention services (birth to age three) to over 2,800 families. These services consisted of therapies, special instruction, sibling support, respite, in-home training, etc.
- conducted customer satisfaction surveys by mail, phone or face-to-face which indicated a high level of satisfaction with service providers and support coordinators. The survey rated support coordinators and providers on such things as

establishing relationships, fostering family involvement and respecting the person's cultures and values.

- provides employment supports and services to over 2,000 people, on-the-job, to help maintain successful employment. Additionally, a workgroup is developing guiding principles for core employment services, evaluation considerations for the initiation of employment supports and services and a structural design of center-based, group-supported and individual-supported employment services.

Vision Statement

Integrates access to non-Division services available throughout the community and across the state.

The Division is collaborating with the Aging and Adult Administration to identify issues for caregivers and people with developmental disabilities as they increase in age. The group will be making recommendations to the Governor to identify actions in line with issues identified that are generic to aging populations regardless of disability.

Vision Statement

Allows families and individuals to identify their role in interacting with the service system.

After a successful pilot of case management options including families and individuals being their own support coordinator, this program has now expanded to the entire state. Consumers and families may also choose a contracted support coordinator or a state employed support coordinator.

All individuals and/or families are allowed to choose their own support coordinator; 52% of individuals and families chose their own support coordinator.

Vision Statement

Bases service delivery on the needs of the individual/family, regardless of geographic location, disability, availability of service options or funding.

The Division supported nearly 400 people to live on their own with services defined through their person centered plan. Over 20,000 people received supports in their families' home. Over 2,000 people live in group homes and approximately 400 people live in Adult Developmental Homes.

Vision Statement

Provides families and individuals with flexible and creative service delivery options, e.g., cash subsidies, non-traditional providers, vouchers, debit card, etc.

The Division contracts with over 3,500 individual providers and over 460 agencies. Nearly 7,000 individuals and families purchased over 10,300 units of support utilizing vouchers.

Pursuant to Arizona Revised Statutes § 36-557, the Division was exempted from the traditional procurement process. Rather than issue a request for proposals, the Division invited providers to apply to become a qualified vendor. This qualified vendor process simplifies and streamlines the entire contracting process and allows new providers to quickly enter into agreements with the Division. The rules developed pursuant to this procurement process focus on individual/family choice of providers.

The Developmental Disabilities Advisory Council distributed over \$286,000 from the Client Services Trust Fund to over 200 consumers. The Division provides full administrative support to this Fund.

Vision Statement

Provides coordination across all facets of the service system in order to maximize the efficient use of resources and minimize the negative impact on families and individuals.

The Division:

- collaborates with the Department of Health Services/Division of Behavioral Health Services to improve the service delivery system to consumers needing behavioral health supports

- routinely meets with the Regional Behavioral Health Authorities to work through specific case issues on a local basis. Solutions have included co-funding supports or collaborating on individual plans.
- participates as an active member of child and family teams across the state to facilitate a single plan for children who have developmental disabilities and also receive behavioral health supports and services

III. Summary

Staff from the Office of Consumer and Family Support work closely with a number of groups to enhance information and support to individuals and families. Staff of this office include family members of people who have developmental disabilities. The activities of this office support the Vision Statements with a focus on individual/family driven supports, self determination, information dissemination, increasing collaboration across and between different service systems and creating more flexible service systems.

The Division continues to improve supports and services to individuals and families and is moving closer to a person centered system which supports self-determination. This will allow for individual budgets, increased choice of providers, individual determination of the amount of support needed, flexibility of supports and increased responsiveness to needs.