

ARIZONA DEPARTMENT OF ECONOMIC SECURITY

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DEPARTMENT OF ECONOMIC SECURITY DIVISION OF DEVELOPMENTAL DISABILITIES

FAMILY SUPPORT ANNUAL REPORT

July 1, 2004 - June 30, 2005



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 the Division evaluates and measures its 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 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. This fiscal year, the Division published four (4)

- general newsletters, three (3) Quality Management bulletins and nine (9) Vendor bulletins.
- provides staff support to the Developmental Disabilities Advisory Council at their regularly scheduled meetings and public forums. The Council holds four (4) open meetings per year. 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.
- in conjunction with the Developmental Disabilities Advisory Council, hosts six (6) 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.
- 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. Five (5) meetings were held. The Council co-sponsored a legislative awareness training and also presented the principles of self-determination at The Arc's Self Advocate Conference. 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.
- created Spanish translations of forms and other publications used by the Division.
- uses the planning process as the foundation for all supports and services to insure a consumer and family focus.
- 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. Of the mailed surveys, 712 were returned (3.1%) and the average satisfaction score for support coordinators was 4.56 on a Likert scale of 1 to 5. The average satisfaction score for providers was 4.77.

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 675 referrals from 7,796 visits to the site in fiscal year 2005.
- provides information and welcome packets to individuals and families at intake.

- developed a "toolbox" to provide information about how to be an employer to consumers and families who use an independent provider.
- 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.
- maintains numerous resources and publications in both English and Spanish to provide program information.

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 eight 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. The eight committees reviewed a total of 3,680 incident reports and 1,042 behavior plans for a total of 3,796 volunteer hours. The committee chairs meet quarterly and made the following recommendations to the Division:
 - continue to explore the feasibility of drafting proposed legislation to implement an abuse registry
 - continue adherence to a previously signed communication agreement
 - continue to expand recruitment efforts to broaden cultural and ethnic composition of the committees

 developed a service cooperative in Northern Arizona that supports approximately 30 families. This cooperative is run by families and provides an alternative to traditional service delivery. Building on that success, a Spanish speaking cooperative is in development to support families in the Phoenix area. Another cooperative is planned for Phoenix in the near future.

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 3,000 families. These services consisted of therapies, special instruction, sibling support, respite, in-home training, etc.
- supported nearly 300 people to live on their own with services defined through their person centered plan. Over 21,000 people received supports in their families' home. Over 2,100 people live in group homes and approximately 450 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 3,000 individual providers and approximately 450 active qualified vendors.
- implemented a Fiscal Intermediary service for over 3500 people who use individual independent providers. This allows the consumer/family to be the employer of the support provider.

 provides full administrative support to the Client Services Trust Fund. The Developmental Disabilities Advisory Council distributed \$171,186 from the Client Services Trust Fund to over 200 consumers.

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. This affected the 1,546 children eligible to receive behavioral health supports and services.
- participates as a member of the Governor's Council on Developmental Disabilities.
- Participates as a member of the statewide Transition Leadership Team for the transition from school to adult life.

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.