

**Partnership
for Community
Development**

BUILDING BRIDGES TO THE COMMUNITY

**The Arizona
Resource Book
on Persons with
Developmental
Disabilities**

College of Human Services

ASU ARIZONA STATE
UNIVERSITY WEST

IN COLLABORATION WITH

The Arizona Drug and Gang Prevention Resource Center
The Arizona Community Foundation
The Governor's Council on Developmental Disabilities

TABLE OF CONTENTS

ACKNOWLEDGMENTS	3
INTRODUCTION	4
Purpose and Scope	4
Developmental Disabilities: Defined	5
Resources	6
HISTORICAL PERSPECTIVE	9
Introduction	9
Condensed History of Developmental Disabilities	10
Evolution of the Service System in Arizona	12
STATEWIDE DEMOGRAPHICS	14
Number of Individuals and Status	15
Member Eligibility	15
Age Ranges	15
Documented Disabilities	15
Ethnicity	16
Placement Information	16
Residential Living Situation	17
Performance Survey	17
HOUSING	19
Accessibility	20
Affordability	20
Housing Discrimination	20
“NIMBY”	20
The Right to Fair Housing	21
General Information on Housing Opportunities	22
EMPLOYMENT	23
High Unemployment Rates	24
Employment Gaps	24
What’s Working?	25
EDUCATION AND TRANSITION	29
Arizona Educational Reform	29
ADE/ESS State Improvement Plan	31
Special Education Personnel Needs	34
School to Work Transition Program	34
Advocacy Efforts	36

SOCIAL DEVELOPMENT: SELF-DETERMINATION/QUALITY OF LIFE	38
Empowered Lifestyles	38
Areas of Empowerment	39
Programs of Self-Determination	40
Maximizing Potential Through Early Intervention	44
HEALTH CARE	46
ALTCS	46
Implications for Public Policy	46
IMPLICATIONS FOR THE FUTURE	48
Self-Determination	48
Housing	48
Employment	48
Education and Transition	48
Health Care	49
Conclusion	50

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As with the *Arizona Fact Books* produced by Arizona State University West's Partnership for Community Development, the intent of this volume, *The Arizona Resource Book on Persons with Developmental Disabilities*, is to provide a tool for policy makers and service providers. The *Resource Book's* aims are not to advocate for particular programs or political agendas, but to present data and other information to inform decisions related to the provision of programs and to serve as a reference for public and community-based organizations. By intention, this book is not an exhaustive discussion of the status of people with developmental disabilities, but rather a presentation of data and issues that are arranged as a "snapshot" of the many facets of an increasingly complex matter. In some areas, data were difficult, if not impossible, to secure and, in other areas, there is much more information than could be responsibly presented within the purpose and scope of this book.

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June, 2000

Introduction

There are over 750 million people in the world today who are living with a disability. The number of disabled people in the world is three times the population of the United States. According to the Governor's Council on Developmental Disabilities, there are approximately 83,000 developmentally disabled people in Arizona.

Many disabilities are highly visible, and many others are not. For most of history, people with visible disabilities were often viewed as "cast-aways," and quickly shuffled off to places where they were "safe" from others. Fortunately, with the support of people with disabilities, their families, community members, advocates, service providers in the public and private sector, and concerned policy makers, the focus of care has evolved from protectionism to self-determination. In similar fashion, to maximize the extent to which care environments are supportive of this movement, the preferred setting has generally moved from institutionalization to independent living.

Purpose and Scope

The purpose of this book is to provide practical, easy-to-understand information for people who must make important choices about the quality of life of individuals with disabilities. As such, this book was created to assist people in their decision-making. This includes those who must make a personal choice about seeking help, a professional choice about identifying resources, or a political choice about advocating for responsible legislation and funding.

This book uses statistical information when it is pertinent to the discussion. However, it is important to note that an emphasis has been placed on discussing those areas that are most critical to maximizing the quality of life and level of self-sufficiency for anyone with a disability. Thus, at times the reader is referred to sources where more statistical information can be found.

The areas to be discussed in this book are as follows:

- Historical Perspective
- Statewide Demographics
- Housing
- Employment
- Education and Transition
- Health Care
- Social Development: Self-Determination and the Quality of Life
- Implications for the Future

These categories were developed on the basis of discussions with noted experts in the field, and although not exhaustive, are viewed as the core areas that are key to any study of developmental disabilities. As such, it is hoped that this book portrays a snapshot of the status of people with disabilities that is comprehensive, yet "reader-friendly." In some instances, sources for additional information are listed.

Developmental Disabilities: Defined

The word “disability” means different things to different people. While some view the word as having medical implications, others associate it with an array of difficulties in performing everyday tasks. In fact, all of us can experience a disability when we attempt to perform certain functions within the context of specific environments, and especially when those environments are unfamiliar and/or non-supportive. While this insight leads to better understanding and improved communication relative to the disabilities of others, there remains a need to further define the word if we are to discern the specific needs of persons with developmental disabilities.

The Federal Government (Developmental Disabilities Assistance and Bill of Rights Act of 1990, Public law 101-496, Section 102) defines “developmental disability” as:

A severe, chronic disability of an individual five years of age or older that:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity:
 - self-care
 - receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living
 - capacity for economic self-sufficiency
- reflects the individual’s need for a combination and sequence of special, interdisciplinary or generic services, supports, or other assistance that are lifelong or of extended duration and are individually planned and coordinated, except that such term when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Although the Governor’s Council on Developmental Disabilities uses the federal definition (because it is funded with federal dollars), the State of Arizona employs a different definition of developmental disabilities. The Arizona Department of Economic Security, Division of Developmental Disabilities, defines developmental disability as a chronic disability attributable to mental retardation, cerebral palsy, epilepsy, or autism. The disability must be manifested before the age of eighteen and result in substantial function limitations in three or more of the seven areas of major life activity that are listed above in the federal definition. Also similar to the federal definition, the state requires that the disability reflect the need for a combination and sequence of special services that are lifelong or of extended duration. Under the state definition, children below the age of six years may be eligible for services if there is a strongly demonstrated potential that the child is, or will become, developmentally disabled.

For the purposes of this book, unless otherwise noted the reference point for defining developmental disabilities is the State of Arizona definition.

Resources

There is a wide range of services provided by agencies and individuals throughout Arizona. Most of these services are available to persons who are eligible as defined by the Arizona Department of Economic Security/Division of Developmental Disabilities (see above), and address the identified needs of individuals and families across three major categories: day programs, home and community-based services, and residential programs. In addition, there are generally three major service methodologies that are employed in each area of need: information and referral, direct services (e.g., case management, home health, therapies), and advocacy. There are numerous service providers in each category, and it is beyond the scope of this book to identify them.

However, it is pertinent to briefly discuss two major resources, which bear heavily on the planning and funding of developmental disability services. They are:

- Arizona Department of Economic Security/Division of Developmental Disabilities; and
- Governor's Council on Developmental Disabilities.

The **Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)**, as authorized by state law, is responsible for providing services and programs to individuals with developmental disabilities. DES/DDD has developed an array of needs-based services that are generally provided through contracts with individuals and agencies. As such, services are available to eligible individuals within state and/or federal guidelines, and according to the availability of funds.

DES/DDD, in partnership with individuals with developmental disabilities, their families, advocates, and community-based providers, seeks to develop and support environments which enable people to achieve and maintain physical well-being, personal and professional satisfaction, participation as family and community members, and safety from abuse and exploitation. Services generally include four major categories:

Support coordination, in which individuals receive help from a support coordinator in determining eligibility, assessing needs, obtaining appropriate services, and locating community resources;

Home and community-based services, which promote and enhance the abilities of individuals to live either alone, with their family, or with others;

Institutional services, which include Intermediate Care Facilities for the Mentally Retarded and Nursing Facilities; and

Medical services, which are provided to ALTCS eligible children and adults to help them maintain optimal health. ALTCS (Arizona Long Term Care System) is a federally funded Medicaid research and demonstration program.

The **Governor’s Council on Developmental Disabilities** works for the benefit of people with disabilities and their families, friends, employers, and schools. Supported by six advisory councils, the Governor’s Council seeks to build partnerships, increase understanding, create opportunities, provide services, banish misconceptions, and change public policy with regard to people with developmental disabilities. In short, the purpose of the Governor’s Council is to help Arizonans with developmental disabilities achieve greater independence, productivity, integration and inclusion in all aspects of community life.

The Governor’s Council plans and advocates on behalf of individuals with developmental disabilities by monitoring current services, identifying unmet needs and gaps in services, and developing plans to address those needs. The Council implements its activities through annual contracts with six regional district councils located throughout the state. The district councils provide local developmentally disabled citizens with advocacy, information regarding services, and referrals to needed services.

The Council’s current plan identifies four major goal areas, as follows:

Self-determination, to actively support the participation and leadership of persons with disabilities and their families in advocacy initiative;

Employment, to identify and implement strategies to assist individuals with disabilities to become employed;

Special education, to promote free appropriate public education for all students with disabilities; and

Family support, to assist state service systems in becoming family-friendly and family/consumer driven.

For additional information on the services and activities of DES/DDD or the Governor’s Council on Developmental Disabilities:

DES/DDD Central Office
1789 W. Jefferson
Site Code 791A
P.O. Box 6123
Phoenix, AZ 85005-6123
602-542-0419

Governor’s Council on Developmental
Disabilities
1717 W. Jefferson
Site Code 074Z
Phoenix, AZ 85007
602-542-4049

References

Developmental Disabilities Assistance and Bill of Rights Act of 1990
Public Law 101-496, Section 102

Arizona Revised Statutes 36-551

The Governor's Council on Developmental Disabilities
State Plan: 1998-2000

Historical Perspective

Introduction

This historical perspective is not intended to be a thorough account of the status of developmental disabilities throughout the ages, but rather a condensed narrative of the perspectives, influences, and progress achieved over the last 200 years.

Throughout history there has been evidence of people with developmental disabilities. In those cases when they were unknown to the public, they were often thought of as “eccentric” or “different” at best, and as “idiots” and “freakish” at worst. In those cases where people with developmental disabilities were known, or even famous, they were often regarded as “genius” or “unique.” In fact, many famous people throughout history are now known to have had developmental disabilities.

To cite just a few of the hundreds of examples:

- The composers Ludwig van Beethoven and Amadeus Mozart, and inventors Leonardo da Vinci and Benjamin Franklin had attention deficit disorder (ADD).
- Charles Dickens, Julius Caesar, and Vincent Van Gogh had epilepsy.
- Albert Einstein, Thomas Edison, and Winston Churchill were dyslexic.
- Both Beethoven and the famous Spanish artist Goya were deaf.

The famous people noted above are just a few of the many great and famous disabled people in the world. In their success and creative geniuses, they have shown others that people with disabilities can achieve great things. These stories are truly inspirational, and while too often the world of developmental disabilities has been viewed through distorted lenses, they have influenced the progressive movement of attitudes and programs over the years.

While much progress has been made over the past several years, it is clear that there continues to be an urgent need for increased public awareness of the many issues facing people with developmental disabilities. Public attitudes shape public policies. And while there is clear evidence that public attitudes and corresponding changes in service philosophies and funding levels have expanded over the years, there is also testimony to the incidence of persons with developmental disabilities being stigmatized, and in the worst scenarios, being victimized by those who act on the basis of misinformation and who still cling to derogatory labels.

The condensed history, which follows, is intended to demonstrate the major highlights of the past two centuries. As such, it will hopefully serve as a mirror for viewing how our country has responded to those citizens who have developmental disabilities, and how this is further exemplified in the history of services here in Arizona.

A Condensed History of Developmental Disabilities

A brief outline of the history of the treatment of people with developmental disabilities follows:

- In the early 1800s the condition of the “idiot” began to attract caregivers and medical researchers in Paris. This led to the first school designed specifically for people with disabilities in Paris in 1838, and represented the **first major effort to “humanize” the treatment of people with developmental disabilities.**
- By the mid-1800s, the first institutions in the United States were built. Designed to protect people with disabilities from exploitation and abuse, they were established as boarding schools and were generally located in remote, pastoral settings. Again, with the help of vocal leaders in the field, there were signs that the public perspective was beginning to shift. In 1843, Dorothea Dix addressed the Massachusetts Legislature by advocating against the inhumane treatment in prisons and asylums of “helpless, forgotten, insane.....men and women.” In 1848, Samuel Gridley Howe established an experimental school in Boston for the purpose of testing the capacity of people with disabilities for instruction. This was soon followed by the creation of numerous schools across the country, as 24 institutions were in operation in the United States by 1888. **This marked the beginning of a major shift in the societal treatment of people with disabilities from the asylum to the “special school” environment.**
- In the late 1800s the remarkable progress of the mid-century took a dramatic turn for the worse as the emphasis changed from “making the deviant undeviant,” to “sheltering the deviant from society,” to “protecting society from the deviant.” By 1900, persons who were mentally retarded were viewed as a menace, and laws forbidding marriage were passed in several states. Medical studies at the time concluded that “social diseases” were inherited, and thus nothing could be done to keep society safe from people living in the institutions, except to pass legislation permitting or even mandating sterilization and permanent custodial care. As such, **segregation and sterilization characterized the first half of the 20th Century.**
- As World War II approached Nazi Germany passed the Act for the Prevention of Hereditarily Diseased Offspring. As a result, there were massive sterilizations and “mercy” killings of people viewed as “mentally defective,” “deformed” and “incurable.” **It is estimated that over 100,000 persons with mental retardation were systematically exterminated.**
- By the mid-1940s the movement away from the institutional model began. Although still holding to a custodial care model, many families were beginning to keep their children at home. **Buoyed by positive studies of persons leaving state institutions and exposes of the effects of “warehousing,” institutional discharges were increasing.**
- The 1950s and 60s witnessed a dramatic increase in the advocacy movement. **As families became concerned about the lack of community resources and alternatives to institutional care, there was a burgeoning of grassroots development for better educational and vocational opportunities.** As a result, specialized schools and vocational workshops began to spring up

throughout the United States, and the National Association for Retarded Children (now known as the Association for Retarded Citizens) was formed.

- **By the 1970s, largely as an outcome of the Civil Rights Movement and a landmark court decision in Kansas (Brown vs. The Board of Education), the issue of inequitable access to quality education was placed as a national priority.** Although this case focussed on racial segregation, it was later used in successful arguments for the right to free and appropriate education in the least restrictive environment for all handicapped children.
- Also in the early 70s, **the Scandinavian principle of “normalization” came to the U.S., where it became the major philosophical foundation of the development of services to people with developmental disabilities for the next twenty years.** Briefly stated, “normalization” refers to the principle that the patterns and conditions of everyday life (i.e., normal routines of life) for persons with developmental disabilities should be as close as possible to the norms and patterns of the mainstream of society.
- Not surprisingly, the 1970s became known as the “age of litigation,” as court decisions in support of the right to education and treatment paved the way for further deinstitutionalization and mainstreaming of people with developmental disabilities. In 1971, the landmark “Right to Education” court decision in Pennsylvania became a model for many states to push for the educational rights of school age children. **This eventually led to the passage of Public Law 94-142 in 1973, which mandated the right to a free and appropriate education for all handicapped school age children in the least restrictive environment.**
- Over the next decade more than 23 states passed “right to treatment” laws, which were based on the common commitment that no citizen could have their liberty restricted or denied without cause or due process of law. **Since persons with disabilities who were committed to state institutions had clearly had their liberties denied, and had not broken any laws, states were obligated to provide the treatment necessary for regaining their liberty.** These obligations brought about massive institutional reform, which was evident in such vital areas as:
 - implementation of training and skill development programs;
 - facility alterations (less restrictive settings);
 - decreased use of physical and medicinal restraints;
 - improved staffing levels;
 - individualized program plans; and
 - protocols for investigating and enforcing complaints of neglect and abuse.
- While the initial thrust of litigation was focussed on institutional reform, **the emphasis soon shifted to the development of community support alternatives so that persons with developmental disabilities could live and learn within the context of the family, work and community environment.** This led to a movement to group homes, sheltered workshops, special community-based schools and other training and development alternatives across the country. This movement has endured until present time, as home and community-based services and family support initiatives have continued to mark the developmental disability landscape since the 1970s.
- **Perhaps the largest movement in the United States during the 1980s and 90s was seen in the self-advocacy movement, whereby people with disabilities spoke out for themselves and exercised a**

major “voice” in the direction of their own lives. Building on the earlier Swedish movement for self advocacy, and embodied in the founding of the People First movement, this movement remains strong, and has empowered thousands of people in achieving a higher sense of self-esteem and skill development, and has created a ground swell of public awareness that persons with developmental disabilities fulfill roles in society that are both valued and highly productive.

- On a parallel course with the self-advocacy movement, there has been a strong movement that emphasizes family participation in decisions regarding the evaluation, treatment and life planning for their children. **The family-centered movement has shifted much of these decisions away from the professionals and funding agencies, and placed more value and responsibility on the family.** Concurrently, there has been a movement away from group homes and sheltered workshops, with increased emphasis on neighborhood schools, real employment, independent living, and total integration into the local community of friends and neighbors. Beyond merely being a member of the community, the focus is on enabling persons with developmental disabilities to be an active, viable part of the community. Of major importance, **significant streams of federal funds now flow to the community, and not just the institutions.**

Evolution of the Service System in Arizona

1952 - 1975: Institutional Services

This era was characterized by educational, vocational, preschool and health services being provided almost entirely within institutions. Institutional programs were built in Coolidge, Tucson, and Phoenix, and plans for institutions were initiated in Flagstaff and Yuma.

- Arizona Children’s Colony, now known as the Arizona Training Program at Coolidge, was built in 1952. Starting with a capacity of 350 residents, the population grew to 1,200 in 1969, and now maintains an ongoing census of about 145 residents.
- The Arizona Training Program was built in Tucson in 1970, starting out with a capacity of 200. It closed in 1997.
- The Arizona Training Program at Phoenix, built in 1973, began with a capacity of 145, and later closed in 1988.

1976 - 1985: Community Based Services

On a parallel track with the national movement of deinstitutionalization, this era witnessed several benchmarks of increasing community responsibility, including:

- more than 250 group homes were developed;
- public schools were mandated to provide special education;
- integrated preschools were developed;
- vocational opportunities expanded to include work stations and supported employment;
- a comprehensive case management system was implemented; and
- “normalization” principles were increasingly visible as the core value in service delivery.

1986 - present: Family and Individual Support Services

For the past decade and a half, the major advances in the service delivery system can be found in the increased advocacy for family and individual empowerment, as evidenced in the following:

- increased community input calling for systems changes;
- legislative emphasis on family support;
- major programmatic themes of DES/DDD on strengthening the family;
- decreased resources being allocated to costly out-of-home placement;
- involvement of individuals being required in decision-making;
- introduction of the person-centered planning system;
- pilot projects on community-supported living;
- increased Title XIX funding for individualized services; and
- building consensus of core values among funders, providers, and people with developmental disabilities.

Today, there continues to be a need for increased public awareness of the many facets of developmental disabilities. There are still too many people who cling to negative biases toward people with developmental disabilities; there remains a need to increase the funding levels of critical gaps in services; and there is still a strong call to advocate for public policy, which upholds the self-determination of individuals and families.

However, there is also a sustained momentum that promotes a better future. There is an evolving consensus on what constitutes a quality of life for people with developmental disabilities, and it is the same list of desires that all people have:

- personal choice in making life decisions (e.g., jobs, friends, leisure, housing);
- control of relationships, finances, and services;
- permanent liberty to live in a community;
- protection from harm and stigma;
- freedom of movement;
- opportunity for financial success;
- sense of personal dignity and respected status;
- healthy relationships with friends, family and partners;
- recognition of abilities;
- privacy of personal matters and living space;
- authentic participation in community matters; and
- passionate advocacy of human rights and life's dreams.

References

History of Treatment of Persons with Mental Retardation, prepared by Lyn Rucker, DES/DDD, 1990

Disable Hotline: <http://www.delphi.com/disable/famous.html>

Statewide Demographics

It is often difficult to provide accurate counts that reflect the true population of people with disabilities. This is due to the fact that different definitions of disabilities are used by different sources, and that usually reports are limited to only those persons who have received services.

For example, according to the Governor’s Council on Developmental Disabilities, there are approximately 83,000 developmentally disabled people in Arizona; the Census Bureau counts people with disabilities as those persons with any limitations in mobility and/or self-care (169,259 people); and the DES/DDD Management Report of September, 1999 indicated that there are 17,591 individuals who are eligible for services (including 228 persons who had applied and were waiting for eligibility determination).

For the purposes of this book, the statewide demographics of people with disabilities will focus on persons who are receiving services for developmental disabilities. However, it remains instructive to see that similar patterns are found across different sources.

According to the **1990 Census of Population and Housing**, Arizona residents reported the following:

- 58,909 people had only a mobility limitation;
- 62,838 people had only a self-care limitation; and
- 47,512 people had both a mobility and self-care limitation.

The majority of the people with disabilities lived in the urban settings of Maricopa and Pima counties, as they accounted for a combined population of 120,482, or 71.2 per cent of Arizonans with mobility and/or self-care limitations. A total breakdown of the full census figures relative to disabilities follows:

County	Mobility	Self-Care	Both	Total	Percent
Apache	831	4,358	1,673	6,862	4.1%
Cochise	1,545	1,318	1,309	4,172	2.5%
Coconino	947	2,374	1,094	4,415	2.7%
Gila	878	1,285	675	2,838	1.7%
Graham	506	591	376	1,473	0.9%
Greenlee	77	50	79	206	0.1%
La Paz	248	397	349	994	0.6%
Maricopa	32,334	32,016	24,608	88,958	52.6%
Mohave	1,559	1,898	1,620	5,077	3.0%
Navajo	1,062	3,235	1,286	5,583	3.3%
Pima	12,496	9,422	9,606	31,524	18.6%
Pinal	2,324	1,423	1,699	5,446	3.2%
Santa Cruz	239	879	324	1,442	0.9%
Yavapai	2,456	1,377	1,641	5,474	3.2%
Yuma	1,407	2,215	1,173	4,795	2.8%
Totals	58,909	62,838	47,512	169,259	100%

According to the Institute for Human Development, in 1993 Arizona ranked 31st for persons per 1,000 with mobility or self-care limitations, 37th for persons per 1,000 with a severe work disability, and 18th for persons per 1,000 with major activity limitations.

The following statewide demographic information was reported in the DES/DDD Management Report of September 30, 1999:

Number of Individuals and Status:

<u>Eligibility Status</u>	<u>Total</u>
Eligible "Open" for DDD Services	17,363
Eligibility Pending	228
Total	17,591

Member Eligibility of Open Individuals:

<u>Membership</u>	<u>Total</u>	<u>Percent</u>
ALTCS	10,422	60%
DDD	6,941	40%
Total	17,363	

Age Range of Open Individuals:

<u>Age Range</u>	<u>Total</u>	<u>Percent</u>
0 – 3	2,070	12%
3 – 6	2,510	14%
6 – 18	5,064	29%
18 – 21	910	5%
21 – 55	6,207	36%
55 and over	602	4%
Total	17,363	

Documented Disabilities for Open Individuals:

<u>Disability</u>	<u>Total</u>	<u>Percent</u>
At Risk	5,184	30%
Autistic	840	5%
Cerebral Palsy	2,140	12%
Epilepsy	1,250	7%
Mental Retardation	7,949	46%
Total	17,363	

Ethnicity of Open Individuals By Age:

Age	Asian	Black	Caucasian	Hispanic	Native American	Unknown	Total	%
0-3	26	97	967	722	197	61	2,070	12%
3-6	22	138	1,301	750	242	57	2,510	14%
6-18	51	282	2,771	1,319	555	86	5,064	29%
18-21	12	40	553	213	84	8	910	5%
21-55	59	294	4,056	1,279	488	31	6,207	36%
55+	3	27	416	118	37	1	602	4%
Totals	173	878	10,064	4,401	1,603	244	17,363	
	1%	5%	58%	25%	9%	2%		

Placement Information of Open Individuals:

Placement	DD	ALTCS*	Total	%
Home	2,020	6,637	8,657	50%
Institution	3	132	135	1%
Adult Development Home	45	254	299	2%
Group Home	210	1,863	2,073	12%
Case Management	4,663	1,536	6,199	35%
Totals	6,941	10,422	17,363	
	40%	60%		

*DES/DDD participates in the Arizona Long Term Care System (ALTCS), a research and demonstration program emphasizing home and community-based services and medical care within a capitated, managed care approach. Eligibility for ALTCS is determined by the Arizona Health Care Cost Containment System (AHCCCS) on the basis of financial and medical/functional criteria.

Residential Living Situation of Open Individuals: (According to DES/DDD, Arizona ranks 6th nationally in the number of people served in home and community-based settings per 100,000 of the general population.)

Living Situation	DD	ALTCS*	Total	%
Individually Designed Living	61	98	159	1%
Family Home	6,576	7,868	14,444	83%
Child Development Foster Home	46	185	231	1%
Adult Development Foster Home	14	130	144	1%
Group Home	205	1,641	1,846	11%
Skilled Nursing Facility	0	78	78	1%
Residential Treatment Center	1	1	2	0%
Transitional Group Home	0	3	3	0%
Nursing Support Setting	0	31	31	1%
Habilitation – No Room & Board	35	328	363	2%
Room & Board – No Habilitation	1	6	7	0%
Totals	6,941	10,422	17,363	
	40%	60%		

Performance Survey

In providing support and services for more than 17,000 individuals per year, DES/DDD contracts with over 250 agencies, 600 group homes, and more than 1,750 individual providers. To assess performance levels, DES/DDD recently conducted a survey of 552 consumers of services for developmental disabilities. The following results were obtained:

- 82% had a physical examination in the last year.
- 66% had a dental examination in the last year.
- 52% of the women had a gynecological examination in the last year.
- The average weekly wage was \$49.31.
- 56% liked living in their home.
- 45% reported they could be alone when they desired.
- 45% stated they had their rights explained to them.
- 38% reported they had friends they liked to socialize with.
- 28% said they felt lonely in the last month.
- 58% had received assistance in learning new things they regarded as important.
- 11% reported they chose where they live.
- 32% chose their daily and weekly schedules.
- 12% chose whom they live with.
- 36% of family members had received information about services and supports.
- 27% of families chose their service provider.
- 57% of families felt the supports received reflected family needs.
- 58% of families felt they were getting the support they needed.

References

Arizona Department of Economic Security: *DDD Management Report, Statewide Totals as of 9/30/99.*

Housing

“The Woman Who Wouldn’t Give Up”

More than once, they had almost given up. After looking for a home of their own for more than four years, and not finding one that served their needs, or one they could afford, Alice and her family were ready to give up. Then one day, Alice attended a Home Fair in Phoenix and picked up a booklet from the Governor’s Council on Developmental Disabilities. The headline read: “If you’ve ever wanted to have a home of your own....we can help you open the door!”

For the first time, Alice had hope. She called the Governor’s Office, who put her in touch with Community Housing Resources of Arizona (CHRA). She met with CHRA staff and explained that she wanted a home for her family that could accommodate their special needs. Her son Shane had been born with Spina Bifida, and needed wheelchair accessibility and freedom of movement with his crutches. This is when she learned about the “Home of Your Own” program. To her great surprise, Alice qualified for the program, which provides for loans well below the market rates. This meant Alice and Shane could now afford the home they needed.

Even though the loan was approved, barriers still loomed. It was difficult to find the right home, in a suitable neighborhood, and some realtors were reluctant to tackle the project. But finally a realtor stepped forward, and after looking at many homes, Alice and Shane found the home of their dreams. With plenty of room to accommodate Shane’s special needs, and with a monthly mortgage payment within their financial ability, he and his mother were able to conquer the two major barriers that many people with developmental disabilities encounter: physical accessibility and financial affordability.

And while there was still considerable work to be done to achieve maximum accessibility and comfort, the “Home of Your Own” Program, Bank ONE, and friends continued to support them until they realized their dream. They now live in close proximity to support services, schools and work, and Shane has become active in community activities. When all appeared so dim and distant, Alice never gave up. She found support in her friends and a program designed to address her needs, and persevered until their dream came true.

(Note: The Arizona “Home of Your Own” Program is supported by the Governor’s Council on Developmental Disabilities, DES/DDD, Arizona Department of Commerce, HUD, and various housing agencies and financial institutions across the state.)

The Arizona Department of Commerce estimates that there are approximately 27,000 persons in the state who are homeless. Using conservative estimates based on average populations, at least 20%, or 5,400 of those individuals have disabilities. According to the Arizona Bridge to Independent Living (ABIL), over one-third of all calls they receive are related to housing issues.

The major issues affecting the lives of people with disabilities fall into four general areas: accessibility, affordability, housing discrimination, and neighborhood exclusion.

Accessibility

The usability of a housing unit is related to size, layout, door width, absence of barriers such as stairs, and the materials used in construction. Most of these affect usability by persons with disabilities. Accessible housing, even in the broadest sense, is a scarce resource across the entire state. Accessible units are most often found in high-cost newer apartment complexes which were built after the enactment of Fair Housing amendments regarding people with disabilities. As such, most of them are not affordable.

Affordability

Since a high percentage of persons with disabilities are on fixed and/or low incomes, their ability to pay market rents and mortgage costs is extremely limited. There are subsidy programs, but many have waiting lists averaging one to four years.

Thus, at a time when “normalization,” person-centered service plans, and “empowered” decision-making are at the core of service philosophies and program designs, there remains a paramount struggle for people with developmental disabilities in achieving the status of independent living. Simply put, housing that is accessible is usually not affordable, and vice versa.

Housing Discrimination

Housing discrimination often occurs against people on the basis of their disability. The most common discriminating practices are:

- Refusal to Deal: People refuse to sell, rent, or negotiate.
- Different Terms and Conditions: Rental rates and security deposits are increased above market rates and/or Social Security Income levels.
- Misrepresentation: Housing units are represented as not available when in fact they are.
- Steering/Assigning: People are directed to areas for discriminatory reasons.
- Unequal Financing: Loans and/or financial terms and conditions vary for different individuals.
- Adults Only: Families with children are excluded in an illegal manner.
- Accommodations: Physical accessibility is not provided in a reasonable, appropriate manner.

NIMBY (“Not In My Back Yard”)

In increasing fashion, neighborhood associations and community groups are rallying against the inclusion of group home settings. This poses a considerable impact on the availability of appropriate residential treatment for those people with developmental disabilities who requires the closer supervision that is provided in such environments, and deter the capacity for people to live in the “neighborhood of choice.”

The Right to Fair Housing: Housing Advocacy and Legal Assistance Resources

Under the law, a landlord (owner, manager, broker, realtor or company representative) is responsible for applying fair housing practices in dwellings such as the following:

- apartments that are rented or leased
- houses that are sold or rented
- boarding and rooming house rentals
- condominiums
- mobile home parks

For more information on the availability of housing, or housing discrimination:

Housing Discrimination:

City of Phoenix Equal Opportunity Department
Compliance and Enforcement Division
251 W. Washington, 7th Floor
Phoenix, Arizona 85003-2295
602-262-7486
TDD 602-534-1557
fax 602-495-0517

Arizona Fair Housing Center
13201 N. 35th Avenue, Suite 19
Phoenix, Arizona 85029
602-548-1599
800-868-3315

Civil Rights Division - Phoenix
Arizona Attorney General's Office
1275 W. Washington
Phoenix, Arizona 85007
602-542-5263

Civil Rights Division – Tucson
Arizona Attorney General's Office
402 W. Congress
Tucson, Arizona 85701
520-628-6500

Southern Arizona Housing Center
1525 N. Oracle Rd, Suite 107
Tucson, Arizona 85705
520-798-1568

Arizona Center for Disability Law - Phoenix
3839 N. 3rd Street, Suite 209
Phoenix, Arizona 85012
602-274-6287

Arizona Center for Disability Law – Tucson
3131 N. Country Club, Suite 100
Tucson, Arizona 85716
520-327-9547

General Information on Housing Opportunities:

To contact DES/DDD or the Governor’s Council on Developmental Disabilities, refer to the information provided in the Introduction Section of this book.

Statewide Independent Living Council
2765 N. Scottsdale Rd, Suite 104L
Scottsdale, Arizona 85257
602-542-6049

“Home of Your Own” Program
602-542-4049
800-889-5893
602-542-4000 (TTY)

Arizona Bridge to Independent Living (ABIL)
602-296-0520
602-254-6407 fax

Employment

Successes and Challenges

Terry Podel

As an autistic adult, Terry possesses some unusual talents that are strikingly similar to the character Dustin Hoffman portrayed in the movie “Rainman.” He can recite the ZIP codes of every city in the United States, works well with numbers and can memorize items after looking at them only momentarily. However, Terry needed assistance finding appropriate employment, and was successful as an employee only after receiving supportive services from a vocational rehabilitation counselor.

Terry’s successful journey began several years ago as a sheltered workshop employee at Cactus Industries and later at Garden Park. Once his confidence and social skills improved, he could be considered for placement in supported employment. Eventually, with the diligent assistance of his VR counselor, the City of Glendale Library employed Terry. His job placement began with a 30-day trial period followed by a 90-day contract between DES/Division of Employment and Rehabilitation Services (RSA) and the Glendale Library. RSA provided him with a job coach who spent time with him every day.

His self-confidence continued to progress to the point to where he was honored by the City of Glendale as “Employee of the Year” by the Mayor’s Committee on Persons with Disabilities. Indeed, both Terry and his co-workers realized how much his work was valued.

Mark Ramirez

On any day in Douglas, Arizona, you can find Mark Ramirez running his own small landscaping business, and doing most of the work himself. A participant in the entrepreneurial program of the Governor’s Council on Developmental Disabilities, Mark has learned how to organize his business, prepare for future growth and get the help he needs from an ever-growing network of resources and support services.

Mark loves working with his hands and being outdoors in the sunshine. He loves seeing a job through from start to finish, and seeing his work develop and mature, and takes pride in making Douglas look better. Being his own boss also means Mark can organize his schedule to spend time with his family and as an active member of the Governor’s Council.

Because of his desire to live life to its fullest, Mark’s disability is almost invisible as he serves as a great inspiration to others.

The value of work to both the individual and society is a common core value that guides the efforts of advocacy groups, service providers, and people with developmental disabilities throughout the country. It is a commonly held planning assumption that if people are to attain their highest level of self-sufficiency, there must be full access to employment opportunities for all people with developmental disabilities. Access to appropriate level jobs, and to the supportive services required to maintain employment, are considered as basic rights.

High Unemployment Rates

The two case examples cited above are but two of countless success stories involving people showing unending courage and perseverance in achieving a sense of independence and self-determination. However, it is also true that insufficient funds and delayed attention to the employment potential of people continue to pose major challenges to the employability of people with developmental disabilities. This assertion is bolstered by the fact that, nationally, the unemployment rate of people with developmental disabilities is estimated to be 70%. Here in Arizona, the Governor's Council on Developmental Disabilities states that approximately 75% of persons with disabilities are unemployed. In addition, 37% of adults with disabilities earn an annual income of \$15,000 or less.

Employment Gaps: Major Employment Issues Facing People with Developmental Disabilities

In the 1998 Harris Survey of Americans with Disabilities, it became evident that while there have been considerable gains in many areas over the years, the overall employment outlook continues to harbor significant concerns. Commissioned by the National Organization on Disability (NOD), the study by Louis Harris & Associates involved 1,000 individuals with disabilities.

The largest margin of disparity between disabled and non-disabled persons was found in the employment statistics. Only 29% of working-age adults with disabilities were working full or part-time, compared to 79% of individuals without disabilities. This 50% gap was attributed to inadequate jobs, experiences of job discrimination, and an increase in the number of individuals with severe disabilities. Over half of the working adults with disabilities reported that their jobs did not fully allow them to utilize their skills and abilities, and inadequate compensation was cited by 47% of the working individuals surveyed.

As an additional obstacle to appropriate employment, many of the participants reported that a lack of employer-provided health care insurance was an obstacle to accepting employment. Many jobs held by people with disabilities do not provide health care coverage or wages that can cover their medical needs. According to the Harris report, 57% of individuals with disabilities currently not working would lose their health care insurance benefits if they were employed full time.

Respondents also reported that they still experience discrimination in the workplace. One-third of the participants believed that workplace discrimination is a leading reason for their unemployment, and 58% believed that they were denied job interviews based on their disabilities.

Finally, 43% of the respondents felt that they had not been awarded more responsibility or considered for promotions because of their disabilities, and one-third of the individuals reported that they received lower wages than their non-disabled co-workers performing equivalent duties.

Note: The complete N.O.D./Harris Survey of Americans with Disabilities is available from the National Organization on Disability, by phone (202-293-5960) or e-mail (newsome@nod.org).

What's Working? A Snapshot of Current Programs

Rehabilitation Services Administration (RSA) Programs

In July, 1993, the Division of Developmental Disabilities employment programs were transferred to RSA. Based on a Project SLIM recommendation, responsibility for all employment programming for persons with developmental disabilities who were clients of DDD were transferred to RSA. An entity within the Department of Economic Security, RSA provides an array of programs for persons with disabilities. As of this writing, RSA Employment Programs had 2,420 open cases on people with developmental disabilities, including 656 clients (27%) in the Vocational Rehabilitation Program, and 1,764 clients (73%) in the Employment Support Services Program.

Vocational Rehabilitation Program (VR)

The VR mission is “to work with individuals with disabilities to achieve gainful employment through the provision of jointly-developed and individually-planned rehabilitation services in a partnership with the Governor’s State Rehabilitation Advisory Council, Community Rehabilitation Programs, and all other stakeholders.” With the transfer of DDD clients to RSA for employment services in 1993, more than 1,400 individuals were transferred to RSA to receive services from the Vocational Rehabilitation program. Successful rehabilitation means that the individual is successfully placed and maintains a specific job for at least 90 days. One acceptable successful VR outcome for people with very severe disabilities is employment that is supported with extended employment support services (ESS).

Employment Support Services Program (ESS)

The majority of the people transferred to RSA in 1993 graduated to the Employment Support Services (ESS) program by 1996. Individuals are referred to ESS based on the following criteria:

- the individual is in school (age 16-21); and
- needs long-term support.

The mission of ESS is to work with individuals with the most severe disabilities to maintain employment through the provision of employment support services. When ESS resources are not available for a person for whom a service program has been initiated, the VR counselor must either terminate his/her employment placement or maintain the VR program until this resource becomes available. The impact of the latter is to increase VR costs and exhaust VR resources that would otherwise be available for other individuals who can benefit in terms of achieving an employment outcome.

During SFY2000, RSA projected that 315 new applications would be referred to the ESS Program. As a result of a growing caseload and level funding, RSA expects the waiting list for appropriate services to grow, resulting in several people being denied long-term employment supports.

School to Work Transition

RSA has been involved in agreements with school districts since the early 1980’s. These agreements enable RSA to increase resources for services to students with disabilities who are transitioning from high school to adult life. The majority of people with disabilities who do not have a job upon leaving high school are still unemployed three years later. Through RSA-school district agreements, more students can be contacted prior to exiting school.

Transition programs allow students to consider vocational options, make decisions on obtainable goals, and acquire skills and job experience.

Note: For further information on RSA programs and priorities, contact:

RSA Administration
1789 W. Jefferson
Phoenix, Arizona 85007
602-542-3651
602-542-6049 TDD
602-542-3778 fax

Comprehensive Employment Reform for People with Disabilities

On December 18, 1999, one of the most far-reaching federal employment initiatives, the **Ticket to Work and Work Incentives Improvement Act of 1999** was signed into law. This act establishes changes in the Social Security system that are designed to remove employment barriers and put more control in the hands of people with disabilities and their families. The provisions of the act, combined with those in the Workforce Investment Act, can return millions of people with disabilities to gainful employment. The act offers the following enhancements in employment opportunities for people with disabilities:

- more opportunity to retain critical health care coverage at the state and federal level;
- consumer choices among public and private employment services providers;
- non-intimidating access to accurate and timely information in making informed choices;
- the option of trying work and not having to reapply for benefits if a work attempt fails;
- work does not trigger a Continuing Disability Review that could potentially lead to termination of benefits and discouragement to work;
- appointment of a consumer-controlled advisory panel to work directly with the Social Security Commissioner to ensure a user-friendly program; and
- demonstration projects to eliminate the \$700 per month “earnings cliff.”

Can’t Afford to Work: A Catch 22

Many people, including those with significant developmental disabilities, want to work and possess considerable experience, skills, and knowledge to offer prospective employers. However, too often they find themselves trapped in social support programs that are costly to the public and restrict their ability to be employed. While Arizona’s economy offers a wide range of employment opportunities, VR offers education and training opportunities, and the Americans with Disabilities Act (ADA) offering discrimination protection, there remains an unemployment rate of 70% for persons with disabilities.

The unemployment rate for persons with significant disabilities who need long-term care is even higher, as they can not afford to work and lose the necessary supports. Simply put, people are unable to earn enough to pay for the entire cost of the vital supports they need. Consequently, they remain unemployed and dependent upon a variety of social programs such as food stamps, subsidized housing, etc.

Currently, there is no mechanism that allows people with disabilities and their spouses to work and maintain ALTCS eligibility by paying a share of the cost, based on their income, until they can earn their way off of the program. Without a buy-in option, the talents and skills of persons with significant disabilities will continue to be unrealized, and Arizonans will continue to unnecessarily bear the full cost of the community supports for the lifespan of that person.

With the passage of the Ticket to Work and Work Incentives Improvement Act of 1999 (discussed above), states are encouraged to develop Medicaid buy-in programs for people needing long-term care. While some states have already implemented buy-in options, Arizona has yet to draft a program.

Other Issues in the Arizona Public Policy Arena

- Currently, federal funds are available to assist vocational training programs in Arizona at the matching rate of 3.69 federal dollars to 1.0 state dollar. However, the State of Arizona has not appropriated sufficient funds to secure the available federal funds. Full funding of the matching vocational training program would effectively transfer 2,200 persons with disabilities from public assistance to the pool of gainfully-employed, tax-paying citizens.
- The State of Arizona continues to not provide adequate incentives for employers to provide vocational training programs.
- Although there are approximately 97,000 Arizonans with mental disabilities, Arizona is one of only two states that does not extend the protection of the Americans with Disabilities Act (ADA) to persons with mental disabilities under state law.

Increasing Employment Opportunities Through Employer Incentives

Considerable progress has been made across the country in obtaining increased job placements by providing incentives to prospective employers. In the Employer Job Training Tax Credit, as proposed by the Governor's Council on Developmental Disabilities, any employer or potential employer who provides remedial or basic skills training for recipients of Temporary Assistance to Needy Families (TANF), General Assistance or SSDI/SSI is eligible for a State Employer Job Training Tax Credit (EJTTC) that is equal to the actual cost of the training. In this format, potential employees can receive marketable skills in a real work setting, and thus acquire work culture values as well as job skills. Employers are guaranteed a return on their investment, and thus the perceived risks are minimized.

Other employment-related recommendations of the Governor's Council include:

- advocate for changes in public policy on critical employment issues, including employment discrimination and funding increases for RSA waiting lists and extended employment supports;
- increase the employment of individuals with disabilities through training and demonstration of entrepreneurship opportunities through collaborations with the business industry;
- increase initiatives in transition and post-secondary education to enhance employment opportunities; and
- assess employment needs of businesses/industries and communicate those labor market trends to schools and employment training programs.

To contact DES/RSA:

DES/Rehabilitative Services Administration
1789 W. Jefferson
Phoenix, Arizona 85007
602-542-3651
602-542-3778

References

1998 National Organization Disability/Harris Survey of Americans with Disabilities. Louis Harris and Associates, Inc.

Education and Transition

“Holding on to Your Dream”

Sherry gives new meaning to the term “perseverance.” Disabled as a young adult with Charcot Marie Tooth Disease,” a form of muscular dystrophy, she quickly sought help and received training from Vocational Rehabilitation services and was successful in finding employment. But within a few years, Sherry sustained a closed head injury in an accident, and returned once again to VR for assistance. Unsure about her physical and intellectual abilities, she underwent a new evaluation and enrolled at Glendale Community College. In her first semester, she had not only earned a perfect GPA of 4.0, but was performing many hours of volunteer work at the Good Samaritan Medical Center and at HOPE Center for Head Injured.

It took Sherry many years of study at Glendale Community College and Arizona State University, but she finally attained her educational goal: a Master’s in Social Work degree. During her schooling years, her muscular dystrophy continued to progress, and as a result of her increased muscle weakness, she went from using a three-wheel motorized chair to an electric wheelchair. She received assistance in paying for her van modifications so that she could drive herself to work and maintain the independence she cherishes.

Sherry became successfully employed as a social worker, and has served on the Governor’s Task Force on Head Injury. She has conducted family support groups and appeared as a public speaker on several occasions. Her commitment to help people with disabilities find the help they need has served as an inspiration to others, and been a vital part of her own journey to empowerment.

Sherry’s story is truly one of perseverance, and stands as clear testimony for the role of education in promoting the independence and self-confidence of people with disabilities. However, too often individuals with disabilities and/or their families do not receive all of the supportive services they need to successfully complete their education. And too often they do not receive adequate training to learn how to effectively obtain those services.

The call for access to a high caliber, free public education for all students with disabilities can be heard across several arenas, including:

- educational reform;
- State Improvement Plan (Arizona Department of Education and Exceptional Student Services);
- special education personnel needs;
- School to Work Transition Program; and
- special advocacy efforts.

Arizona Educational Reform

The Arizona Department of Education (ADE) is restructuring the state’s public education system. Educational reform is being occurring in a comprehensive manner, and addresses virtually all facets of the ADE. With a strong focus on “achievement” and “accountability,” all state systems are undergoing substantial change. This can be seen in four major initiatives:

- State Academic Standards for All Students;
- Arizona Instrument to Measure Academic Standards (AIMS Test);
- Performance-Based Teacher Certification System; and
- Student Information and Accountability System (SAIS).

State Academic Standards for All Students

Through the participation of parents, students, educators, and concerned citizens, the State Board of Education assumed responsibility for establishing content standards in nine areas: arts, comprehensive health, foreign language, language arts, math, science, social studies, technology, and workplace skills. Each content is divided into five learning levels, ranging from readiness level (kindergarten) to distinction level (students who have mastered the grades 9-12 proficiency level).

Exceptional Student Services (ESS) has partnered with parents, teachers, administrators and state/community agencies to develop a functional skill level of achievement to be included in the State Academic Standards for students with disabilities. The Arizona State Board of Education has approved alternative performance objectives in self-care, health/safety, daily living skills, language arts, math, art and recreation/leisure, and technology.

Arizona Instrument to Measure Standards (AIMS)

The AIMS was designed to determine whether students are meeting academic standards. Administered to sophomores in 1999, the AIMS is to become the graduation requirement of the class of 2002. As a standardized tool for benchmarking student progress, the AIMS is a tool for holding education stakeholders accountable for student growth and achievement.

ADE/ESS is currently developing alternative assessments to measure functional achievement levels for students with disabilities in the areas of listening/speaking, reading, writing, and math. It is important to note that all students are to be assessed with the AIMS, regardless of their disability. The IEP Team (Individual Education Plan) is responsible for determining the course of study leading to graduation for students with disabilities. The team decides the appropriate AIMS level test that each student will be required to pass, and may also decide whether an alternative assessment is the more appropriate in as a graduation requirement.

Performance-Based Teacher Certification System

This system, which was revised in 1998, is designed to ensure that teachers possess the knowledge and skills to teach in their certification areas. Using a combination of requirements which include formal education and scores on knowledge and certification portions of the Teacher Proficiency Assessment, teachers receive either a Provisional or Standard Certificate. It is feared that such rigorous requirements, combined with no provisions for reciprocity with other states, will deepen the already existing teacher shortages. This will have particular impact on Special Education area, where teacher shortages and recruitment problems are major barriers in ensuring quality education for students with handicaps.

Student Accountability and Information System (SAIS)

SAIS is a centralized database/information system that streamlines electronic data exchange and on-line data processing. This allows statewide connectivity via the internet, and ensures that information about student, school and financial matters is accurate and timely.

ADE/ESS State Improvement Plan

The ADE/ESS State Improvement Plan was developed within the context of the ADE initiatives discussed above. To seek improved achievement and accountability in the education of students with disabilities, the plan identified the needs, barriers, and the corresponding strategies for addressing them. To ensure a comprehensive set of needs and barriers, a broad range of stakeholders were enlisted to identify and discuss those areas that must be addressed if statewide improvements for students with disabilities are to be achieved. The group discussed critical areas of early intervention, general and special education programs, student outcome measures, and system outcome measures. All of these areas were viewed as critical to making systemic changes that would have a long-term affect.

The major findings of the ADE/ESS State Improvement Plan area as follows:

Lower percentages of children were being served for all ages and disability groups under IDEA in Arizona than nationally. This is in contrast to the fact that , according to the Arizona Special Education Census from 1994-1998, there was an overall increase of 22% in the numbers of students with disabilities. The most common disability categories served in Arizona in 1998 were reported as follows:

<u>Disability</u>	<u>Percent of Enrollment</u>
Specific learning disability	57.7%
Speech/language impairment	20.0%
Mild mental retardation	6.1%
Emotional disability	5.5%
Moderate mental retardation	2.1%
Other health impairment	1.5%
Orthopedic impairment	1.4%
All mental retardation	8.6%

In the 1998-99 school year, 47% of the 73,529 students enrolled in special education in Arizona were in regular education classrooms, 34% in resource rooms, 18% in separate classes, and less than 1% were in separate schools. Most (75%) of the students with mental retardation were in resource rooms. Typically, students with health impairments (e.g. hearing and visual impairment, autism, orthopedic) were served in regular classrooms. Students with emotional disabilities, specific learning disabilities, multiple disabilities, and traumatic brain injuries were evenly distributed between regular classrooms and resource rooms.

In regular classrooms, speech and language disorders represented 50% of the 6-11 year olds receiving special education, while specific learning disabilities accounted for 40%. Among the 12-17 year olds, specific learning disorders represented 78% of the special education students in regular classrooms, while speech and language disorders accounted for 8%. The study found that separate classrooms and

schools have a much higher proportion of students with mental retardation, and that the number of students being placed in separate settings increased as the students get older.

Overall dropout rates across all grades remained fairly constant from 1994 to 1998, ranging from 8.5 to 9.5 percent, with the overall rate higher for boys (9.3%, compared to 7.6% for girls). Not surprisingly, the high school dropout rates for both boys and girls was substantially higher, with rates ranging from 11.5 to 12.8 percent.

As discussed in the chapter on Employment, *the transition from school to employment (and college) remains the greatest area of discrepancy between people who are disabled and those who are not.* Many special education students have reported that they lacked education in daily living skills such as money management and job/career seeking. Both students with disabilities and their parents consistently report that more transitional services are needed.

Based on their findings in the “Follow Along Project,” the authors (Love and Malian, 1998) identified increased commitment to potential dropouts as one of the most important strategies in preventing joblessness, imprisonment and drug use. Bolstered by high rates of unemployment, the authors strongly recommended early identification of students at risk of dropping out to ensure that they receive appropriate transition services.

In a study of transition services available to youth with disabilities, the Institute for Human Development at Northern Arizona University found the following:

- most students did not have paid employment as a transition goal;
- most students included college as a transition goal;
- most students were not working in the community as they neared graduation.

The programs reporting the most successful transition practices reported the following as essential components:

- community involvement and support;
- collaborations between schools and employers; and
- school-agency partnerships.

Recommendations for improving transition outcomes included:

- increasing in-service and pre-service opportunities;
- increasing the number of transition specialists in school districts;
- following-up with students after graduation; and
- improving communications and collaborations among all stakeholders (i.e. all levels of education, state agencies, employers, and families).

The survey also revealed that there is inadequate communication and collaboration between secondary and post-secondary programs for young adults with disabilities. In addition, the survey indicated the following:

- overall, people with disabilities have not been successful in post-secondary programs, with enrollment rates at 50% lower than the general population;
- post-secondary students with disabilities are often solely responsible for their own educational accommodations;
- linkages between secondary and post-secondary entities are often limited to one-time events or distribution of materials; and
- post-secondary disability programs/specialists have few linkages with adult service agencies.

In a study involving college disability support coordinators, the two most significant barriers identified were the lack of appropriate evaluation data (to substantiate eligibility for campus disability support services), and the lack of funding for evaluations of students who are no longer IDEA eligible. It was determined that each year there are about 400 students seeking disability support services who have no current evaluations and insufficient financial resources to obtain evaluations.

Other barriers reported by the support coordinators included:

- lack of skills for self-advocacy, independence, and problem solving among students with disabilities;
- failure of secondary school documentation to identify the types of accommodations needed by students;
- a tendency of high schools to waive college preparatory courses rather than provide accommodations in classes;
- poor preparation (e.g. study skills, syllabus comprehension) for the academic rigors of higher education;
- a tendency of high schools to focus on remediation rather than compensatory skills and the use of accommodations; and
- limited awareness among teachers, parents, and students about higher education as an option for students with disabilities.

There is an increasing number of students with disabilities receiving education in secure facilities (i.e., correctional facilities). As of September, 1999, 46 secure facilities in Arizona were serving approximately 315 special education students, with the majority being served by the Departments of Corrections and Juvenile Corrections. This number should continue to increase statewide as there is more awareness of the role of education in reducing recidivism and the requirements of IDEA of 1997 are implemented.

Special Education Personnel Needs

Over the next decade, there will be a dramatic shortage in teacher supply. According to the National Center for Education Statistics (NCES), expected increases in student enrollment, accompanied by increased teacher attrition as the baby boom generation approaches retirement, will cause unprecedented teacher shortages. In special education, the highest shortages, in rank order, are expected in: learning disability, multiple handicapped, audiology, physically handicapped, hearing impaired, and visually impaired.

In August, 1999, the Northern Arizona University Social Research Laboratory conducted a survey of personnel needs of charter and district schools to ascertain their needs relative to special education and transition personnel. The survey revealed that the most needed category of personnel were teachers, followed by related services personnel and teacher aides. Schools reported the greatest need for teachers with multiple certifications, with 41% indicating learning disabilities as the most needed area. The most needed related services personnel was speech therapists.

Nearly all Arizona school districts experience shortages of speech and language pathologists, and many employ personnel who do not have full qualification. In the 20th Annual Report to Congress on IDEA, Arizona ranked fourth in the nation in the number of vacant positions for speech/language pathologists.

It is estimated that there are 256,000 children and youth who are of Hispanic origin, out of which about 47% live in homes in which Spanish is the primary language. Current data indicate that the incidence of speech and language disorders is about 18%, and when applied to Arizona statistics, suggest that over 21,657 Hispanic youth may have speech and language disorders. With the recommended maximum caseload of 40 students per pathologist, it can be concluded that Arizona is in need of at least 541 speech/language pathologists who can address the needs of these language-minority students. While the actual number of Spanish-English bilingual speech-language pathologists in Arizona schools is unknown, it is estimated that there are between 25 and 50 statewide.

There is a national concern about teacher retention that is even further displayed here in Arizona. The American Association of Employment in Education reports that almost half of the education majors do not enter teaching upon graduation. Furthermore, about 22% of all new teachers leave the profession within the first three years. DES estimates that of the more than 41,000 employed teachers in Arizona, 20,000 will be eligible for retirement in the next ten years.

School to Work Transition Program

If one of the primary purposes of high school is to guide and prepare students to successfully negotiate their transition into their emerging adulthood, then it is of particular importance that attention be paid to the outcomes generated on behalf of those who have disabilities.

As with the general population, students with disabilities emerge into an array of adult roles: employees, higher education students, community members, renters/home owners, relationship builders, etc. Successful transition into these roles requires the support of school programs, support service agencies, and a broad range of supports within the greater community. To be successful, transition efforts should begin much earlier in life, during elementary school years.

In a 1999 status report commissioned by the Governor's Council on Developmental Disabilities, the Institute for Human Development (IHD) at Northern Arizona University found that Arizona has made significant progress in its transition services delivery system between 1991 and 1997, with particular mention of the numbers of students having some level of transition planning in their Individualized Education Program (IEP) documents.

IHD also found that program limitations and gaps continue to demand stronger linkages between educators, adult agency providers, higher education officials, community members, and state and local administrators. The most important continuing concern centers on the need to establish self-

determination training for at-risk students, especially those with disabilities, beginning in the elementary school years. As the core value in addressing this need, there is a strongly-held belief that “.....a self-advocating, self-determined, self-aware student who facilitates his/her IEP and/or school-to-work transition plan will develop into the best long-term transition investment for all stakeholders.”

Many students with disabilities are also at risk because of an array of conditions: poverty, limited language proficiency, early pregnancy, and criminal behavior. Successful transition practices must provide resolution to all issues that students encounter.

Based on their survey of secondary and post-secondary representatives, there is a variable degree of transition programming and successful practices throughout Arizona. However, the survey respondents indicated that those practices are far from comprehensive or statewide. The survey revealed that:

- there are not enough trained providers in special education and adult service agencies;
- most educators are aware of the need for transition programming, but have had difficulty “selling” it to their colleagues or administrators, and do not obtain sufficient training, materials and partners;
- employers, community members and post-secondary institutions are supportive of transition programs, but are typically not linked to each other;
- there is not a consensus regarding the concept of transition being a community responsibility; and
- communication and collaboration among stakeholders has not yet gained momentum.

Finally, IHD put forth a set of core recommendations aimed at maximizing statewide efforts to assist people move from high school to the workforce. They are:

- Establish an Interagency Director’s “working group” to ensure that common values and goals exist that will further efforts for a statewide transition program.
- Address the many gaps and inter-agency “disconnects” that exist in transition services.
- Plan and develop a coordinated statewide system to provide training and technical assistance to the full range of professionals who are key to effective transition services.
- Ensure that students with disabilities, families, advocacy and support groups receive training and support to ensure informed and active participation.
- Implement a self-determination curriculum for all high-risk students, beginning in elementary school.
- Ensure that every student has a Transition Plan and Portfolio, beginning at least in middle school.
- Develop and monitor junior high/middle school curriculum and transition practices.
- Advise universities and credentialing bodies about specific transition competencies for inclusion in pre-service curriculums and graduate coursework.
- Create a statewide management information system to collect, analyze and disseminate information about transitioning youth in all areas.
- Consider support for legislation that provides resources to alleviate lengthy waiting lists for young adults needing adult services.

Advocacy Efforts

While many of the issues have been presented earlier in this chapter, it remains important to emphasize the role of advocacy groups in promoting the public policies and educational practices that are known to maximize the probability that people with disabilities will lead meaningful and productive adulthoods.

To quote the Governor's Council on Developmental Disabilities: "Individuals with disabilities and/or their families are not currently receiving all of the services and supports that they need to successfully complete their education, nor are they receiving adequate advocacy training to learn how to effectively demand those services."

Subsequent to interviewing several agency representatives, advocates, and persons with disabilities about the barriers and solutions to effective statewide education, the following concerns were most often presented:

There are insufficient funds to ensure an effective statewide effort in providing adequate support services, work/school opportunities, and special education.

Transition services often occur too late to ensure effective emergence into adulthood for persons with developmental disabilities. It is frequently documented that the most successful programs throughout the country are those that provide early intervention.

Although considerable progress has been made in the last decade, there remains a tendency to isolate students with disabilities (e.g., self-contained classrooms, portable units).

There is a need for more training of teachers and families on issues related to behavior management plans and IEPs.

More advocacy is needed at the post-secondary levels, as students with disabilities are "on their own," and must prove their disability to gain access to special needs accommodations.

Efforts must be put forth to increase public awareness of the benefits of investing in educational and support services for students with disabilities. This includes positive media campaigns relative to the benefits of special education.

References

Transition from School to Work and Adult Life: Arizona Status Report. Institute for Human Development, Northern Arizona University, November, 1999

Special Education Personnel Needs Survey. Social Research Laboratory, Northern Arizona University, September, 1999

Social Development: Self-Determination and the Quality of Life

“Free at Last”

John moved from Chicago to Phoenix in 1991. He remembers the exact day, and can even tell you the flight number of the plane that brought him here, because for John, that was a very important day. To John, that day represented the final release from what John calls the “warehouse for the mentally ill.” This is because John had lived for nearly 35 years in institutions. And once he arrived in Phoenix, he moved into a small guesthouse and began to exercise his newfound independence.

In 1993, John rented a small studio apartment. He also remembers it well, as it was the first time in his entire life that he had lived on his own. He loved it, but was not content to stop there.....he wanted more.....he wanted to own a home. John established a good credit history, received professional advice and assistance from a realtor, financial lender, and friends, and by 1996 had moved into his own home, a condominium on a quiet residential street in Phoenix.

John is employed in the food service industry, and thoroughly enjoys his duties, which include serving lunch to school-age children, who like him very much. After work, he likes to work on his home, and often works part-time cleaning homes. He is an accomplished model-maker, and likes to use the exercise and clubhouse facilities as the condominium complex where he lives.

John is proud to be investing in his own future, building equity, and securing his continued independence.

Social Development and Empowered Lifestyles

It is easy to assert that most people, both disabled and not disabled, seek to participate in those life activities (e.g., employment, socializing, money matters, health) that have a direct impact on their quality of life. Indeed, if our lives are to be viewed as “self-determined,” it requires a sense of participation and ownership in the decisions and directions that brought us to the moment and place where we stand.

As has been discussed in this book, the lives of people with developmental disabilities are especially sensitive to the many decisions that must be made relative to education, work, health, social participation, and general quality of life issues. And, as reported in the Harris Survey of Americans with Disabilities in 1998, large gaps still exist between adults with disabilities and other adults with regard to these issues.

According to the Harris survey, these gaps, along with gaps in frequency of socializing and entertainment, can arguably be linked to the gap that exists in life satisfaction. Only about 33% of people with disabilities say they are very satisfied with life in general, compared to 61% of people without disabilities.

As stated by the Governor’s Council on Developmental Disabilities: “Many Arizonans with disabilities have not had the opportunity to actively participate in or direct the decision-making process regarding their service programs, supports or basic life decisions. In many cases they have not known the facts to enable them to make those decisions.” Clearly, as more value is placed on the need to affect one’s own future, it is easy to see the correlation between self-determination, self-advocacy, and life satisfaction.

For purposes of this discussion, the following four areas of empowerment will be briefly presented:

- self-determination;
- community inclusion; and
- leadership development.

Following that section, four programs will be presented that illustrate self-determination paradigms:

- People First;
- Person-Centered Planning;
- Family Support; and
- DES/DDD initiatives that empower consumers and families.

Areas of Empowerment

Self-Determination

People experience self-determination when they have direct participation and authority in their own life decisions. This does not mean that the “right” or best decisions are always made, but rather that there is ownership in both the decisions and their consequences. Simply put, self-determination is indicated when there is freedom to choose. Thus, it becomes imperative that the range of consequences are known, that choice options are known, and that as a bottom line, informed decisions are being made.

If people with disabilities are to seek and achieve a level of independence, they must have the opportunity to make their own decisions. With increased control over their lives, they also must receive adequate information about their choices. In this sense, self-determination can also be viewed as self-advocacy. Whether they have control and choice about their housing options, employment possibilities, and/or social relationships, people with disabilities must have access to accurate information, supportive training, and technical assistance in acquiring the tools they need to exercise responsible decision-making.

Community Inclusion

According to the Harris Survey, a majority of adults with disabilities feel that access to public facilities (75%), the quality of life for people with disabilities (66%), public attitudes toward people with disabilities (63%), how the media portrays people with disabilities (62%), access to public transportation (60%), and including people with disabilities in advertising (57%) have all improved over the past four years. In addition, 69% of people with disabilities claim to have voted in the 1996 presidential election.

As people with disabilities become more independent, and feel a stronger sense of control over their own lives, they are also more likely to identify as a real member of the community. Self-determination and self-advocacy lead to self-confidence and a sense of pride, which are vital tenets of community involvement. For all people, with and without disabilities, activities aimed at self-improvement and empowerment will also have an immediate impact on the community context in which they live. And, as people become invested in the quality of community life, they are more likely to identify as a member of that community.

Leadership Development

Self-determination, self-advocacy, and community inclusion are naturally entwined with leadership development. If people with disabilities are to acquire control over their own lives, engage in decisions based on knowledge and skill, and relate to the larger community context, they are necessarily embarking on a path to leadership.

If individuals with disabilities and their families are to have an effective voice in the policy-making and service delivery strategies that affect them, they leadership development programs must be accessible and affordable. This is clearly seen in the activities of the Governor's Council on Developmental Disabilities, whereby they seek to increase the number of individuals with disabilities and/or their families who are involved in systems change efforts. Such activities must be translated into board memberships, work group experience, and legislative work in advocating on disability issues.

Programs of Self-Determination

People First of Arizona

As noted in the discussion of the history of developmental disabilities, the People First movement was founded in the 1960s in Sweden as a core component of the self-advocacy movement. As such, it brought strong representation to the need for people with disabilities to speak out for themselves and have a major "voice" in the direction of their own lives.

Since the early 1980s, the Arizona movement has served to empower people with disabilities to become self-advocates in obtaining the necessary supports to fulfill their dreams and lead productive lives of their own choosing. People First, as a self-advocacy movement by and for people with disabilities, promotes the following:

- self-advocacy;
- self-determination;
- leadership opportunities;
- personal growth and financial control;
- consumer-driven programs and services; and
- education and training.

People First of Arizona strives to fulfill three major goals:

- Teach self-advocacy skills to people with disabilities.
- Promote self-determination and Person-Centered Planning.
- Influence public policy decisions at all levels by developing the leadership of persons with disabilities.

For more information on People First of Arizona, contact:

People First of Arizona
P.O. Box 6123-791A
Phoenix, Arizona 85005
602-542-6825

Person-Centered Planning

Person-centered planning refers to an approach in which people with disabilities direct their own services. As such, it is a service delivery approach that is based on a fundamental belief in the right of self-determination, and is characterized by having the services and funds flow as directed by the client.

In person-centered planning, the services are determined in accordance with the “preferred future” of a person with disabilities and/or his/her family. The preferred future is what the person and family want to do in the future, and is based on their strengths, capabilities, lifestyle, and cultural background. In essence, person-centered planning is based on the awareness of and sensitivity to the lifestyle and cultural background of the consumer and his/her family, and is fully grounded in the principles of self-determination and self-advocacy.

In Arizona, DES/DDD has established the Design Team for the purpose of furthering self-determination principles in the planning and delivery of services to people with developmental disabilities. Comprised of people with developmental disabilities, their parents and family members, service providers, and DES/DDD staff, the Design Team is charged with taking a comprehensive view of services, and examining the extent and ways in which member-directed services can occur.

The Design Team has recommended that “a person/family-centered planning process be implemented throughout the system in FY 2000 and serve as the basis for determining funding levels in FY 2001.” As its first major focus, the Design Team is examining the issue of fairness and equity in service costs. Thus far, the team has also been working on the following areas:

- development of a personal payment system;
- making the system less complicated;
- making more information available;
- making planning more meaningful;
- improving training in planning; and
- measuring changes.

While person-centered planning is not suited for all consumers and/or families, it does represent a larger nation-wide movement toward increased consumer participation and independence. And while the program requires careful steering to safeguard against budgetary and service quality concerns, it does serve as a looking glass to the future of an ever-evolving continuum of care for people with disabilities and their families.

Family Support Act

If people with disabilities and/or their families are to realize self-determined futures that are based on their own personal preferences, then service delivery systems must be “family-friendly.” If services plans are to allow for individual and/or family control, then they must be driven by consumer/customer priorities. And, if services are to be flexible in meeting varied needs and cultural contexts, then they must provide a breadth of options and opportunities for choice.

The Family Support Act, enacted by the Arizona Legislature in 1993, requires that DES/DDD take action to expand decision-making opportunities for families and persons with developmental disabilities. It encourages the availability of choices in services, innovation in service delivery, and gives families and individuals more authority and responsibility in determining needs and developing service plans. The Family Support Act also calls for the availability of cash subsidies and vouchers, which enable families and individuals more authority and choice in carving out their own service delivery system.

DES/DDD is responsible for administering the Family Support Act, and has empowered the Family Support Steering Committee to develop, implement and monitor the family support programs of the Division. The Steering Committee is comprised of family members, advocates, service providers, DDD staff, and representatives of the Department of Health Services and the Arizona Health Care Cost Containment System.

The guiding principles adopted by the statewide Family Support Steering Committee of DES/DDD are as follows:

Family Empowerment: Family control, responsibility, and decision-making regarding the family member with a developmental disability should be encouraged and increased.

Family Integrity: Services should promote and enhance family unity, competence, and independence while minimizing dependency.

Family Needs: Services must be based upon the issues identified by families and be flexible enough to meet the unique needs of each family.

Family Values: The values of mutual support and interdependence, long-term caring relationships, and unconditional acceptance of all family members should be promoted throughout the service system.

Community Development: When families have needs which can not be met through state-funded services, schools, churches, neighbors, and local community organizations must be integrated with the family support services network.

A Family Support Planning Retreat was held early in fiscal year 2000. As a result of the input from the participants, who included a diverse group from across the state, the Office of Advocacy, Family Support and Self-Determination was formed. The activities of this office, which includes consumers and family members, support the visions of the Steering Committee with a particular focus on the following:

- individual/family-driven supports;
- self-determination;

- information dissemination;
- increasing collaboration across and between different service systems; and
- creating more flexible systems.

DES/DDD Initiatives

In addition to the formation and activities of the Family Support Steering Committee, DES/DDD has promoted other initiatives aimed at consumer and family empowerment, including:

Robert Wood Johnson Foundation Grant: Individual Decision

This project, titled “This is My Life: Arizona’s Response to Consumer Control, Choice and Responsibility,” seeks to enhance consumer control and self-determination by empowering people with disabilities and their families to control their own service budgets, live how and where they choose, contract directly with service providers, and enhance their quality of life through expanded opportunities for community integration and inclusion. Using a mentoring approach, DES/DDD has committed to continuing this project beyond the grant cycle.

Home of Your Own

This project assists people with disabilities in buying their own homes by providing down payment or closing costs, without jeopardizing their eligibility for federal and state subsidies and services. The Division’s goal is for 100 people to purchase their own homes per year.

Core Indicators Project

Arizona is one of seven states to participate in this project to establish and pilot a set of quality measures called “core indicators.” These indicators, which focus on individual choice and quality outcomes, are intended to assess the following:

- community integration;
- choice and self-determination;
- independence;
- quality of relationships;
- quality of life;
- satisfaction with service coordination and service providers;
- access to supports and services;
- safety;
- health; and
- respect and rights.

Results of the pilot should allow states to develop practical strategies to improve the quality of supports and services.

Voucher Program

With more than 1,000 people using vouchers to purchase services, individuals and families are being empowered to choose providers. This program improves efficiency and effectiveness of services, and by increasing the level of family involvement, leads to increase responsibility and satisfaction in service quality.

Maximizing Potential through Early Intervention

The development potential of people with developmental disabilities can be maximized if developmental delays and/or conditions known to be associated with delays are identified very early in life. To maximize the development potential of Arizona children from birth to three years of age who show signs of developmental delays, the Arizona Early Intervention Program for Infants and Toddlers (AzEIP) has been established, which is based on and funded by the Individuals with Disabilities Education Act (IDEA).

Consistent with the operating philosophy of other family-empowerment models, AzEIP utilizes a family-centered philosophy that is based on the premise that families know what their children need as well as what the family as a whole needs. Using a “strengths-based” approach, AzEIP recognizes that the family is the constant in a child’s life and that services and programs must support, respect, encourage and enhance the strengths and competencies of the family.

Utilizing a network of early intervention services administered by a wide range of agencies, AzEIP seeks to develop and implement a comprehensive, coordinated, community-based delivery system that is family-focused and culturally appropriate. In this manner, families can be assisted in identifying and making informed decisions about the early intervention services that are most suitable to their needs. These services typically include audiology, nursing, nutrition, occupation and physical therapy, psychological services, individual and family counseling, specialized instruction, transportation, speech and language pathology, vision, and many other services that are designed to help children become ready to learn.

To advise and assist DES in carrying out its responsibilities relative to AzEIP activities, the Governor has appointed the Interagency Coordinating Council (ICC), which is comprised of parents and representatives of public and private agencies. In Arizona, there is an interagency agreement between DES, the Department of Health Services (DHS), the Department of Education (ADE), AHCCCS, and the Arizona School for the Deaf and the Blind.

AzEIP has established a public-awareness program focusing on early identification of eligible infants and toddlers, and strives to inform the public and referral sources about how to make referrals and how to gain access to evaluation and support services. It has established a comprehensive child-find system for hospitals, physicians, parents, day care programs and others to refer children to the early intervention system for evaluation and assessment. Other mechanisms have also been operationalized (i.e., Community Advisory Councils, local Interim Service Coordinators) to facilitate the implementation and coordination of community resources.

Each year, approximately 3,000 infants and toddlers receive early intervention services in natural settings such as home or in day care. Whenever a family has a disagreement, complaint or grievance relative to an early intervention service or program, AzEIP provides for procedures to ensure that the rights of families in the early intervention system are protected.

For more information on Early Intervention Services, contact:

Arizona Early Intervention Program
3839 N. Third Street
Phoenix, Arizona 85012
602-532-9960
602-200-9820 fax

References

1998 National Organization Disability/Harris Survey of Americans with Disabilities. Louis Harris and Associates, Inc.

Health Care

If people with disabilities are to strive for and realize their full potential for living self-determined lifestyles, they must have access to medical and dental care that maximizes their health status. If people with disabilities are to live independently, pursue educational goals, be a member of the workforce, and be maintain community inclusion, they must receive medical and dental services that are responsive and appropriate to their needs.

Arizona Long Term Care System (ALTCS)

In its efforts to provide effective, quality health care, DES/DDD provides medical services to people with disabilities who are eligible for the Arizona Long Term Care System (ALTCS), a federally funded Medicaid research and demonstration program. Services are provided through contracted health plans, and are coordinated by a primary care physician.

ALTCS, provides eligible recipients both acute and home/community-based medical services, including, but not limited to, the following services:

- augmentative communication devices
- attendant care
- Early Periodic Screening Diagnosis and Treatment (EPSDT)
- health plan (acute care) services
- home health aides and nurses
- hospice
- mental health (in coordination with ADHS and regional behavioral authorities)
- non-emergency transportation
- physical and respiratory therapy
- respite care
- speech/hearing therapy

Health Care Concerns: Implications for Public Policy

The eligibility for ALTCS services is determined by the Arizona Health Care Cost Containment System (AHCCCS), the Arizona system for Medicaid. When people with disabilities are referred for eligibility determination under ALTCS, they must cooperate in the determination or, according to state law, will not receive other services from DES/DDD.

In Arizona, Medicaid health care services for people with disabilities can only be provided if they are determined as a “medical necessity,” but the Arizona definition of “medical necessity” often prevents people from receiving services, pharmaceuticals, and equipment. In addition, Medicaid often will not cover certain dental services such as dentures, because they are considered “cosmetic.” This creates a major policy dilemma when medical procedures considered as only “cosmetic” often pose insurmountable barriers to people’s plans for employment and community inclusion. This stands in direct contrast to the program movements toward “person-centered” plans and “preferred futures.”

According to the 1998 Harris Survey, Although nine out of ten (90%) of adults with disabilities are covered by health insurance, they are nearly twice as likely (23% to 13%) to report that they are not satisfied with the health care services they and their family have used. Among those who are insured, one out the three (32%) say they have special needs because of their disability (e.g., special therapies, equipment and/or medicine) that are not covered by their health insurance.

The Harris study also reported one out of five (21%) adults with disabilities did not get medical care that they needed on at least one occasion during the previous year, which is also twice the rate of people without disabilities. One out of four (28%) of adults with disabilities postponed getting health care they thought they needed as a result of not being able to afford it. Furthermore, among adults with disabilities who were not covered by health insurance, nearly one in five (18%) were not able to get insurance due to their disability or pre-existing health condition.

As is true throughout the country, the assurance of appropriate health care for all people, and in particular for at-risk populations such as people with disabilities, can only be provided through substantive reforms in the public policies. In this sense, if people with disabilities are to have guaranteed access to appropriate health and dental care, it will only be achieved through supportive legislation.

To this end, in Arizona, the Governor's Council on Developmental Disabilities supports legislation that protects the rights of people with developmental disabilities to secure access to appropriate health and dental care in the following areas:

- expanding Medicaid services to include dental and vision services;
- developing a Patient Protection Bill of Rights; and
- requiring of private insurance companies to include both mental and physical health care coverage.

References

1998 National Organization Disability/Harris Survey of Americans with Disabilities. Louis Harris and Associates, Inc.

Implications for the Future

As stated in the Introduction, the purpose of this book is to provide information for people who must make important choices about the quality of life of individuals with disabilities. This book has intentionally not provided advocacy for the agenda of particular organizations. However, as is the case with any examination of human needs and levels of response, this book has necessarily brought attention to many areas that require both immediate focus and future actions. These areas can be briefly summarized as follows:

Self-Determination

Over the past couple of decades, there has been a growing movement which advocates for the real participation and self-determination of people with disabilities and their families in making their own decisions about support services and future planning. This major trend will continue in the coming years. **Thus, it is imperative that the larger service delivery networks provide seamless efforts to provide accurate information, increased breadth of services (i.e., culturally appropriate options), and flexible financial policies. To ensure individual and family control and that services are customer-driven, continued emphasis should be placed on developing programs and services that are consistent with the values of the Family Support Act.**

Housing

People with disabilities continue to face overwhelming barriers in securing housing that is accessible and affordable. Housing discrimination continues to exist on the basis of disability, and community exclusion is still evident in many neighborhoods. With the help of advocacy organizations and the major public and private stakeholders, **it will be important to bring high visibility to the right to fair housing and legal assistance resources for people with disabilities. In addition, innovative programs and practices such as the “Home of Your Own” program will play an increasing role in promoting creative solutions the call for self-sufficiency and independent living arrangements.**

Employment

With nearly 75% of Arizonans with disabilities being unemployed, the need to provide adequate funding for vocational training and employer incentives, so that jobs are both attainable and sustainable.

Education and Transition

Although there have been sweeping advances in the overall state of education for all people, including people with disabilities, too often school-age children and their families do not have adequate access to high quality, free education and academic support services. **The major stakeholders of public education and people with disabilities must seek to continue in their efforts to bring remedy to the need for academic accountability and barrier-free education** (as evidenced in the ADE/ESS State Improvement Plan). **Transition programs must shift toward earlier intervention, and more attention must be placed on partnering among schools, employers, and institutions of higher education. In addition, special efforts must be made to promote increased interest and hiring of special education**

teachers who are trained in the needs of people with disabilities and appropriate behavioral management practices.

Health Care

Similar to the housing needs of people with disabilities, the major barriers to health care needs are accessibility and affordability. **If people with disabilities are to receive adequate, affordable health care, there will have to be a streamlining of access procedures and a broadening of health care choices within the state-contracted health plans.** At the same time, it will be important to promote better education in the medical community of developmental disabilities so that they can successfully prescribe the appropriate medical supports to the funding mechanisms. Similarly, the correlation between prescribed medications, their adverse affect on dental health, and subsequent employability requires extensive attention.

In addition to the major areas noted above, there are several implications for services that cut across all areas. They include, but are not limited to the following:

People with disabilities are living longer. This necessarily affects the design and delivery of support services in the areas of housing, employment, health care and social development, and means that more attention must be given to emerging programs aimed at transitioning people from independent to group living situations, and from the workforce to retirement. There will an increased need to the view the needs of people within the natural context of aging, conservatorship, and guardianship. Transition issues related to aging are also the result of the “graying of the care-giver population,” which draws attention to the gaps in support that await the aging person with disabilities.

People with disabilities have limited access to transportation. With the passage of Transit 2000, and renewed attention to mass public transit in the communities, which border Phoenix, there is some optimism regarding the development of a seamless regional system across city boundaries. As a key to employment and community participation, this development is paramount for people with disabilities. It will be important for advocates to ensure that the special needs of people with disabilities (e.g., accommodations for attendants, accessibility) remain visible during the planning and implementation phases of new transit systems.

Conclusion

As the State of Arizona continues to witness dramatic growth, especially in the urban areas, there will be corresponding increases in all populations, including people with disabilities. Accordingly, the demand for services and funding levels will also grow, requiring the steadfast attention of service providers, planners, funders, and policy makers. As identified in this book, there are several major initiatives (most of which support the movement towards family support, self-determination and advocacy) that can have an enormous positive impact on the quality of life for thousands of Arizonans, their families, their communities, and the socio-economic health of Arizona as a whole.

Thus, while considerable progress has been made, much work remains to be done. If the living conditions for people with disabilities are to be truly comparable to those without disabilities, then information, dialogue, and collaborative commitments must occur that bring community leaders, service providers, and policy makers to a common ground of vision and action.