

The American Dream Belongs to Everyone:

A Report to Congress, the President,
and the National Council on Disability

Fiscal Years 2003-2004



Prepared by the
Administration on Developmental Disabilities
Administration for Children and Families
U.S. Department of Health and Human Services










A Message from Commissioner Patricia A. Morrissey Administration on Developmental Disabilities

The American dream belongs to everyone. This belief provides a foundation for the work that the Administration on Developmental Disabilities (ADD) and its many grantees (180 plus) do on behalf of individuals with developmental disabilities and their families.

There are approximately 4.5 million individuals with developmental disabilities in the United States. Developmental disabilities are severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22. Developmental disabilities result in substantial limitations in three or more areas of major life activities:



-  capacity for independent living
-  economic self-sufficiency
-  learning
-  mobility
-  receptive and expressive language
-  self-care
-  self-direction

Fortunately, we have strong Federal policies and Executive Branch leadership to help these individuals and families realize their dreams to live and thrive in communities across America. ADD carries out its mandate through the direction given to us in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402). The law states:

The purpose of this title (Title I, P.L. 106-402) is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title...

The rationale for this legislation and many other Federal laws is that historically, individuals with disabilities have often been isolated and segregated from the mainstream of society. Individuals with developmental disabilities still experience discrimination in critical areas such as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services. Discrimination is experienced in various forms, including the failure to make modifications to existing facilities, policies, and practices. Individuals with developmental disabilities are frequently offered lesser services, programs, activities, benefits, jobs, or other opportunities.

Through the DD Act and other laws such as the Americans with Disabilities Act, the Social Security Act, the Rehabilitation Act, and the Individuals with Disabilities Education Act, each of which addresses one or more of the forms of discrimination faced by individuals with disabilities, ADD's grantees are empowered to:

- ✚ Help individuals with developmental disabilities and their families to become effective advocates for themselves;
- ✚ Build the capacity among service providers and other professionals to treat individuals with developmental disabilities in an appropriate and respectful way; and
- ✚ Bring about changes in human service systems and communities so that individuals with developmental disabilities and their families have more choices and control over services and supports.

ADD and its grantees are also empowered by two new initiatives of President George W. Bush related to individuals with disabilities. First, President Bush launched the New Freedom Initiative on February 1, 2001. The purpose of the New Freedom Initiative is to fully integrate Americans with disabilities into the mainstream population, allowing them full access to voting, employment, education, home ownership, community activities, transportation, and many other aspects of life and liberty that all Americans should enjoy. Through Federal Government actions and public-private partnerships, three broad goals are being addressed. Those goals are to:

1. Increase access to assistive and universally designed technologies;
2. Expand educational opportunities for Americans with disabilities; and
3. Promote full access to community life.

Second, on June 18, 2001, the President signed the Executive Order on *Olmstead* (*Olmstead v. L.C.*, 527 US 581 (1999)), Executive Order 13127, in which he directed Federal agencies to address the decision in the *Olmstead* case. In that decision, the Supreme Court determined that the Americans with Disabilities Act required states to place qualified individuals with mental disabilities in community settings rather than institutions whenever treatment professionals determine that such placement is appropriate, the affected persons do not oppose such placement, and the state can reasonably accommodate the placement, taking into account the resources available to the state and the needs of others with disabilities. In the Executive Order, the President directed the Federal Government to assist states and localities to implement the *Olmstead* decision quickly, so as to ensure that all Americans have the opportunity to reside near their families and friends, live more independently, engage in productive employment, and participate in daily community life.

Finally, ADD and its grantees are empowered by Secretary Michael Leavitt's goals for the Department of Health and Human Services to:

- ✚ Transform the health care system by eliminating inequalities;

- ✦ Modernize Medicare and Medicaid so that individuals with disabilities will be cared for in their home and community; and
- ✦ Protect life, family, and human dignity by advocating that individuals with disabilities be cared for with dignity and respect by the health care system and by rewarding self-reliance and work.

ADD's grantees help individuals with developmental disabilities and their families in many different ways. The DD Act directs them to assist individuals with developmental disabilities through activities in one or more areas, including: quality assurance, education and early intervention, child care, health, employment, housing, transportation, recreation, and other services available or offered to individuals in a community, including formal and informal community supports, that affect their quality of life. In addition, what ADD's grantees do with the funds they receive from ADD is influenced by the suggestions and advice they receive from individuals with developmental disabilities and their families. The DD Act requires grantees to collect and consider their suggestions and advice.

By listening to and caring about individuals with developmental disabilities, by having a strong, but flexible law behind them, and by sharing a common mission with the President and Secretary Leavitt, ADD's grantees play a central role in bringing the American dream to individuals with developmental disabilities and their families.

This report tells stories about ADD's grantees and how they have changed lives – through technology, new jobs, new opportunities, empowerment training, and protection of rights. Here are some highlights.

- ✦ As the result of grantees' efforts, individuals with developmental disabilities are more independent and self-sufficient. In Minnesota, individuals with developmental disabilities have been taught document scanning and now have white collar jobs in technical and medical environments. In rural Arkansas, a mobile van allows individuals with developmental disabilities to have access to dental services for the first time. In Mississippi, a Smart Car has been developed that allows individuals with developmental disabilities to drive. In Georgia, an ongoing study is tracking the experiences of individuals with developmental disabilities who recently moved from institutional placements to homes in the community, thereby enabling state officials to ease future transitions.
- ✦ As a result of grantees' efforts, children with developmental disabilities are integrated through inclusive education, early intervention, and child care. New Mexico and Indiana train child care providers to work with children with developmental disabilities. Connecticut offers training for parents and professionals. New York provides early intervention services that allow for access to appropriate resources and services. Montana and Massachusetts support programs that teach students with developmental disabilities social and career skills in order to ease the transition from school to work. Other grantees are promoting inclusion of children with developmental disabilities at all stages of education.

- ✦ Through grantees' efforts, individuals with developmental disabilities have better quality services and support. Ohio has a "report card system" that allows people with developmental disabilities to "grade" care providers. California provides activities and community involvement opportunities to seniors with developmental disabilities.
- ✦ Through the work of grantees, individuals with developmental disabilities are trained and active in self-advocacy. Now, in every state, after many years of having little voice in laws and services that are important to them, individuals with developmental disabilities are creating change. Some initiatives that are helping to facilitate this change include self-advocacy and system advocacy training in Alaska and Tennessee, outreach in Hispanic communities in Illinois, and the availability of legal information over the telephone in Arizona.
- ✦ Through grantees' efforts, individuals with developmental disabilities have their complaints of abuse, neglect, discrimination, and other civil rights violations addressed in varied settings. In addition to addressing rights violations on a case-by-case basis, many states and Territories support programs to prevent these violations from occurring in the first place. Wyoming provides a variety of resources specially designed for people with developmental disabilities who become victims of crime. California provides individuals with developmental disabilities and their families and caregivers with health and safety training designed to minimize risk of abuse and keep people with developmental disabilities safe.

ADD's grantees are committed to bringing the American dream to individuals with developmental disabilities. This report documents and celebrates their efforts to secure choices and control for individuals with developmental disabilities and their families. Through the efforts of ADD's grantees, individuals with developmental disabilities have greater freedom and independence regarding where and with whom they live, and where they work. They have better access to health care, education, child care, transportation, and recreation and are protected from abuse, exploitation, and denial of rights. It is a great story and a powerful record!

Together, we believe these policies, grants, and advocacy activities establish a powerful record of achievement in service to individuals and families challenged by developmental disabilities.

/s/

Patricia A. Morrissey, Ph.D.

Commissioner

Administration on Developmental Disabilities

**The American Dream Belongs to Everyone:
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Prepared by the Administration on Developmental Disabilities**

Executive Summary

As required by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), the fiscal year 2003-2004 report is based on the analysis of individual grantee reports submitted annually to this Department. The report has been organized to reflect the achievements of ADD's grantees: the State Councils on Developmental Disabilities (Councils), Protection and Advocacy Agencies (P&As), University Centers for Excellence in Developmental Disabilities (UCEDDs), and Projects of National Significance (PNS).

ADD's goal and responsibility is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

In order to best showcase ADD's achievements, this report is structured around ADD's Program Assessment Rating Tool (PART) Long Term Goals and Annual Measures, which were approved by the Office of Management and Budget (OMB) in fiscal year 2002.

The PART was developed to assess the effectiveness of Federal programs and help inform management actions, budget requests, and legislative proposals directed at achieving results. The PART examines various factors that contribute to the effectiveness of a program and requires that conclusions be substantiated with evidence. The PART assesses if and how program evaluation is used to inform program planning and to corroborate program results.

ADD's PART measures are the same measures used to evaluate its results in compliance with the Government Performance and Results Act (GPRA). Highlights of this report, as structured by the PART/GPRA performance measures, are as follows. It should be noted that these numbers, and other statistics throughout this report, are measures of persons served by each grantee in specific issue areas. In a given year, one person may be assisted by multiple programs; these statistics refer to the number of services rendered rather than the number of people served:

Individuals with developmental disabilities are more independent and self-sufficient as a result of employment, transportation, housing, and health services

Employment:

- ✦ Through the activities of 61 UCEDDs, 70,806 people participated in projects that helped individuals with developmental disabilities to acquire, retain, or advance in employment.
- ✦ Forty Councils reporting on this priority made employment more available or obtainable for 2,937 people with developmental disabilities.

- ✦ Thirty-nine P&As reporting on this priority supported 391 people with developmental disabilities in obtaining or maintaining employment consistent with their interests, abilities, and needs.

Transportation:

- ✦ UCEDD projects resulted in 32,965 people with developmental disabilities having increased access to accessible, reliable transportation.
- ✦ Twenty-two Council programs aimed at improving transportation options helped 17,241 people with developmental disabilities get to work, school, church, health appointments, and other important needs and services, furthering their independence.
- ✦ Thirty-three P&As helped 165 people with developmental disabilities determine ways of getting where they needed to go.

Housing:

- ✦ UCEDDs enabled 37,000 people to participate in projects promoting equal access to community housing, including assistance related to renting, owning, or modifying an apartment or house.
- ✦ Twenty-eight Councils made housing more accessible for 2,867 people with developmental disabilities by participating in deinstitutionalization efforts and ensuring that those with independence can continue to maintain it.
- ✦ Due to the efforts of P&As, 494 individuals were able to obtain or retain a residence and live where and with whom they chose.

Health:

- ✦ Through UCEDD projects, 110,752 people participated in activities that allowed individuals with developmental disabilities to acquire the knowledge and skills to gain access to appropriate health services.
- ✦ Council activities in 24 States increased health care availability for 8,666 individuals by educating health professionals on the needs of people with developmental disabilities, teaching self advocacy, and encouraging facility accessibility conversions.
- ✦ A total of 52 P&As increased access to affordable health care for 1,362 individuals with developmental disabilities by providing them with advice, advocacy training, legal intervention, or other forms of assistance.

Children with developmental disabilities are integrated through inclusive education, early intervention, and child care

- ✦ Due to the efforts of UCEDDs, 38,989 people participated in projects that allow families of children with developmental disabilities to have access to appropriate, accessible child care services.
- ✦ UCEDD projects allowed 136,359 people to participate in activities supporting the increased availability of inclusive and appropriate education for people with developmental disabilities.

- ✦ Sixteen Councils worked to increase availability of quality child care for 2,048 families who needed accessible child care.
- ✦ Councils in 43 States increased the knowledge, capabilities, and self-advocacy skills of 27,351 students with developmental disabilities and their families to ensure the schools they attend are providing inclusive and appropriate local educational opportunities.
- ✦ A total of 15 P&As assisted 35 families in finding or maintaining child care that met the needs of both the parent and the child.
- ✦ By working with parents, educators, school administrators, and policy makers, 56 P&As helped to ensure that 11,289 students with developmental disabilities gained or maintained access to appropriate educational opportunities in their local area.

Individuals with developmental disabilities have better quality services and support

- ✦ UCEDD programs allowed 62,024 people to participate in activities that improve services, support, and assistance available to people with developmental disabilities.
- ✦ Through the activities of 46 Councils, quality assurance was advanced for 87,358 people with developmental disabilities, increasing their safety or personal welfare and maintaining their personal authority through training in self advocacy, information dissemination, and public awareness.
- ✦ Thirty-nine Councils helped 45,636 people with developmental disabilities and their families take advantage of available local community services.
- ✦ A total of 56 P&As secured or maintained quality assistance for 5,917 people with developmental disabilities, increasing their safety and/or personal welfare and helping them to maintain their personal authority.

Individuals with developmental disabilities are trained and active in self-advocacy

- ✦ Through the efforts of 48 Councils, 41,200 people with developmental disabilities were trained in leadership, self-advocacy, and self-determination, ensuring their ability to make choices for their lives.
- ✦ The activities of 39 Councils helped 1,851 people with developmental disabilities or their family members to attain membership on public and private bodies and boards, enabling them to speak out on behalf of themselves and others with disabilities.

Individuals with developmental disabilities have their complaints of abuse, neglect, discrimination, or other human or civil rights violations addressed

- ✦ A total of 56 P&As investigated and, if necessary, corrected instances of abuse, neglect, discrimination, or rights violations, ensuring that people with developmental disabilities live free from abuse and neglect, and preserving their ability to make choices for their lives.

The information highlighted above is a representative sample of the activities performed in fiscal years 2003 and 2004 in order to improve the lives of people with developmental disabilities.

ADD is pleased with the achievements of its grantees and with the significant progress that has been made, but recognizes the need for additional improvement of the services and opportunities available to individuals with developmental disabilities. We look forward to continued work with

our partners and grantees to continue to meet the challenges that lie ahead, and to strive to achieve a better way of life for all Americans.

Additional data are provided throughout the body of this report, and detailed statistical tables are available in *Appendix A*.

How this Report is Structured

Chapter 1: The Administration on Developmental Disabilities provides an overview of the major ADD grant programs established through the DD Act, explaining the unique role that each grant program plays in improving the lives of people with developmental disabilities.

In *Chapter 2*, detailed examples of ADD program achievements are structured around OMB's PART Performance measures.

Additionally, the report provides information regarding accountability (*Chapter 3*) and Projects of National Significance (*Chapter 4*).

Chapter 5: DD Network Collaborative Projects, Activities, and Progress gives an overview of how collaboration allows ADD's grantees to maximize the impact their programs have on the lives of people with developmental disabilities. *Chapter 6: Technical Assistance and Interagency Activities* provides information about the technical assistance ADD offers its grantees, and discusses ADD's participation in interagency committees. *Chapter 7: New Freedom Initiative Activities* explains the Supreme Court's Olmstead Decision and President George W. Bush's New Freedom Initiative, and ADD's contribution to that initiative.





Appendix A of this report provides detailed statistical information regarding the outcomes of the various initiatives supported by ADD's grantees. *Appendix B* lists contact information for all grantees.

Though it cannot possibly describe the entire scope of activities conducted by ADD's grantees, ADD hopes that this report will give readers a sense of how these programs work to improve the lives of all Americans and to help individuals with developmental disabilities achieve greater independence and self-sufficiency.








Chapter 1: The Administration on Developmental Disabilities

The U.S. Department of Health and Human Services, through the Administration for Children and Families, has delegated responsibility to the Administration on Developmental Disabilities (ADD) to manage four grant programs. These programs are authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) to ensure that individuals with developmental disabilities and their families not only receive the services and supports they need, but also help to plan and design those services.

The four ADD grant programs are:

-  Protection and Advocacy Agencies;
-  State Councils on Developmental Disabilities;
-  University Centers for Excellence in Developmental Disabilities Education, Research, and Service; and
-  Projects of National Significance.

Each ADD grant program plays a unique role in the lives of people with developmental disabilities through a range of activities such as:

-  Upholding and advancing their civil and human rights;
-  Researching and planning of long-term systems change;
-  Training health care professionals and other specialists;
-  Educating policymakers and the public;
-  Testing innovative service models to determine their effectiveness;
-  Training individuals as self-advocates; and
-  Disseminating cutting-edge research findings.

ADD's grant programs received funding from ADD in the amounts of \$144.8 million and \$149.9 million in fiscal years 2003 and 2004, respectively.

ADD grantees in each State work collaboratively with other grantees and with consumers, businesses, and communities to form statewide networks of support that are tailored to meet the needs of individuals with developmental disabilities. Under the DD Act, ADD programs are required to support capacity building activities that will benefit people with developmental disabilities as well as individuals with other types of disabilities. Capacity building activities are defined as activities intended to build a system for sustaining and expanding the successful delivery of services, support and other assistance to individuals with developmental disabilities and their families.

ADD is required by the DD Act to prepare a report, at least every two years, for the President, Congress, and the National Council on Disability, detailing the recent goals and outcomes of these four programs.

State Councils on Developmental Disabilities (Councils): Councils are composed of individuals with significant disabilities, their parents and family members, and representatives of

State agencies that provide services to such individuals. Council members develop and support local and system-wide services that enable persons with developmental disabilities to achieve their maximum potential and participation in their communities, thereby leading independent and fulfilling lives.

Councils help people with developmental disabilities by:

- ✦ Developing a State Plan that lays out activities for demonstration of new approaches for enhancing their lives;
- ✦ Conducting training activities;
- ✦ Educating the public about their abilities, preferences, and needs;
- ✦ Providing information to policymakers to increase their opportunities;
- ✦ Supporting their inclusion in communities; and
- ✦ Eliminating barriers to full participation in community life.

Grants are allotted on the basis of population, financial need, and service needs to the 55 Councils. In fiscal year 2003, ADD had \$71.1 million available for grants to the Councils. In fiscal year 2004, \$73.1 million was available for Council grants.

Protection and Advocacy Agencies (P&As): P&As protect and advance the legal and human rights of individuals with developmental disabilities. The DD Act requires each State to establish a P&A system to empower, protect, and advocate on behalf of persons with developmental disabilities. P&A agencies must be independent of service-providing agencies. P&As are authorized to provide information and referral services, and to exercise legal, administrative, and other remedies to resolve problems for individuals and groups of clients. P&As are also required to reach out to people who traditionally have been unserved or underserved. The following Federal laws other than the DD Act give P&As the power to assist people with types of disabilities other than developmental disabilities, including mental illnesses:

- ✦ Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act – 42 U.S.C. §10801 et seq. 42 C.F.R. § 51.1 to 51.46;
- ✦ Protection and Advocacy of Individual Rights (PAIR) – 29 U.S.C. §794e; and
- ✦ Assistive Technology for Individuals with Disabilities (PAAT) – 29 U.S.C. §3012(a)(1).

The DD Act authorizes P&As to investigate incidents of abuse and neglect. When necessary, the P&As obtain or help clients to obtain records of previous abuse or neglect. The P&As help people with disabilities navigate the legal system to achieve resolution. Although individuals with developmental disabilities compose less than two percent of the total population of the United States, they are among the most vulnerable members of society. P&As often begin working on a case to help a single individual and conclude by attempting to correct the underlying problem, be it abuse, neglect, discrimination, lack of information, misinformation, or service system failure. P&As ensure that individuals with developmental disabilities have the ability to exercise their rights to make choices, contribute to society, and live independently.

Fifty-seven P&As receive grants on the basis of population, financial need, and service needs. In fiscal years 2003 and 2004, available grant monies from ADD were \$36.3 million and \$38.4 million, respectively.

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs): ADD administers a discretionary grant program providing for operational and administrative support to UCEDDs in all U.S. States and Territories as part of a national network to support interdisciplinary training, exemplary services, technical assistance, and information dissemination activities. UCEDDs serve as liaisons between academic spheres and service delivery systems to positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity, and integration into communities.

Activities of UCEDDs include: providing interdisciplinary pre-service preparation and in-service training of leadership, professional and paraprofessional personnel; research on developmental disabilities and living with such disabilities, offering community service training for persons with developmental disabilities, their families, professionals, and volunteers; and dissemination of information and findings which validate best practices and contribute new knowledge to the field of developmental disabilities.

In fiscal year 2003, \$25 million was available in grants from ADD for the 61 UCEDDs. In fiscal year 2004, \$27 million was available.

Projects of National Significance (PNS): Short-term projects (between one and five years) provide ADD with the opportunity to work on targeted issues important to the developmental disabilities community. PNS projects focus on emerging areas of concern for persons with developmental disabilities and their families by working with the developmental disabilities network in one or more States and other interested public and private non-profit entities.

Project issues transcend the borders of States and Territories, while project designs are oriented to permit local implementation of practical solutions. Examples of PNS activities include: data collection and analysis; technical assistance to Councils, P&As, and UCEDDs; technical assistance to develop information and referral systems; family support projects; youth projects; projects which improve supportive living and quality of life opportunities; projects to educate policymakers; and efforts to pursue Federal interagency initiatives.

In fiscal years 2003 and 2004, ADD had available \$12.4 million and \$11.6 million, respectively, to support PNS discretionary grants.

Presidential Initiatives: Some of the projects that ADD grantees execute originate from Presidential initiatives. In February of 2001, President Bush announced the



New Freedom Initiative, a plan that delineates aggressive goals to improve the lives of people with disabilities. The initiative outlines the Bush Administration's determination to increase access to assistive technology, expand educational opportunities, promote community inclusion, increase access to transportation, and encourage independent living and

homeownership for people with disabilities. Because the New Freedom Initiative is directly related to disability, ADD and its grantees have a major role in its implementation. ADD's efforts complement the work of many other agencies within the Department of Health and Human Services, as well as other Federal agencies within the Department of Education, Department of Housing and Urban Development, the Department of Labor, and the Department of Transportation.

Chapter 2

2.1 Individuals with developmental disabilities are more independent and self-sufficient as a result of employment, transportation, housing, and health services

ADD grantees share a mission and vision: helping individuals with developmental disabilities to achieve greater independence and self-sufficiency in all facets of private and community life. To reach that goal, ADD grantees often focus on employment, housing, transportation, and health services, among other areas. Through education, advocacy, and the implementation of diverse projects, ADD grantees help individuals with developmental disabilities excel in the careers of their choice, travel freely, live independently, and make informed choices about the kind of services and supports they receive.

In the 21st century, new technology and forward-thinking projects are helping ADD and its partners to achieve these goals. Changing technology impacts the lives of individuals with developmental disabilities on a daily basis, offering everything from new job opportunities to improved accessibility.

Employment

Locating and/or maintaining reliable employment is one of the most important steps individuals can take towards personal and financial independence. Yet this step can be significantly more difficult for individuals with developmental disabilities than it is for the general population. People with disabilities have an employment rate of about 30 percent, in comparison with 70 percent of the population as a whole. Fourteen percent of people with disabilities who are seeking work are unemployed, compared with five percent of the population as a whole.¹

The **Minnesota** Governor's Council on Developmental Disabilities (GCDD), funded by ADD under the State Councils on Developmental Disabilities (Council) grant program, is one of many ADD grantees calling attention to the ability of people with developmental disabilities to fill positions created by new technology. Through a digital imaging demonstration project, 18 workers with developmental disabilities were employed by the Minnesota Department of Human Services to scan approximately 28,600 pages of records.

At the conclusion of this pilot project, two individuals with developmental disabilities gave a live demonstration of scanning procedures at the December 2003 Association of Minnesota Counties Conference in Minneapolis. The project resulted in the creation of a resource package designed to teach other organizations how to replicate the digital imaging program, and this information has been shared with hundreds of agencies. GCDD also developed a marketing presentation to prompt other agencies to consider the savings that can be realized by converting paper records to electronic formats, as well as the availability of people with developmental disabilities who want to work and are well able to perform digital imaging functions. As a result, 22 individuals with developmental disabilities were employed by two government agencies to scan records.

¹ Laplante, Mitchell P.; Kennedy, J.; Kaye, H. Stephen; and Wenger, Barbara L.; Disability Statistics Abstract No. 11 "Disability and Employment", Disability Statistics Rehabilitation Research and Training Center, University of California- SF, published by US Dept. of Education, National Institute on Disability and Rehabilitation Research (NIDRR); 1996.

The following table, and others like it in this report, represent the outcomes of the many projects funded and sponsored by ADD's three grantees: State Councils on Developmental Disabilities (Councils), Protection and Advocacy Agencies (P&As), and University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs). It should be noted that many of these programs require longer than one year to yield noticeable results.

Council Employment Statistics

	Adults have jobs of their choice through Council efforts		Employers provided vocational support to students on the job	
	FY 2003	FY 2004	FY 2003	FY 2004
Total	5,156	2,937	995	1,164
Number of Councils	35	40	24	24

Like the technology job market, the health care field is growing rapidly and presents significant career opportunities for individuals with developmental disabilities. The U.S. Department of Labor projected that 12 of the 25 fastest-growing occupations during the 1996-2006 period would be in health-care related fields. The health care field encompasses widely diverse jobs, and some of the many career options include nurses, nurses' aides, dental assistants, pharmacy packaging, and medical records specialists.

The Center of Self-Determination at **Oregon** Health & Science University, an ADD-funded University Center for Excellence in Developmental Disabilities (UCEDD), has proposed a project to increase the number of individuals with developmental disabilities in health care and human services jobs. This project will allow at least 200 individuals to participate in health care training and will assist at least 100 individuals in unsubsidized employment in these career areas.

UCEDD Employment Statistics

	Number of people reached through UCEDD's Activities in Employment	
	FY 2003	FY 2004
Total	29,990	70,806

P&A Employment Statistics

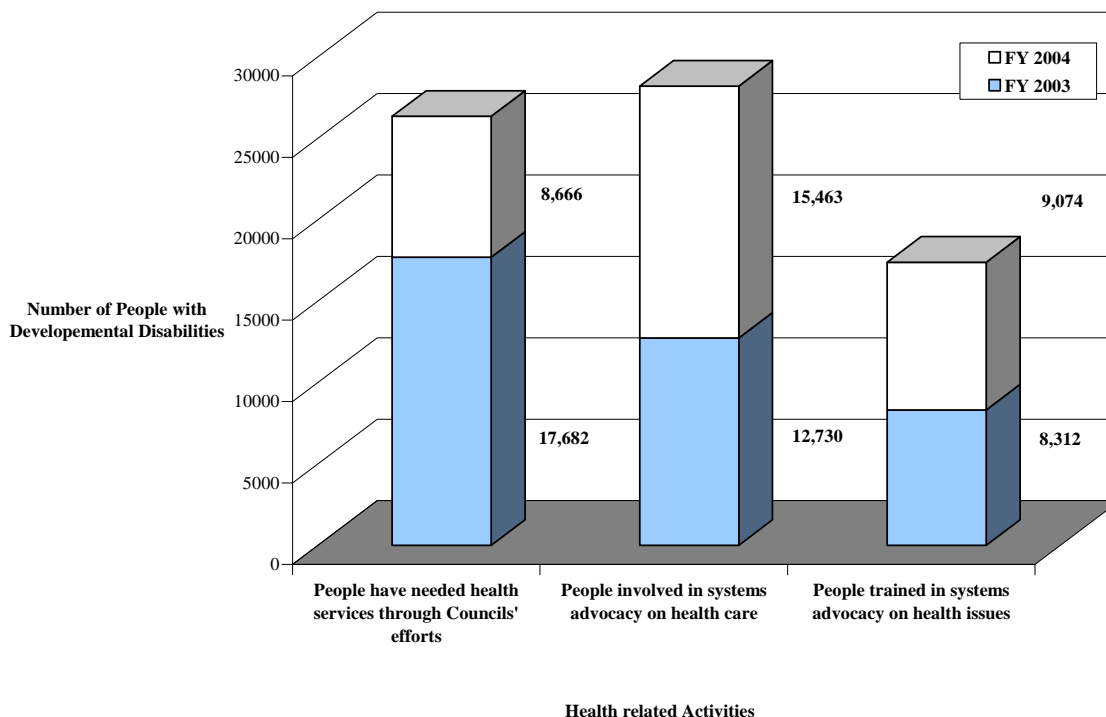
	Adults obtained or maintained employment due to P&A interventions	
	FY 2003	FY 2004
Total	524	391
Number of P&As	40	30

Health Care

While the health care field offers numerous career opportunities, obtaining quality health care services can present challenges for some people with developmental disabilities. Individuals may require support when filling out insurance forms, filing claims, or making medical decisions. They may need assistance securing transportation to and from health care services or finding a qualified medical professional with the training to work effectively with individuals with disabilities. The process can be overwhelming.

Many grantees focus on simplifying this process by bringing medical information and health care services directly to the individual. One example of this is a mobile dental services project funded by the **Nevada** Council on Developmental Disabilities. The Donated Dental Services Program received initial funding from the Council as a demonstration project in collaboration with the Community College of Southern Nevada. The project matched patients geographically with dentists who volunteered to donate their services to the program. The project also included a mobile dental facility (Miles for Smiles) to travel to the various elementary schools in the Las Vegas area to provide free dental care and education about dental hygiene. The Donated Dental Services program serves an average of 38 people with developmental disabilities per year and now includes training college interns both in dental services and in advocating for systems change in health care for people with DD. The successful program has now been fully incorporated into the College's dental health care system, and fiscal year 2003 was the last year Council funding was required.

Council Health Care Statistics



Partners for Inclusive Communities, **Arkansas'** UCEDD, is improving health care services to individuals with developmental disabilities by funding a continuing education training program to help medical professionals treat and communicate with people with developmental disabilities in an effective and appropriate manner. Training is provided to individuals in a broad range of medical professions, including physical therapists, speech therapists, occupational therapists, social workers, nurses, dieticians, and other health care professionals currently practicing in the state of Arkansas.

Professionals living in rural areas of Arkansas face a series of challenges in developing and maintaining skills to work effectively with people who have disabilities. Training received may be outdated because of the many changes in the field of disabilities in recent years. New concepts are just starting to become a part of pre-service training in universities. Most continuing education is offered in larger sites and requires rural professionals to travel long distances at considerable costs. Partners for Inclusive Communities provides these professionals with training programs that meet their needs.

The program collaborates with local and state agencies, professional organizations, and self-advocacy groups to identify and develop training topics to be presented in one-day and two-day sessions.

Some training sessions, for example, have focused on providing updated information on emerging trends and current changes in the provision of services for persons with developmental disabilities. The training includes information on recent changes in the field of developmental disabilities.

Other topics include sensitivity training designed to facilitate positive relationships between medical professionals and families. Two-day sessions entitled “The Tears and Cheers of Parents and Professionals” are now being presented. Professionals, consumers, and family members serve as presenters as appropriate.

UCEDD Health Care Statistics

	Number of people reached through UCEDD’s Activities in Health care issue and training	
	FY 2003	FY 2004
Total	167,011	110,752

P&A Health Care Statistics

	Number of people who obtained or maintained health care due to P&A interventions	
	FY 2003	FY 2004
Total	1,749	1,362
Number of P&As	50	52

Transportation

With the achievement of getting a job or securing appropriate medical services comes the need for reliable transportation. A person’s ability to find and maintain employment, consult the health care professional of his or her preference, live in the location of his or her choosing, and participate in community activities is dependent on transportation to and from these services. This can pose greater difficulties for people with developmental disabilities than it does for the general population. Without access to transportation, even simple activities such as buying groceries and paying bills can be difficult or impossible to pursue.

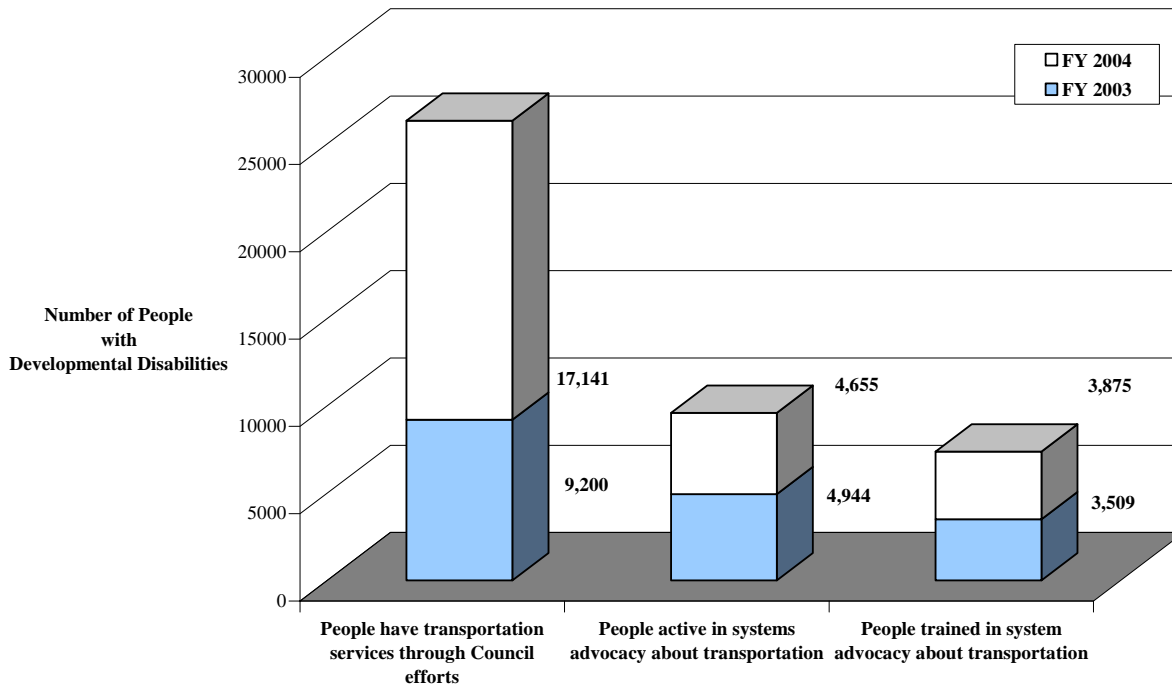
For people with developmental disabilities, reliable and accessible transportation can be the key to a more independent and self-sufficient life. Many individuals with developmental disabilities have no access to transportation at all or have to rely on family or friends to transport them. The availability of accessible transportation, either public or privately owned, provides an individual with a degree of personal freedom that would not be possible otherwise.

The **Mississippi** Council on Developmental Disabilities is addressing this need for reliable and accessible transportation through an initiative intended to facilitate the development of a “smart car” designed to be used by people with developmental disabilities who are unable to have a regular vehicle modified to suit their needs. Initial development of the car was completed in fiscal year 2004.

Even with existing technologies for sedans, minivans, and vans, some individuals with developmental disabilities are unable to drive cars with standard adaptations. The “smart car” is the world’s first dedicated low-speed commuter car designed to be driven by a state-of-the-art drive-by-wire system. The research team anticipates that elements of adaptive technologies being employed in the project have the potential to help individuals with developmental disabilities overcome some physical, cognitive, and sensory limitations. Additionally, the team is looking into the possibility of developing a rear-entry system to accommodate a single wheelchair user. While the initial funding for the project has come to an end, the research is ongoing as Mississippi State University’s Center for Advanced Vehicular Systems continues to work on the smart car.

In the **Commonwealth of the Northern Mariana Islands (CNMI)**, the Council collaborated with CNMI Legislators and a local business to establish transportation service systems for individuals with developmental disabilities on two islands, Tinian and Rota. A new van and seed money was provided by the Council to assist with the start up costs. The Council also provided orientation and training to the van operators and collaborated with the Department of Public Safety to instruct the van operators on CPR. Council efforts leveraged funds from Real Choice Systems Change to help offset the high cost of operating new systems. To ensure continued interest in addressing transportation issues and needs of residents with developmental disabilities from other islands, the council formed a transportation task force to explore increasing the availability of accessible transportation while maintaining the cost effectiveness and feasibility of several transportation service systems.

Council Transportation Statistics



Transportation Related Activities

The effect that transportation issues can have on other aspects of an individual’s life can be seen in the story of “Carlos,” a young man with developmental disabilities. Carlos had a part-time job at a local grocery store. He enjoyed the work and performed the job functions well. However, when he missed several days of work due to difficulties with transportation, his employer threatened to fire him. Concerned about the possibility of losing his job, Carlos contacted the **Louisiana** Advocacy Center, Louisiana’s Protection and Advocacy Agency (P&A). The Advocacy Center staff assisted Carlos in obtaining more reliable transportation, thus ensuring that he would miss fewer days of work. He gained the independence afforded by reliable transportation, which allowed him to maintain self-sufficiency by keeping his job.

P&A Transportation Statistics

	Number of people who have access to appropriate transportation due to P&A interventions	
	FY 2003	FY 2004
Total	201	165
Number of P&As	32	33

UCEDD Transportation Statistics

Number of people reached through UCEDD's activities in transportation issues
FY 2004 32,965

UCEDD Transportation statistics were not available for FY 2003.

Housing

Safe, independent, and accessible housing provides individuals with freedom and self-sufficiency. Independent living allows individuals to achieve independence and become part of a community. It also gives people with developmental disabilities housing options other than nursing homes and group settings.

“Deborah” is a 39-year old woman with developmental disabilities. She is deaf and communicates exclusively through sign language. As a result of misunderstandings and behavioral problems caused by Deborah’s inability to communicate with those around her, she was repeatedly placed in living conditions that were more restrictive than her health care provider believed were necessary. For years, she lived in state institutions. Her involvement with the community was limited, and she became increasingly frustrated with her inability to communicate her needs to those around her.

Staff of the **South Carolina** P&A recognized that many of the problems associated with Deborah’s living situation could be alleviated by simply facilitating more effective communication. A Certified Sign Language Interpreter was brought in to work with Deborah and, as a result, P&A was able to better understand what Deborah wanted and needed, in order to help advocate on her behalf.

Deborah moved out of the institution and into a home in the community. She attends regular church services. Her church has a large deaf population and provides a sign language interpreter. Additionally, she has become involved with the deaf community and is participating in many group activities that were impossible in her previous living environment.

P&A Housing Statistics

	Number of people who have access to accessible housing due to P&A interventions	
	FY 2003	FY 2004
Total	591	494
# of P&As	49	49

Steps are being taken across the nation to reduce the number of individuals who live in institutional settings and to help people like Deborah find appropriate housing in the community.

The **Georgia** Institute on Human Development and Disability, an ADD-funded UCEDD, is sponsoring an ongoing study on Georgia citizens who have moved from institutional placements to community living. The study focuses on 38 individuals who formerly lived at Rivers Crossing, a residential facility for individuals with developmental disabilities in Athens, Georgia. These individuals moved from the facility to community residences across the state in the summer of 1996. By gaining access to long-term data from successful institutional closures, state officials can strengthen the transition process for future individuals moving from institutions to the community.

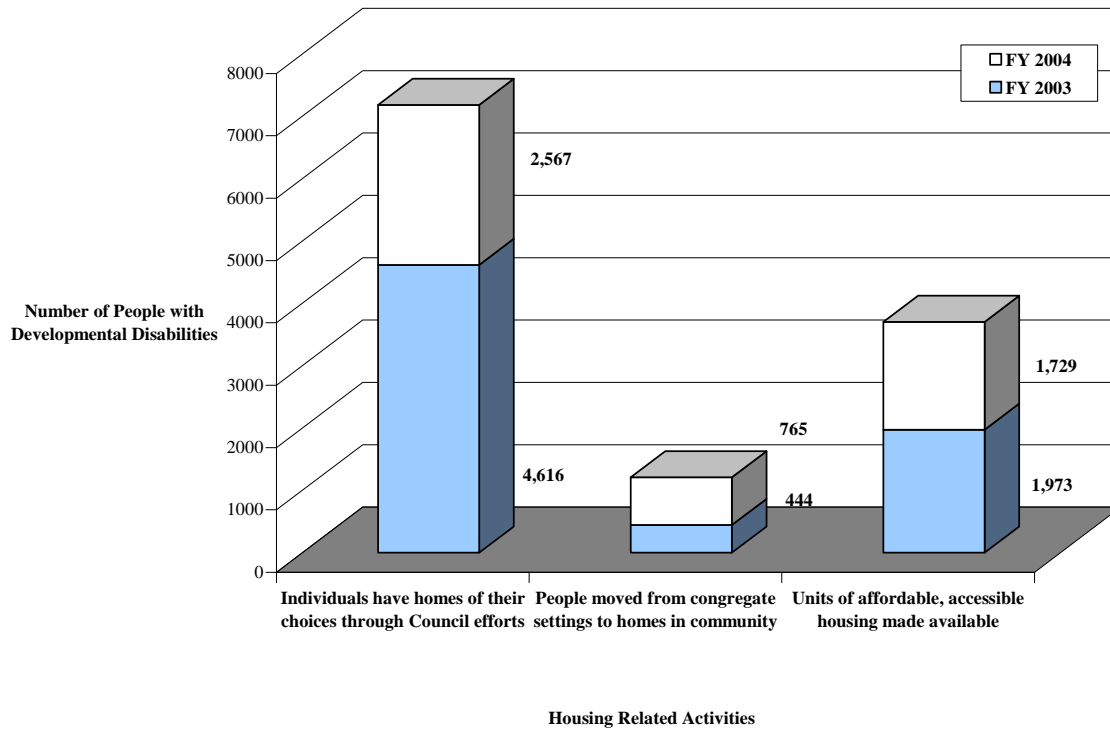
Two initial phases of the study have been completed, but the project is ongoing in order to complete a comprehensive, multi-phase follow-up study of these individuals. Each follow-up phase focuses on housing, daily activities, employment, satisfaction, friendships, support, health, community roles, and future plans. Emphasis is also placed on changes in providers, moves from one residence to another, and community inclusion and choice. Project staff members conduct interviews with the individuals who moved from Rivers Crossing, their families, and their residential providers to learn about their lives and to assess the strengths and weaknesses of their transition into the community.

Approximately one conference presentation per year will be developed from the follow-up study. When the study is complete, several detailed reports will provide information about the lives of people with developmental disabilities that will be used by policy makers and program administrators to improve the quality of community services in Georgia.

UCEDD Housing Statistics

	Number of people reached through UCEDDs' Activities in housing issues	
	FY 2003	FY 2004
Total	11,802	37,000

Council Housing Statistics



2.2 Children with developmental disabilities are integrated through inclusive education, early intervention, and child care

The **Connecticut** Council on Developmental Disabilities (Council) is currently funding the fourth year of the Understanding Special Education Project. During the three previous years that the project has been active, more than 916 parents and educational professionals in 93 school districts have participated in a 10-hour course designed to equip them with the skills they need to negotiate the special education system and improve its effectiveness for students with disabilities.

As a result of the training provided by this project, parents reported feeling better equipped to advocate for their children and to actively participate in planning their child's education program. Educators reported having increased knowledge of special education laws and an improved ability to work collaboratively with families.

Education-related initiatives like Connecticut's Understanding Special Education Project are an important component of the services that ADD and its partners provide. Developmental disabilities, by definition, begin before the age of 22. Therefore, the vast majority of individuals with developmental disabilities require assistance with education and early intervention issues. State Councils, P&As, and UCEDDs work extensively in this field:

1. *State Councils on Developmental Disabilities (Councils)* work to educate parents, educators, and the community about inclusive education issues.
2. *Protection and Advocacy Agencies (P&As)* focus substantially on educational issues. Historically, 80-90% of the workload and cases handled by P&As deal with securing an education in an inclusive setting for children with developmental disabilities. P&As have been involved in a large number of landmark cases and work closely with other collaborative partners, especially Councils and UCEDDs.
3. *University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)*, as mandated by law and by virtue of residing in universities, often work on promoting or securing inclusive educational opportunities for children with developmental disabilities, either by training the teachers or by educating the public.

By working collaboratively as well as individually, ADD grantees are meeting the educational needs of individuals with developmental disabilities as they progress from early childhood through elementary and secondary school and into adulthood. Areas of focus include early intervention and child care, inclusive education, and the transition from school into the working world.

Early intervention is a process that begins, between birth and three years of age, by correctly identifying children who have disabilities and making an assessment of their needs. Early intervention services are authorized in the Individuals with Disabilities Education Act (IDEA) to help children prepare for school by ensuring not only an appropriate education but access to necessary services and community support.

Through the funding of early intervention activities, **New York's** UCEDD, the Strong Center for Developmental Disabilities, is helping to ensure that children with developmental disabilities have the advantage of the best possible resources and services from the very beginning of their lives. The UCEDD-funded Regional Early Childhood Direction Center serves 11 counties, providing information, support, and referral assistance to parents and professionals who are concerned about a child with special needs or a developmental delay. Children are eligible for the service if they are between birth and five years of age, and are having problems performing the same functions as other children their age. This may include problems with:

- ✚ Sitting;
- ✚ Crawling;
- ✚ Walking;
- ✚ Eating;
- ✚ Speaking;
- ✚ Hearing;
- ✚ Seeing;
- ✚ Playing; and
- ✚ Getting along with others.

The staff provides free consultation and assistance to parents and professionals and helps link the child and parent to the appropriate service.

After developmental disabilities have been initially identified, it is important to secure the services and supports that will provide the child with a quality education, an independent lifestyle, and inclusion in the community. One of the first challenges that the parents of a child with developmental disabilities often face is locating accessible, affordable child care staffed with appropriately trained professionals.

In **New Mexico**, the State Council on Developmental Disabilities is taking steps to expand the availability of appropriate child care with inclusive practices and staff trained to care for children with developmental disabilities. Through a Council-funded project, training and technical assistance that emphasizes inclusion is being provided to child care workers. Previously, training provided through the state child care certification agency did not include information on issues related to integration of children with disabilities in child care settings. The Council-funded training has been well received, and the program has had a high rate of participation. In FY 2004, the new training model was expanded to include additional communities, and an effort is well underway to promote systems change through the initiation of this training on a state-wide basis.

Indiana's UCEDD is taking similar steps to assure access to appropriate, inclusive child care. Through a collaborative partnership with several other agencies, the UCEDD created the "Indiana Partnership for Inclusive Child Care." This project aims to develop a model inclusive child care system and to facilitate the coordination of a statewide system of accessible, family-centered, developmentally appropriate child care. Emphasis is placed on providing supports, training and technical assistance for enhanced integration, as well as on coordination of existing community-based child care services. The project is also intended to increase retention of child

care providers and ensure consistency, thus increasing stability of care and continuity of services for children with developmental disabilities. In fiscal year 2004, the project was in its early stages, and over a three-year period, across all ninety-two Indiana counties, children with developmental disabilities and their families will benefit from improved child care services.

The project includes resource and referral services to families. It also provides training and technical assistance to providers, families, and the community at large, as well as innovative distance learning technologies for outreach to underserved areas. Materials and procedures developed by the project will be incorporated into manuals and CD-ROM's and made available on the web. The project is constructed to allow replication by other states, thus enhancing and increasing inclusive child care in communities across the nation.

When children with developmental disabilities are ready to move into a preschool or kindergarten setting, it is essential that they are provided with an environment that will create a foundation for successful lifelong learning.

In **Maine**, the families of six preschool students with autism were concerned that their right to an appropriate early education was at risk. The children were attending a neighborhood pre-school as part of their early intervention program. The school offered developmental therapy as well as other services to meet the needs of the children, and the parents were pleased with the education their children were receiving. However, the local education agency decided to take measures that would require the children to travel outside of their community to attend a different preschool that served only children with disabilities. The parents of these children contacted the Disability Rights Center, Maine's Protection and Advocacy Agency (P&A) for people with developmental disabilities. P&A advocated for the children and worked with the parents and the school. Through the efforts of the P&A staff, the children were able to remain in their integrated neighborhood program, rather than being isolated in a separate school.

The following table represents the outcomes of the many projects funded and sponsored through ADD's three grant programs: State Councils on Developmental Disabilities (Councils), Protection and Advocacy Agencies (P&As), and University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD). It should be noted that many of these programs require longer than one year to yield noticeable results. Also, a variety of factors may cause the numbers of individuals reached to fluctuate from one year to the next. Grantees may choose different areas to emphasize based on the needs of their communities, significant success in one year may mean that fewer people need assistance the next, and different projects may have varied approaches or goals that yield differing numbers.

Council Child Care Statistics

State	Children in inclusive child care settings through Council efforts	
	FY 2003	FY 2004
Total	4,918	2,048

Number of Councils	12	16
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P&A Child Care Statistics

	Obtained or maintained child care services due to P&A intervention	
	FY 2003	FY 2004
Total	56	35
Number of P&As	16	15

The success of the P&A's efforts in Maine was important because the children were allowed to remain in their local school, interacting with their peers. The P&A's intervention helped to build a foundation for the parents to advocate for the children's future needs. It also helped to educate the school district about the importance of inclusive education, which will hopefully lead to systems change.

Inclusive education means that all students are based in age appropriate regular classrooms, and can access the services or special programs necessary to meet their individual needs.

Every child has a right to belong to a community and to share common experiences with family, neighbors, and friends. Children with developmental disabilities have a right to a free, appropriate education in their local schools, rather than being isolated in separate special education programs. Working side by side with peers with varied skills and strengths helps all children to develop the skills necessary to live in a diverse community in the future.

Historically, children and young adults with developmental disabilities were segregated from their peers who were not disabled for a variety of reasons. This separation compromised the quality of the education provided to children with developmental disabilities, and denied them the social interaction and community inclusion that they wanted and needed. These practices are changing, and ADD and its grantees advocate for inclusive education. Inclusive classrooms provide students with developmental disabilities with opportunities to build skills for interacting with people who do not have disabilities. Placing all students together teaches understanding and acceptance to younger generations, which in turn may build a foundation for community inclusion in the future.

"Mark" is a young man with cerebral palsy who wanted to spend his last year of high school in an inclusive environment. He had always been educated in segregated settings, despite continued assurances from his school district that he would be moved to an inclusive school. When discussing vocational training as part of Mark's education, the district only gave Mark the option of pursuing a career as a janitor, a job for which he was neither inclined nor suited. Additionally, this recommendation did not reflect Mark's strengths and interests, namely his enthusiasm for auto mechanics.

Concerned that the school district was not meeting Mark's needs, Mark and his parents contacted Equip for Equality (EFE), the P&A in their state of **Illinois**. EFE filed for due process and the district was ordered to complete a comprehensive vocational evaluation. EFE also helped Mark

to enroll in his neighborhood high school for his senior year. He was accompanied to classes by an aide and received a modified curriculum, but was continuously with his peers. When Mark graduated from high school with his classmates, he received a standing ovation.

Washington's Special Education Advocacy Project is one of many ADD grantees' projects designed to give families like Mark's the information and resources they need to advocate for an appropriate education. The project, funded by the Washington State Developmental Disabilities Council, is in its fifth year. It provides several services to concerned parents and educators. An overview of these services is provided below:

- ✦ Ongoing information about special education issues is provided to interested individuals through an email list serve.
- ✦ Project staff present information at community meetings and keep the community informed about special education legislation and policy issues.
- ✦ Parents and professionals receive training so that they are better able to influence school district policy on inclusion.
- ✦ Parent coordinators develop and disseminate pertinent materials and information to parents and community members. The coordinators also assist parents in understanding their rights under the Individuals with Disabilities Education Act (IDEA), including connecting parents to legal advice through the Washington Protection and Advocacy System and other local resources to resolve compliance issues with school districts.

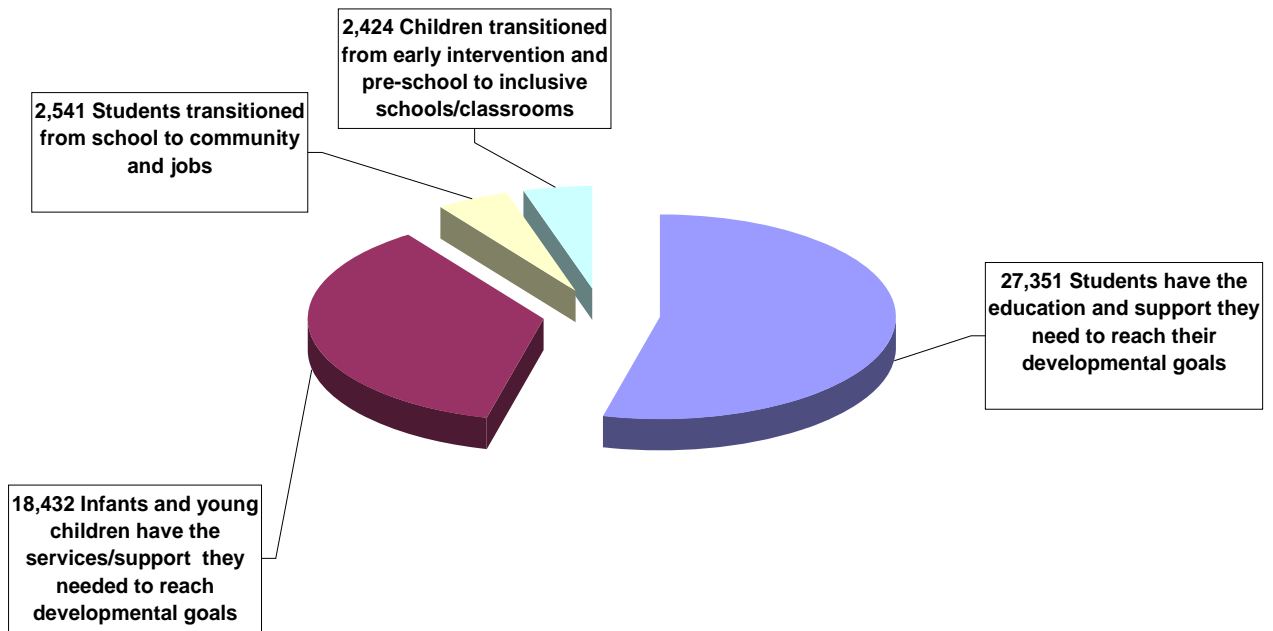
The project ensures that families like Mark's have the tools they need to make decisions about the kind of education that is appropriate for their child and the resources to overcome any obstacles that may they face in carrying out those decisions. This supports ADD's goal of capacity building. Capacity building activities are activities intended to build a system for sustaining and expanding the successful delivery of services, support and other assistance to individuals with developmental disabilities and their families. This can mean empowering a community, organization, or individual to gain the capacity to advocate for individual rights and bring about systems change.

When Mark attended his neighborhood high school, one of the modifications made was providing him with an aide that accompanied him to his classes. Aides, assistants, or paraprofessionals can help ensure a student's success in an inclusive setting. Paraprofessionals help in the inclusive classroom in a variety of ways and have a direct effect on students' academic performance. They provide tutoring, implement teacher-developed instruction, provide personal care for students with developmental disabilities, observe the student and provide suggestions related to instruction, and participate in team meetings.

The Center on Disability & Community Inclusion, an ADD-funded UCEDD in **Vermont**, is partnering with the State Department of Education to address the use of paraprofessionals in an integrated educational setting. The Vermont project is designed to develop, implement, and evaluate a model for the effective use of paraprofessionals to support students with disabilities in

general education classes. The model includes ten steps that can be used by teams of school personnel to utilize the recommended practices in ways that meet unique needs of individual schools and the students they serve. This approach provides school districts with a proven model that can be effectively replicated throughout Vermont and across the Nation, in any classroom from preschool through high school.

FY 2004 Council Education Statistics



P&A Education Statistics

	Students obtained or maintained inclusive education due to P&A interventions	
	FY 2003	FY 2004
Total	11,117	11,289
Number of P&As	57	56

UCEDD Education Statistics

State	Number of people reached through UCEDDs' Activities in Education	
	FY 2003	FY 2004
Total	78,049	136,359

When students like Mark graduate from high school, it is important that they receive the assistance they need to make a smooth transition to a higher education institution or the working world. For any student, the period after graduation is difficult, as he or she learns to live alone, handle finances, and make decisions affecting the future. Students with developmental disabilities face unique challenges during this transitional period, and often require additional services and supports to successfully make the adjustment to the working world.

In the interest of providing programs that help ease the shift from a school setting into the community, the **Massachusetts** Council on Developmental Disabilities helped to fund the Northampton School Department's project "Northampton Opportunities to Work (NOW)." The project was designed to provide community supports and normalized activities to 16-22 year old individuals with developmental disabilities. In an effort to ease the transition, the program reached out to these students before they left the Northampton Public Schools and special education services. NOW provided innovative community-based supports to complement and reinforce school-based instructional activities. Additionally, business owners and other potential employers from the community visited the schools to discuss their expectations as employers.

In **Missouri**, the University Center for Excellence in Developmental Disabilities at the University of Missouri-Kansas City sponsors a program called Continuing Education for People with Developmental Disabilities (ACED). ACED offers adults with developmental disabilities the opportunity to attend non-credit classes in an integrated educational and social environment. The Missouri Department of Elementary and Secondary Education encouraged the development of the project to enhance the high school transition and post-high school educational opportunities of people with developmental disabilities.

Each semester, approximately 150 individuals with developmental disabilities enroll in classes ranging from horseback riding lessons to sessions on how to navigate the public bus system. Class size is small, with about 12 students per class. The program teaches independent living skills and provides life-enhancing experiences. The courses provide students with educational, social, and recreational opportunities and help the students become part of the community.

The University of Montana Rural Institute, Montana's UCEDD, implemented a similar project to help make the school-to-work transition successful. The "Graduate to Work Project" aims to increase access to community employment for students with developmental disabilities graduating from Montana schools. Piloted in Missoula, Montana, the program was designed to be easily replicated by other locales. The project emphasizes individually driven vocational planning. The individualized approach better matches students to jobs, increasing job

satisfaction and retention while reducing the cost and duration of outside supports.

2.3 Individuals with developmental disabilities have better quality services and support

Part of ADD's mission is to promote independence by ensuring that individuals with developmental disabilities have access to appropriate, accessible services that allow them to lead a full and self-sufficient life as a part of an integrated community.

Individuals with developmental disabilities need clear and consistent information regarding services and supports, as well as access to training and tools to enable them to make informed decisions, choose between service providers, and manage various services.

ADD grantees provide individuals with services that allow them to participate in recreational and cultural activities, advocate for their personal rights, and move from institutional settings to homes in the community. Grantees constantly work to protect the rights of individuals with developmental disabilities and to improve the quality, accessibility, and flexibility of the services provided to them.

ADD encourages programs that rely on the personal knowledge, experience, and voices of people with developmental disabilities to shape the standards by which programs are expected to operate.

In an effort to make sure these voices are heard and understood, the **Ohio** Council on Developmental Disabilities (Council) funded "My Voice, My Choice," a five-year project that was in its fourth year in 2004. The purpose of the grant was to develop a "report card" that would allow individuals with developmental disabilities to "grade" service providers, thereby promoting informed choice for individuals and accountability for service providers.

This report card, which has been developed and tested in a pilot program, gives individuals with developmental disabilities a method to voice their opinions regarding their service providers. It also allows them to use the comments of others to make informed choices about the services they receive.

The first four years of the project have been dedicated to developing and testing a statistically reliable report card that is user-friendly and allows for maximum participation by individuals with developmental disabilities and their guardians. Approximately 14,225 people were contacted to participate in the project during the first statewide pilot, and 4,905 individuals or their guardians were included in the final data pool.

Quality assurance programs like Ohio's "My Voice, My Choice" project exist to ensure that people with developmental disabilities have the facts, skills, opportunities, and supports needed in order to live free of abuse, neglect, rights violations, and inappropriate restriction. These projects expand the ability for individuals with developmental disabilities to live independent, productive lives as a part of an inclusive community. They also promote capacity building and system change. Capacity building activities are activities intended to build a system for sustaining and expanding the successful delivery of services, support, and other assistance to

individuals with developmental disabilities and their families. Systemic change means a sustainable transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families. These quality assurance activities are mandated by law in the Developmental Disabilities Assistance and Bill of Rights Act of 2000, as outlined below.

Section 102(23) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 states that the term quality assurance activities:

"...means advocacy, capacity building, and systemic change activities that result in improved consumer and family-centered quality assurance and that result in systems of quality assurance and consumer protection that-

(A) include monitoring of services, supports, and assistance provided to an individual with developmental disabilities that ensures that the individual-

(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and

(ii) will not be subject to the inappropriate use of restraints or seclusion;

(B) include training in leadership, self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians to ensure that those individuals-

(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and

(ii) will not be subject to the inappropriate use of restraints or seclusion; or

(C) include activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life, of individuals with developmental disabilities."

Helping individuals with developmental disabilities find the services and supports they need to participate fully in the community is an integral part of the quality assurance activities performed by ADD grantees. Creating inclusive communities helps build a foundation for acceptance of disability as a part of life. Most people with developmental disabilities are capable of leading independent lives as productive and valuable members of their communities, although some individuals need support and services to do so.

In the interest of encouraging community integration during all phases of life, the **California** Council on Developmental Disabilities funded the “Harmony Project,” which partnered 23 senior citizens with developmental disabilities with seniors who shared common interests but did not have disabilities. Together, the integrated group of seniors participated in culturally sensitive inclusive activities at 11 Orange County senior centers.

The goal of this program, which expects to soon serve 40 senior citizens with developmental disabilities, is to provide meaningful community integration to an underserved segment of the senior population. By allowing the same flexibility and choice experienced by the general population, it offers senior citizens with developmental disabilities a retirement-age-appropriate alternative to traditional day programs. Attendance and activities are based on personal interest and choice, rather than a rigid programming schedule dictated by the staffing patterns of a program or home catering exclusively to individuals with developmental disabilities.

The first phase of the program was extremely well-received, not only by the participants with developmental disabilities, but also by the senior citizens in the general population. In teaching the senior citizens without disabilities about people with developmental disabilities, empathy training on an individual basis proved to be more successful than formal group presentations.

Culturally-sensitive, multi-lingual outreach was an important component of the program. ADD strongly encourages its grantees to fund programs that reach out to underserved or unserved groups, such as minority communities with cultural or language barriers that can restrict access to appropriate services. To make sure that they reached out to individuals who did not speak or read English well, “Harmony Project” staff advertised the program through flyers written in specific languages, articles in local newspapers published in multiple languages, and outreach activities conducted at various cultural festivals. Person-centered planning allowed the program to meet the needs of ethnically diverse senior citizens by providing individuals with appropriate transportation, flexible schedules, and staff members who spoke the primary language of each individual and his or her family.

“Margaret,” a senior citizen with developmental disabilities and a participant in the “Harmony Project,” was unknown to the developmental disability service system in California before she enrolled in the program. Margaret lives at home with her 96-year-old mother, neither of whom previously participated in activities outside of their home. Margaret now chooses to participate in social and recreational activities up to four times a week, which fosters a new-found sense of inclusion in the community and enhances her quality of life.

The following table, like other tables in this report, represents the outcomes of the many projects funded and sponsored by ADD's three grant programs. It should be noted that many of these programs require longer than one year to begin to yield noticeable results, and therefore statistics for fiscal year 2004 may not yet represent the full impact of these programs.

Council Quality Assurance Activities

	Number of people who benefited from Council Quality Assurance Activities	
	FY 2003	FY 2004
Total	103,275	87,158
Number of Councils	44	45

Council Community Support Activities

	Number of people who received formal/informal supports through Council efforts	
	FY 2003	FY 2004
Total	58,795	45,436
Number of Councils	40	38

Like Margaret, "Kate" is an adult with developmental disabilities who was able to begin participating in her community because of services offered by ADD's partners. Because of behavioral issues, Kate used to reside on the campus of a large regional center for individuals with developmental disabilities. After some of these behavioral problems were resolved, Kate's family was eager to begin transition planning so that Kate could reside in a smaller state-run group home in the community. The Legal Center, **Colorado's** Protection and Advocacy Agency (P&A) became involved in Kate's case at the request of her parents. The Legal Center's staff helped Kate and her family to understand the details of the transition process and the benefits of living in a more integrated setting.

In order to help Kate succeed in a more self-sufficient environment, the Legal Center's staff helped her to secure supplemental services, including a supported employment arrangement. Kate initially found the transition into the community-based home to be difficult, but the Legal Center's staff persisted in their efforts to help her adjust. Kate now enjoys a more independent life in an integrated setting.

Appropriate services, such as Kate's supported employment arrangement, are a crucial step towards leveling the playing field so that individuals with developmental disabilities can participate in the community without arbitrary restrictions and are able to make the choices that determine the courses of their lives.

“Jamal,” a young adult with cerebral palsy, initially contacted the **Guam** Legal Services Center, Guam’s P&A, because of difficulty obtaining legally-mandated services required under the Individuals with Disabilities Education Act (IDEA). The Legal Services Center agreed that the Department of Education had failed to provide an appropriate education, and staff members successfully represented Jamal in a due process hearing. During the hearing, it became apparent that the lack of educational services had also impacted Jamal’s ability to develop employment skills. After successfully obtaining a decision for compensatory education time and a provision of appropriate assistive technology, the Legal Services Center further advocated for Jamal, helping him to receive training and transition services that allow him to pursue the employment of his choice.

P&A Quality Assurance Statistics

	Number of people who obtained or maintained quality services and supports as result of P&A intervention	
	FY 2003	FY 2004
Total	16,955	5,917
Number of P&As	57	56

Often, individuals like Jamal have access to services intended to help them, but sometimes the services are ineffective. ADD grantees help to improve existing services so that they meet the needs of individuals with developmental disabilities. In Jamal’s case, the educational services being provided were inadequate, and the Guam P&A helped to resolve the problem and educate the Department of Education about the rights of individuals with developmental disabilities. Because of Jamal’s efforts and P&A’s assistance, it is likely that the Department of Education will improve the way it provides services to individuals with developmental disabilities, thereby promoting long-term systemic change. Systemic change means a sustainable transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

Many other ADD-funded programs are targeting specific services that need improvement and working with individuals with developmental disabilities to find out how these services can better meet their needs. Through these efforts, individuals are helped in the short-term. In the long term, ineffective systems are changed, eliminating a source of problems for future generations. Promoting system change is an important part of quality assurance activities performed by ADD’s partners.

The Schiefelbusch Institute for Life Span Studies, **Kansas’** University Center for Excellence in Developmental Disabilities (UCEDD), is partnering with disability organizations, service providers, and state agencies in Kansas to improve personal attendant services and increase opportunities for Kansans with disabilities to exercise choice over all aspects of the services they receive. This effort focuses on increasing personal care attendant options for people with

developmental disabilities who are eligible for the Kansas Medicaid Waiver program and on empowering them to personally manage their attendant care services.

In order for some individuals with developmental disabilities to live and participate fully in their communities, personal care attendants must be available in the individuals' homes, at work, and when they are away from home. The goal of the program is threefold:

1. *Address availability issues:* Individuals report a lack of availability of qualified attendants and a lack of access to consistent information about services. Activities are planned to address these issues as well as consumers' access to personal care attendants regardless of location.
2. *Maximize control:* Consumers need to have maximum control in exercising choice over all aspects of personal assistant services and to have sufficient training to be able to direct these services. A pilot program with service providers and consumers served by three Community Developmental Disability Organizations (CDDOs) was conducted in order to develop an effective model.
3. *Create support infrastructure:* Individuals with developmental disabilities and/or their families/guardians need support in developing and exercising management skills, in obtaining and evaluating customer feedback, in using customer feedback to identify and correct problems, and in creating a plan for dealing with recurring issues. Data was collected regarding these needs, and efforts are underway to improve supports and services related to attendant care.

Delaware's UCEDD, The Center for Disability Studies, is helping people with developmental disabilities learn to provide important services, not just receive them. By promoting volunteer opportunities and other ways to serve the community, the Delaware Service Inclusion Project is helping people like Margaret, Kate, and Jamal to take an active role in their community, while developing skills that will be useful throughout their lives. The project has worked with state and local service organizations such as AmeriCorps, Jaycees, Lions Clubs and other groups to encourage the inclusion of people with developmental disabilities in service activities. Some of the steps taken by project staff to achieve this goal included:

- ✚ Conducting a needs assessment of current service opportunities and the recruitment strategies of civic organizations;
- ✚ Developing relationships between service projects and disability organizations;
- ✚ Providing training to increase service project staff's awareness of disabilities issues;
- ✚ Making presentations to individuals with developmental disabilities to increase awareness of volunteer opportunities in Delaware; and
- ✚ Producing, publishing, and disseminating materials that promote volunteer opportunities for Delawareans with disabilities.

As a result, a large number of individuals with developmental disabilities have become active members of various civic organizations. Through involvement in inclusive community service organizations, individuals with developmental disabilities play an active role in improving their community and promoting causes that are important to them. By working as volunteers, they

build confidence, develop leadership and teamwork skills, learn to make the most of the resources available, and share ideas, successes, and goals.

The table below represents UCEDD activities in fiscal years 2003 and 2004. Information was tracked differently in fiscal year 2003, and “activities in community support” refer to projects that improved the quality of services and supports available to people with developmental disabilities, thereby allowing greater inclusion in the community.

UCEDD Quality Assurance Statistics

Number of people reached through UCEDD's Activities in Quality Assurance	Number of people reached through UCEDD's Activities in Community Support
FY 2004 62,024	FY 2003 99,296

2.4- Individuals with developmental disabilities are trained and active in self-advocacy

ADD encourages its grantees to fund programs that aim not just to resolve a specific problem or seek justice in a specific case, but to seek long-term solutions through strengthening the human service systems and training individuals with developmental disabilities to advocate for themselves.

In the past, people with developmental disabilities have often been on the receiving end of change, having very little voice in the laws that affect them, the kinds of services that are available to them, or the accommodations made for their housing, education, and employment. Today, people with developmental disabilities are *creating* change by advocating for their rights and shaping the world around them. ADD encourages programs that promote and support that change. Through these programs, ADD is helping individuals with developmental disabilities to create an environment of self-sufficiency, inclusion, and acceptance for the current population as well as for future generations.

To support these goals, **Tennessee**'s University Center for Excellence in Developmental Disabilities (UCEDD) sponsored the "Self-Determination Project," which teaches self-advocacy skills to students with developmental disabilities in high schools, middle schools, and elementary schools. Instructors work directly with the students and their support networks to teach approaches that promote empowerment, advocacy, and self-direction. The project provides opportunities for students to learn about themselves, take a strong role in the Individual Education Program (IEP) process, and learn how to best take advantage of resources that will lead to employment after graduation.

In addition to teaching self-advocacy skills that enable individuals to take an active role in planning their own lives, ADD's grantees teach them how to use these skills to influence the laws and policies that impact all individuals with developmental disabilities.

"Partners in Policymaking" is one program that has been particularly successful in teaching self-advocacy skills nationwide. "Partners in Policymaking" was created by the **Minnesota** Governor's Council on Developmental Disabilities in 1987. It is an innovative, competency-based leadership training program for adults with disabilities and parents of young children with developmental disabilities. Since 1987, Partners programs have been implemented in 46 states, the **Northern Mariana Islands**, the Netherlands, the **U.S. Virgin Islands** and the United Kingdom.

Alaska is one of the many states that have found success with Partners in Policymaking. Supported by the state Council in cooperation with the UCEDD, the project provides hands-on training and technical assistance to help individuals with developmental disabilities and their families acquire the necessary skills to effectively advocate for systems change. Additionally, the program organizes and facilitates statewide training for community and regional development.

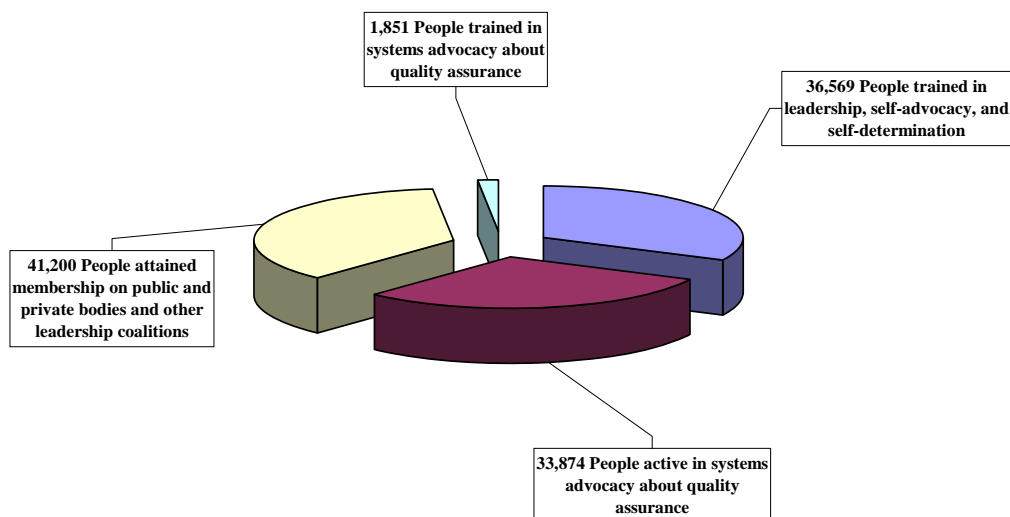
Projects like “Partners in Policymaking” are important on several levels. They promote capacity building by empowering individuals, organizations, and/or communities to gain the skills they need to advocate for individual rights and bring about systemic change. Capacity building activities are defined as activities intended to build a system for sustaining and expanding the successful delivery of services, support and other assistance to individuals with developmental disabilities and their families. Systemic change means a sustainable transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families. Additionally, these programs help ensure that policies regarding individuals with developmental disabilities are shaped by the people they influence the most – the individuals themselves and their family members.

The **Hawaii** Council on Developmental Disabilities (Council) also funded a “Partners in Policymaking” project. Hawaii operates a “Partners in Policymaking Leadership Academy” that teaches self-advocacy and leadership skills; to date, the training program has been completed by 149 individuals with developmental disabilities or their family members. Additionally, the Council has helped 90 self-advocates and family members from Oahu and the neighbor islands to meet with legislators and staff to share their personal stories and express concerns about issues that impact the lives of individuals with developmental disabilities. Legislative advocacy training was provided to more than 120 individuals with developmental disabilities and their families.

The **American Samoa** Council on Developmental Disabilities recently helped form a new organization to promote self-advocacy. The Center for Families of Developmental Disabilities helps families to build community capacity for the delivery of information, training, and support to individuals with developmental disabilities and their parents and family members who are unserved or underserved, particularly in remote areas. An important part of the Center’s work is to help parents understand the Individuals with Disabilities Education Act (IDEA) and learn how to most effectively advocate for their children’s rights.

Similarly, **West Virginia**’s Council supports “The Fair Shake Network,” an organization that provides self-advocacy training and support for people with disabilities and their families. Activities include training and education about the legislative process, civil rights, and other important issues. The Fair Shake Network also provides education and technical assistance to public officials about issues affecting people with disabilities, such as employment, transportation, health care, education, housing and personal assistance services.

Council Self-Advocacy Statistics



Equip for Equality, the P&A in **Illinois**, has created the “Latino Outreach and Advocacy Project” as a means to teach self-advocacy skills to an underserved population. The project has significantly improved the service delivery system for Latinos with developmental disabilities. The community is receiving better access to legal advocacy services and training, which are being delivered in a more culturally sensitive manner. The P&A’s work, especially on educational services, has been particularly critical in the wake of the closing of the National Center for Latinos with Disabilities. The P&A staff has also been assisting Latino parent groups to establish themselves as viable non-profit organizations, thereby improving the capacity of the Latino community to independently advocate for themselves and their families.

Like education, employment is important because it provides a foundation of competency and self-sufficiency upon which an individual can build for the rest of his or her life. Individuals with developmental disabilities have the right to pursue the careers of their choice free from discrimination. P&As often work to educate individuals with disabilities about their legal rights concerning employment and help take appropriate actions if these rights are violated.

The **Arizona** Center for Disability Law, Arizona’s P&A, has developed the ADA Employment and Vocational Rehabilitation Rights Legal Advice Line. The advice line promotes knowledge of state and federal law protecting people on the basis of disability, including the Americans with Disabilities Act. Attorneys staffing the ADA Employment Line advise individuals with developmental disabilities, as well as their families and job coaches, about advocating for people with disabilities. The Employment Line operates three hours a day, four days a week, and provides a valuable and accessible source of information.

2.5 Individuals with Developmental Disabilities have their complaints of abuse, neglect, discrimination, or other human or civil rights violations corrected

All people – both individuals with disabilities and members of the general population – have the right to lives free of abuse, neglect, exploitation, and rights violations. ADD supports programs that seek to eliminate discrimination based on disability and to ensure that all individuals with developmental disabilities have access to the supports necessary to make their voices heard and have their complaints of abuse, neglect, discrimination, and other illegal practices investigated and appropriately addressed.

Grantees also provide legal support when rights in these areas are violated, thereby helping individuals on a case-by-case basis as well as working to create systemic change and foster an environment wherein these discriminatory practices are a thing of the past. Systemic change means a sustainable transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

Protection and Advocacy Agencies (P&As) are charged with investigating and addressing instances of abuse, neglect, and discrimination. State Councils on Developmental Disabilities (Councils) and University Centers for Excellence in Developmental Disabilities (UCEDDs) are not directly involved in legal activities related to these issue areas. However, both the Councils and the UCEDDs empower individuals with developmental disabilities to be less vulnerable to abuse, neglect, and discrimination through training and educational activities that allow individuals to protect their rights, increase their safety and personal welfare, and maintain their personal authority.

In fiscal years 2003 and 2004, several Councils undertook projects to educate people with developmental disabilities and their families and caregivers about discrimination, abuse, and neglect and to help individuals to understand and protect their rights, often by training them to be effective self-advocates.

- ✦ **Maine**'s Council provided financial and other types of support to “Speaking Up for Us (SUFU),” the state’s self-advocacy organization for individuals with developmental disabilities. Local SUFU groups met regularly and members learned from each other about protecting themselves from abuse and taking care of their health, among other issues.

- ✦ In **California**, more than 2,600 individuals with developmental disabilities, family members, providers, and professionals have received personal health and safety training designed to minimize the risk of abuse and keep individuals with disabilities safe. Through Council projects in Northern and Southern California training was provided on topics such as “Providing Personal Care Safely and with Dignity,” “Personal Care Protocols,” “Respecting Yourself,” “Personal Safety and Healthy Relationships,” and other topics designed to improve the ability of individuals with disabilities to live free from abuse or neglect.

- ✦ The **Colorado** Council worked with a legislative representative to stop a bill that would reduce protections and recourse for children in residential facilities who experienced abuse or neglect.

Like the Councils, UCEDDs educate individuals with disabilities, their families, their caregivers, and other community stakeholders about the rights of people with disabilities and methods for the prevention of abuse and neglect.

In **North Dakota**, the Center for Persons with Disabilities (NDCPD), the state's UCEDD, is working directly with service providers to ensure that caregivers for individuals with developmental disabilities are properly trained in order to minimize the potential for instances of abuse and neglect.

Together with an independent contractor, NDCPD created an online course for caregivers. The course focuses on strategies for preventing abuse and neglect, and participants learn how to:

- ✦ Recognize risk factors for staff as perpetrators and individuals as potential victims;
- ✦ Develop coping skills for staff members in challenging situations;
- ✦ Identify corporate and environmental supports that foster positive relationships;
- ✦ Implement positive practices that decrease the likelihood of mistreatment; and
- ✦ Recognize and report the occurrence of mistreatment.

While many people who work in the disability service community may benefit from this course, it is written specifically to meet the needs of the direct support staff who have contact with people with disabilities on a regular basis.

In **North Carolina**, psychologists are providing training to individuals who work with children with developmental disabilities who have been the victims of abuse. The Clinical Center for the Study of Development and Learning (CDL) at the University of North Carolina at Chapel Hill is North Carolina's UCEDD. CDL psychologists provide regular training and consultation to offices of the North Carolina Mentor Network, which provides direct service to children and adults with developmental disabilities, many of whom have been the victims of severe abuse. The staff also provides continuing education to therapeutic foster parents and other direct service providers. The benefits of this approach are a better trained workforce and greater support for innovative service.

In **Wyoming**, efforts are being made to help individuals with developmental disabilities who have been the victims of a crime. Being a crime victim is a terrifying experience for anyone, but for individuals with disabilities, the trauma of the crime is often compounded by the fact that there are no available resources to help them process the event and seek closure. In a joint venture with the U.S. Department of Justice's Office for Victims of Crime and the Association of University Centers for Excellence in Developmental Disabilities, the Wyoming Institute for Disabilities (UCEDD) is taking steps to help people with developmental disabilities who become victims of crime.

The project has led to the creation of the “Victims of Crime with Disabilities Resource Guide,” which provides an online, searchable database of training, technical assistance, and general informational resources focusing on victims of crime with disabilities. The web site has several hundred entries including books, videos, training programs, and training products all geared towards the disability and victim assistance fields.

All of these projects lead to the empowerment of individuals with developmental disabilities, their friends and families, and the people who provide their care. While P&As do provide education about the rights of individuals with developmental disabilities, they also provide direct advocacy and support if these rights are violated.

In **New Jersey**, the state P&A was consulted because of several falls experienced by “Peter,” who has developmental disabilities, is blind, and resides in a state developmental center. Peter sometimes engages in self-injurious behavior, and a report by the developmental center stated that Peter had fallen in the bathroom and sustained a head wound requiring closure with staples. His sister contacted the P&A because of concerns that his safety was being neglected. Peter’s family requested a special Interdisciplinary Team meeting, and a plan was developed to enhance Peter’s safety through staff education and modifications to his environment. In addition, Peter’s psychiatrist provided new medication to reduce Peter’s self-injurious behavior. After the changes had been implemented, P&A staff visited Peter to monitor his condition. Peter and his family are pleased with his progress and with the developmental center staff’s attentiveness to his needs.

The **Alabama** P&A intervened to investigate allegations of abuse after “Frank,” an adult with developmental disabilities, was discharged from a large developmental center and placed in a smaller group home in the community. Frank was attending a day program that was separate from his residential program, and both his guardian and the day program staff were concerned that Frank’s needs were not being adequately addressed by his residential program’s staff. There were allegations of rights violations, abuse, and neglect. The P&A visited Frank at his residence and identified a number of concerns, including inability to exercise religious beliefs, unreliable transportation, inadequate staff training/education, lack of adequate food, and inadequate opportunities for community integration. The P&A sent a memo to the Regional Mental Retardation Services Office outlining the identified concerns. P&A staff then worked with various regional and state services offices to successfully remedy concerns identified at Frank’s residential program. Frank and his family are now happy with his living situation and with the quality of the care he receives.

In addition to the investigation of concerns related to the safety and well-being of people like Peter and Frank, P&As investigate potential discriminatory practices and work with involved parties to find appropriate solutions.

As discussed earlier in this report, one of the most important rights of any individual in this country is the right to a free, appropriate education. Having access to education sets the stage for success at every phase of life. It opens doors and broadens prospects for the future. ADD’s grantees sponsor a number of programs to promote inclusive education practices, but occasionally, intervention is necessary in individual cases to address discriminatory practices.

Through correcting individual instances of discrimination, P&As educate school districts about the legal ramifications of such practices, and help to foster long-term system change.

“Miguel,” a child with developmental disabilities living in **Maryland**, was not being provided with appropriate educational services by his school district. His rights, as outlined under the Individuals with Disabilities Education Act (IDEA), were being violated. The school district refused to accept the diagnosis of Autism/Asperger’s Syndrome, refused to provide the necessary special education supports and accommodations required by IDEA, illegally placed Miguel in a home teaching program, and attempted to place him in a program for children with emotional disturbances. The P&A filed a complaint with the Maryland State Department of Education on Miguel’s behalf. It was found that the school district had violated Miguel’s educational rights and owed him compensatory educational services. A new Individualized Education Program (IEP) was developed for Miguel, and he was placed in an appropriate program that meets his needs.

In **Rhode Island**, the parents of “Pablo,” an 8-year-old boy with developmental disabilities, contacted their state’s P&A because Pablo’s school was refusing the one hour of inclusion required in Pablo’s IEP. In the prior year, Pablo had one hour of inclusion, but the school district stated that time in an inclusive setting was going to be decreased due to behavioral problems. Pablo’s parents wanted his level of inclusion to be *increased*, not decreased. Also, due to behavior issues, Pablo was not allowed to go on a school field trip. The P&A represented Pablo at an IEP meeting, and due to staff efforts, Pablo was able to maintain his current hour of inclusion, with quarterly reviews scheduled to increase inclusion time. The P&A also helped to develop a behavior plan and educate the school department on disability-related behavior. The P&A advised the school that failure to include the client in field trips was discriminatory and illegal.

	Complaints of abuse, neglect, discrimination, or rights violation were investigated	
	FY 2003	FY 2004
Total	57	56
# of P&As	10,056	9,939

Chapter 3: Accountability

The Administration on Developmental Disabilities (ADD) uses Monitoring and Technical Assistance Review System (MTARS) site visits to evaluate three of its grant programs:

1. State Developmental Disabilities Councils (Councils);
2. State Protection and Advocacy Systems (P&As); and
3. University Centers for Excellence in Developmental Disabilities Education, Research and Services (University Centers, UCEDDs).

MTARS benefits ADD, the States experiencing an MTARS review, and all ADD grantees nationwide. ADD relies on MTARS as a significant component of its Federal stewardship and uses the information obtained from MTARS reviews to strengthen its position when justifying its programs to Federal oversight agencies. States learn how to become even more effective, and all grantees gain through the sharing of innovative practices that are highlighted through the MTARS process.

The MTARS process provides opportunities for consumers and program peers to participate with Federal program officials in their review and assessment of the Council, P&A and UCEDD grantees within a State. The MTARS process focuses on a grantee's:

- Program compliance with the DD Act;
- Organizational structure for effective implementation of the DD Act;
- Accountability and achievement of program goals;
- Collaboration with other ADD programs within the State;
- Technical assistance needs; and
- Innovative practices.

In 2004 MTARS evolved from primarily focusing on grantee compliance with the law to the multi-element approach bulleted above. The traditional compliance model did little to promote collaboration among grantees in a State, a theme emphasized in the DD Act. Moreover, throughout the Federal Government, there is increased emphasis on accountability and on justifying programs and budgets by showing their positive impact on people. It is no longer sufficient only to describe procedures or processes. This new Federal climate is an opportunity to bring more attention to the collaboration among a State's DD network grantees, to the effect they have in the State on issues affecting people with developmental disabilities and to the benefits of technical assistance that fosters partnerships, promotes collaboration, and encourages program compliance and effectiveness.

During an MTARS evaluation, grantees are asked to demonstrate *compliance* with the law by documenting how they meet requirements regarding such areas as governance, authority and independence, monitoring and evaluation, reporting and recordkeeping, and fiscal management. They are also asked to demonstrate *accountability* with information regarding progress on achieving goals, activities and outcomes tied to goals, resources targeted on goals, processes to verify and validate program outcome data, costs associated with goals and evidence of consumer satisfaction. Finally, they are asked to provide evidence of *collaboration* within the DD network. This includes information on the number of projects that include substantive joint efforts with

other ADD grantees in the state, the extent of collaboration within a given project, the areas addressed by these joint efforts, and the impact of collaboration on project outcomes.

Technical assistance to ADD grantees is not limited to the needs that arise during an MTARS review. ADD, through its technical assistance contracts and other resources is ready to help grantees at any time to remedy issues and address areas where help is needed to yield better outcomes. Because MTARS is comprehensive in scope, intensive, involves follow-up activities, and has many opportunities for dialogue with ADD staff, peers, and consumers, it is advantageous for grantees to disclose areas where they would like to improve so that technical assistance resources can be activated early in the MTARS process.

The MTARS is one vehicle ADD uses to identify *best practices* that can be added to the strategies used by other grantees to do an even better job. ADD is proud of all the good work that grantees do each day to better the lives of individuals with developmental disabilities and seeks innovative practices to recognize, promote, and disseminate throughout the nation.

The outcomes of the MTARS in 2004 revealed a number of strengths, some weaknesses, and some innovative practices. In one State, the recent structural and leadership changes were found to strengthen the organizations. The strong collaboration within one State with regard to joint needs assessment and development of goals and priorities laid a strong foundation to fulfill recommendations to build collaboration in other areas. One review identified the need for increased outreach across a State and for parent leadership training programs. One review revealed a number of strengths in a university based program, including the scope and quality of the research and clinical services; the resources made available at the local, state and national levels; the efficacy of training in terms of student outcomes; the quality and commitment of faculty and staff; and the breadth of effective collaboration across State agencies and organizations. An innovative practice in one State's attempt to enhance the independence of people with impairments caused by brain injuries or autism was teaching them to use personal digital assistants (PDAs) to remember to perform daily activities. These MTARS visits supported ADD's stewardship role, gave assistance to grantees to improve their programs, and shared worthwhile ideas throughout the grantee network.

MTARS Review Recipients in Fiscal Years 2003 and 2004

<u>Region</u>	<u>2003</u>	<u>2004</u>
I	MA	
II		
III		VA
IV		AL
V		WI
VI	TX	AR
VII	KS, NE	
VIII		CO, UT
IX		
X		

Chapter 4: Projects of National Significance

An individual with a developmental disability acquires the disability before the age of 22 and often faces the need for a wide range of services and supports in order to engage in activities of daily living. The right combination of services and supports helps individuals with developmental disabilities and their families stay together, participating in the full range of community life.

To help ensure that those services best meet the needs of people with developmental disabilities, ADD funds Projects of National Significance (PNS), which are short-term projects that provide ADD with the opportunity to work on targeted issues that are important to the developmental disabilities community.

These projects focus on the most pressing issues affecting people with developmental disabilities and their families. Project issues transcend the borders of States and Territories, while project designs are oriented to permit local implementation of practical solutions. Over the years, PNS funds have supported families and caregivers, increased community living options, promoted inclusive education, developed quality assurance standards, explored avenues to promote self-determination, assisted with family leadership development, and increased opportunities for self-advocates to be involved in system change initiatives. Examples of PNS projects in fiscal years 2003 and 2004 include youth center grants and family support projects.

Youth Information, Training, and Resource Centers Grant.

In fiscal year 2004, 15 organizations across the country were awarded three-year grants to undertake projects which enable them to design information, resource, and training centers for youth (13 – 17 years old) and emerging leaders (18 – 30 years old) with developmental disabilities. Grants were awarded to organizations in California, Delaware, District of Columbia, Iowa, Illinois, Maryland, Minnesota, New Mexico, North Carolina, Oklahoma, Oregon, and Washington. Centers will help youth and individuals with developmental disabilities on national and local levels.

Three of the grantees are working to become national resource centers, expanding their existing national networks. All of the grantees plan to serve youth with developmental disabilities and emerging leaders in unserved and underserved communities. Each grantee was awarded up to \$100,000 annually for three years from ADD to support their model youth center.

On-going Data Collection and Information Dissemination

Under Projects of National Significance, ADD has funded a nationwide study of public financial commitments and programmatic trends in developmental disabilities services and supports. The Project is a "benchmarking" study of states' performance as they work to implement President Bush's New Freedom Initiative and the U.S. Supreme Court's Olmstead decision, both of which promote community living and greater independence.

The Project will:

- ✦ Analyze developmental disabilities financial and programmatic trends in each state and the District of Columbia;
- ✦ Identify trends and innovations in the financing of family support, supported living, and supported employment;
- ✦ Complete a special study of Medicaid spending for special education; and
- ✦ Conduct in-depth analyses of developmental disabilities services and supports in individual states, including a special study of family support in California in collaboration with the University of California.

Family Support 360

While many service programs are available in this country, human service systems often fail to meet the diverse needs of an individual with developmental disabilities and his or her family. A family may need several services and many human service systems address primarily one need, such as health, education, or employment. These systems usually focus on one individual, not the person *and* his or her family.

Funded under Projects of National Significance, Family Support 360 projects help not only the individual with disabilities, but also his or her entire family. These families often need assistance securing services and help when a service is not available, not coordinated with other services, or is not delivering what the family needs.

Family Support 360:

- ✦ Is in-step with President Bush's New Freedom Initiative;
- ✦ Empowers and strengthens families;
- ✦ Increases responsiveness to the needs of individuals and families;
- ✦ Promotes more public-private partnerships to assist people;
- ✦ Encourages wiser spending of money; and
- ✦ Reduces duplication of effort.

Family Support 360 grants are funded through Title I, Subtitle E, Projects of National Significance (42 USC 15081 through 15083), of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 USC 15000 et seq.) (DD Act). In fiscal year 2003 ADD gave 31 planning grants to help states design a one-stop center to meet the many needs of individuals with disabilities and their families. In fiscal year 2004, ADD awarded nine additional planning grants, as well as 21 implementation grants to help states meet the goals set in the planning stage. These projects are working with diverse human service agencies and public and private groups to help families.

The goal of every one-stop is to assist a family to stay together as a family and thrive. Each implementation grant is to provide family support to 50 families of individuals with developmental disabilities through a one-stop. The families helped are to be members of





unserved or underserved populations. Through the one-stop a family will have a family assessment and participate in the development of its individual family plan. The plan is to include the services and supports (e.g., health and/or mental health care, housing, counseling and/or marriage education, parenting skills development, child care, employment, transportation, respite care, personal assistance care, financial assistance and/or management) the family needs that may be provided by public human service agencies and/or private community- and faith-based groups. Services and supports are for any family member as needed, not just the member with a developmental disability. As a family's plan is implemented, if the family encounters a problem, it is to have access to assistance from a navigator employed by the one-stop, who is to help resolve the problem.

In order to be a Family Support 360 implementation grantee, an applicant had to be designated as the recipient by the governor in the application. In addition, the applicant had to involve a local elected official or his or her designee and agree to work with other grantees of ADD in the state in the operation of the one stop. The other state grantees include the State Developmental Disabilities Council, the State Protection and Advocacy Agency, and the University Center(s) for Excellence in Developmental Disabilities.








Grant funds are used for operating the one-stops. Other federal, state, and local funding streams, as well as support from faith-based and community organizations, cover services and supports included in the plans of eligible families.

Each of the Family Support 360 implementation grantees was one of 31 grantees that received a Family Support 360 one-year planning grant of \$100,000 in 2003, awarded on a competitive basis. In 2004, these 31 grantees competed with each other again for implementation grants (\$250,000 per year for five years), and ADD was able to award implementation grants to 21 of the grantees. In 2004 ADD also funded another round of one-year planning grants at \$100,000 each.

Grantees and their public and private partners have the opportunity to:

-  Focus on families in depth;
-  Develop the capacity to work with many systems;
-  Become more culturally aware; and
-  Take the time to learn from families what really works for them.

These grants:

-  Support the emergence of new leaders in delivery of human services;
-  Achieve greater credibility with customers;
-  Generate greater buy-in and impact on communities;
-  Demonstrate new models that others want to replicate for reaching and serving people;
-  Increase public and private partnerships, fostering trust and collaboration efforts;
-  Provide families the services and supports they need, when they need it; and
-  Show policy makers and administrators something that works.

Distribution of Family Support 360 Grants to States and Territories

Name of State/Territory	FY 2003 Planning Grant	FY 2004 Implementation Grant	FY 2004 Planning Grant
Alabama	Yes		
Alaska	Yes	Yes	
American Samoa			
Arizona			
Arkansas			
California			
Colorado	Yes	Yes	
Connecticut			Yes
Delaware			Yes
District of Columbia	Yes	Yes	
Florida	Yes		
Georgia	Yes		
Guam			
Hawaii	Yes	Yes	
Idaho	Yes	Yes	
Illinois			Yes
Indiana			
Iowa			Yes
Kansas			
Kentucky	Yes		
Louisiana			
Maine			
Maryland	Yes	Yes	
Massachusetts	Yes	Yes	
Michigan	Yes	Yes	
Minnesota	Yes	Yes	
Mississippi			Yes
Missouri	Yes	Yes	
Montana			
Nebraska			
Nevada	Yes		
New Hampshire	Yes	Yes	
New Jersey			Yes
New Mexico	Yes	Yes	
New York			
North Carolina	Yes	Yes	
North Dakota			Yes
Northern Mariana Islands	Yes	Yes	
Ohio			Yes
Oklahoma	Yes	Yes	
Oregon	Yes	Yes	
Pennsylvania			
Puerto Rico	Yes		
Rhode Island	Yes	Yes	
South Carolina			
South Dakota	Yes	Yes	
Tennessee			Yes
Texas			
Utah	Yes	Yes	
Vermont	Yes	Yes	
Virgin Islands	Yes		
Virginia	Yes		
Washington	Yes		
West Virginia			
Wisconsin	Yes	Yes	
Wyoming	Yes		
Totals	31	21	9

Chapter 5: DD Network Collaborative Projects, Activities, and Progress

As discussed earlier in this report, ADD manages several grant programs three of which are: State Councils on Developmental Disabilities (Councils), University Centers for Excellence in Developmental Disabilities (UCEDDs), and Protection and Advocacy Agencies (P&As).

Collaboration among all three ADD grantees in a State or Territory (the DD Network) is crucial in order to maximize the impact these programs have on the lives of people with developmental disabilities. Through collaboration, the partners bring their unique role and capabilities to the table and coordinate their resources to achieve common goals and bring about systems change.

In addition to collaboration among sister DD entities, ADD grantees and DD networks also cooperate with other local, state, and national organizations to maximize their ability to provide the best services possible.

In its purest form, collaboration encompasses interdependent systems and a shared vision. Partners make decisions jointly and initiate strategic planning to identify shared goals, outcomes, and resources.

There are several steps, or phases, that help States and Territories move towards full collaboration.

1. **Contribution:** States and Territories make progress towards full collaboration when each grantee contributes to and affects what the other grantees are doing -- exchanging ideas, providing input, responding to input received, and supporting each other's efforts.
2. **Coordination:** Next, grantees compare needs, share the workload to achieve outcomes, pool resources, and sponsor joint activities.
3. **Cooperation:** This involves an awareness of other programs, missions, limitations, and challenges; a willingness to assume complementary roles, eliminate redundancy, and adopt joint goals; and the ability to recognize, accept, and use the strengths and needs of partners, to do more than we could do alone.

The following are examples of collaborative projects that took place during fiscal years 2003 and 2004.

In **Colorado** the P&A spearheaded what resulted in a collaborative strategic planning effort across the three programs to move people who were in an institutional setting into the community. In 1997, there were 160 residents at the Grand Junction Regional Center, and the network wanted to reduce this number by moving people into the community. The network collaboratively decided to co-sponsor a two-day planning retreat to bring together various representatives from the community at which time they developed a unified effort with the following goal:

To reduce the number of people with developmental disabilities living on the Grand Junction campus to zero, but with the condition that every person who moves off campus wants to move to the community is safe and is receiving appropriate, good quality service in the community.

The P&A, the Council, and the UCEDD agreed to accept responsibility for the initiative and to form a steering group to move the strategic planning effort forward.

By 2004, there remained just over 60 residents at the Grand Junction Regional Center. Although the network fell short of their intended goal of zero residents, they felt much progress had been achieved through the collaborative effort. Evaluative information from the effort supports this perspective. Survey responses measuring participants' satisfaction with the initiative indicated overall satisfaction with how the move was planned and how community services were being provided.

In **Virginia** the developmental disabilities network has developed a successful collaborative working relationship. This working relationship enables the network to address both statewide and national issues relating to developmental disabilities. The executive directors of the Council, P&A, and UCEDD maintain effective and consistent communication. They have one regularly scheduled meeting a month, but are in frequent contact to discuss projects and current happenings in the state.

Each of the three grantees provides input into the planning process of the other grantees, contributes to the other grantees' newsletters, and has representatives on the other grantees' boards of directors. They jointly participate in activities to improve special education experiences, to train professionals to prevent maltreatment of individuals with disabilities, and to address community living issues inherent in the Olmstead decision. All three programs participate in Partners in Policymaking. The Council and P&A work together on the Youth Leadership Forum and the Council and UCEDD are sponsors of New Voices, an initiative to provide self-advocacy and other system change opportunities to people with developmental disabilities who have been isolated and have not previously participated in such activities.

In **Idaho** the Council convened a task force to examine supported living in the State. Both P&A and UCEDD were represented on that task force. The task force also served in an advisory capacity to a contract funded by the Council to conduct research on how to amend two Home and Community Based Services waivers for persons with developmental disabilities to encourage the use of supported living. A report was released in June and is being used, in part, to assist with the development of the self-determination waiver. Recommendations from the report have also been incorporated into changes in billing procedures for supported living services statewide. A copy of the report was also provided to Region X Centers for Medicare and Medicaid Services during their Idaho site visit.

The three network components in **Mississippi** are involved in an initiative entitled "Justice for All" that is designed to support individuals with developmental disabilities and people with disabilities who are victims of crime. The Council funds the initiative with the UCEDD. All

three serve on a Youth Leadership initiative through a local private/non-profit organization entitled Coalition for Citizens with Disabilities.

The **Alabama** DD Network partners collaborated on the Meet Your Neighbor (MYN) project. The UCEDD served as the lead agency, while the Council provided funds for that project. Both the Council and P&A served on the committee and supported the UCEDD during that project. The project resulted in a video and an informational packet to make the community aware of what individuals with disabilities can do and how they can be a productive part of a community.

In **New Jersey**, the Elizabeth M. Boggs Center on Developmental Disabilities, the Protection and Advocacy Agency, and the Council on Developmental Disabilities, together with other partners, collaborated to create a conference, “The Latino Community and Disabilities; Confronting the Barriers.” The conference, held on September 17 -18, 2004, focused on building awareness and strategies for disability service providers to serve Latino communities and helping community and faith-based organizations to identify and support the needs of children and adults in their communities.

Each year in **Arkansas**, the Arkansas Governor’s Developmental Disabilities Council plans a state conference attended by people with disabilities and their family members, direct support professionals and service providers. The conference is designed to further the cause of individuals with developmental disabilities. Over the 14-year history of the conference, attendance has grown from 150 to approximately 800 individuals. The 2004 conference was entitled: “KEYS to COMMUNITY - Unlocking the Door to Independence for People with Disabilities.” As with previous conferences the Disability Rights Center (P&A) and Partners for Inclusive Communities (UCEDD) collaborated in the planning of the conference and conducted various workshops. The 2004 conference was held September 16 – 17, 2004, in Hot Springs, Arkansas. The Arkansas network partners are also involved in the needs assessments meeting which takes place in the State prior to development of the Five-Year State Plan and annual state plan modifications. They generally hold between three and six public forums/local meetings each year.

The **Wisconsin** Council on Developmental Disabilities, the Waisman Center UCEDD and the Wisconsin Coalition for Advocacy (WCA) work together as a DD network on many activities. Examples of how they coordinate include joint public hearings, regular joint meetings of executive directors, participation in one another’s boards and committees, work groups with members across the network, and shared funding and resources. The Wisconsin ADD network has a longstanding involvement with the Survival Coalition, a community-wide initiative, and DAWN, a grass roots self-advocacy coalition, in which the Council has taken the lead in supporting activities. In addition, the UCEDD assumed the lead role in the Health Disparities Initiative, for which they coordinated planning for a conference, solicited state-wide input, and drafted a summary document. The WCA has the lead role for the network’s special education initiatives, advocacy and litigation.

The Council, the P&A and the University Center in **Louisiana** cooperated with one another to initiate and advocate for legislation to create the state’s official Olmstead planning group and all three agencies continue to work together in the Olmstead planning process. The Council is

assisting in a project of the state's University Center to develop an introductory curriculum for Direct Support Professionals (DSPs) and recommendations for creating a comprehensive system of educational opportunities and career advancement for DSPs.

The DD network in **Arizona** identified students, family members, and educators as having a lack of knowledge about appropriate transition services. To rectify the situation the network agencies took a threefold approach. The network provides training and support to students, family members, and educators to facilitate self-determination and successful transition outcomes. Additionally, the network is making plans to initiate a public awareness campaign in order to educate the general public on the community integration of individuals with developmental disabilities. Finally, the Arizona network has identified a lack of qualified related service personnel as a result of the job requirements and the prospective compensation and plans to identify barriers and implement systems change activities.

The **Utah** P&A, the Disability Law Center (DLC), performed an annual needs assessments focused on how best to serve the rural population. They found that people wanted to be taught self-advocacy skills, especially around physical access issues and education. The DD Network has decided to address this systemic issue collaboratively. The Council and P&A hired a shared staff person to assist with outreach, education and training. The UCEDD worked with the staff person to provide the training. A space was donated by a mental health service provider in the community. This office serves southern Utah and is closely located to the two state operated facilities.

The state of **Nebraska** implemented a Statewide Telehealth Network to create an opportunity for all hospitals and public health departments to connect, providing services including video conferencing for patient consultations, provider and public education, administrative meeting capabilities, emergency alert follow up capabilities, and data transmission. The Telehealth system is capable of linking all acute care hospitals and affords an opportunity for secure two-way interactions. The Nebraska UCEDD provided telehealth services as a joint venture between the Munroe-Meyers Institute and the Nebraska Departments of Health and Human Services and Education. The joint project provides a comprehensive link between providers at the Munroe-Meyer Institute and community providers for children with special health care needs and developmental disabilities. The network increases access to specialty services throughout Nebraska, offering enhanced health care options to rural communities.

Chapter 6: Technical Assistance and Interagency Activities

Technical Assistance

The Administration on Developmental Disabilities (ADD) uses technical assistance (TA) to help meet agency goals and to advance the mission of ADD. ADD endorses the use of technical assistance for grantees when they have a need that they cannot address independently or if the population's needs cross program or State lines. Technical assistance can take many different forms. TA contractors are called on to help build capacity for greater service, provide training to personnel, improve interagency communication, facilitate cross-agency collaboration, streamline administrative processes, collect information, implement technology advances, and provide expert advice in a wide range of areas. The targeted result of technical assistance is a greater ability for ADD and its grantees to meet ongoing needs and sustain progress.

In fiscal years 2003 and 2004, ADD funded several contracts that provided technical assistance and/or training to grantees, and to ADD as a whole, including the following:

- ✦ National Association of Councils on Developmental Disabilities (NACDD);
- ✦ National Association of Protection and Advocacy Systems/Training and Advocacy Support Center (NAPAS/TASC);
- ✦ Association of University Centers on Disabilities (AUCD);
- ✦ Disability Advocacy Training and Technical Assistance (DAT2A); and
- ✦ Z-Tech Corporation – Online Data Collection (OLDC), Information Dissemination.

Other sources of technical assistance that may be arranged directly by ADD grantees include the following:

- ✦ Peer developmental disabilities program consultation and assistance;
- ✦ National organizations and foundations;
- ✦ Private providers and agencies; and
- ✦ National experts.

Technical Assistance to State Councils on Developmental Disabilities

An ADD Technical Assistance contract through the National Association of Councils on Developmental Disabilities (NACDD) encouraged and supported individuals with developmental disabilities and family members to attend and speak at an annual conference in Washington, DC. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) requires that individuals with developmental disabilities and their families participate in the design of community services, supports, and assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. ADD supports consumers and families attending the annual TA Institute to benefit from their leadership and networking abilities and to foster skills development. Through the TA contract, NACDD has provided significant assistance to State Councils on Developmental Disabilities on Olmstead and the New Freedom Initiative. Information on the Olmstead Decision can be found in *Chapter 7: New Freedom Initiative Activities*. Additional information on the New Freedom Initiative can be found in the *Chapter 1: An Introduction to ADD*, and in *Chapter 2: Challenges and Opportunities*.

NACDD technical assistance helped to move individuals out of institutions and increased home and community based services and supports. TA also helped increase the number of direct support staff available to provide assistance for individuals with disabilities ensuring or increasing the stability of their independent living arrangement. NACDD facilitated conference calls on the topics and generated resources and reports from literature reviews.

Technical Assistance to Protection and Advocacy Agencies

The Training and Advocacy Support Center (TASC) provided training and technical assistance to help P&A staff enhance their ability to effectively advocate on behalf of all people with disabilities. Using the phone, e-mail and listservs, the contract responded to approximately 6,000 specific requests for information on a range of topical areas including abuse and neglect, ADA Titles I, II, and III, community integration, education; housing, employment, criminal justice, voting and management (including human resource) issues.

Additionally, the contract provided four major training sessions to approximately 1,000 P&A staff and/or Board members at the Skills Building Conference, the new CEO meeting and training, the P&A Annual Conference, and the Fiscal Managers Training. In addition, the contract provided teleconference and web-based trainings on emerging topics.

Technical Assistance to University Centers for Excellence in Developmental Disabilities

Technical assistance was provided to the UCEDD network through a variety of activities. Through the contract with the Association of University Centers on Disabilities, UCEDDs are provided regular updates and information about issues pertinent to developmental disabilities. The ADD staff also provides technical assistance on individualized basis. In addition, technical assistance visits are conducted to address individual program needs. Wisconsin received a Technical Assistance visit in fiscal year 2004, and technical assistance was provided to programs through the States that were reviewed through the MTARS process, including **Nebraska, Texas, Colorado, Utah, Wisconsin, Arkansas, Alabama, and Virginia.**

Technical Assistance for Projects of National Significance, Family Support 360

In fiscal year 2004, BETAH Associates of Bethesda, Maryland was awarded a contract to provide technical assistance to ADD's Family Support 360 grantees. BETAH staff coordinated the annual grantee technical assistance institute, hosting conference calls, providing expert knowledge upon request, and facilitating peer-to-peer grantee learning and problem solving. Additionally, BETAH fostered collaboration between ADD's Family Support 360 initiative and the Administration on Aging's (AoA's) and Center for Medicare and Medicaid's (CMS's) Aging and Disability Resource Centers.

Information Collection and Dissemination

ADD received technical assistance from Z-Tech Corporation to facilitate the collection and dissemination of information on ADD programs and developmental disabilities. The Online Data Collection System makes it possible for ADD to meet the reporting requirements of the DD Act and the Government Performance and Results Act of 1993 (GPRA), have quality assurance measures, and maintain communication between the grantees and ADD. In 2003 and 2004,

information was gathered, through Program Performance Reports, from 112 grantees. Z-Tech maintained the frequently asked questions and general content/appearance of the ADD web site and produced electronic and hard-copy publications to make collected information available to ADD headquarters and regional staff, grantees, consumers, the public, and other agencies.

Interagency Activities

The Administration on Developmental Disabilities has been working with interagency committees in the interest of individuals with developmental disabilities. Below are the interagency committees with whom ADD worked during this report period.

- ✦ For OMB, ADD's Commissioner co-chairs a working group to simplify data collection across eight federal Protection and Advocacy Systems grant programs.
- ✦ The Commissioner, as a representative of HHS, is a member of the U.S. delegation to the United Nations participating in the development of a disability rights treaty.
- ✦ For the Secretary, the Commissioner of ADD serves on the Interagency Committee on Muscular Dystrophy, the Interagency Autism Coordinating Committee (IACC), and the Interagency Committee on Disability Research.
- ✦ ADD, as ACF's representative, serves on multiple working groups led by the Secretary's Office on Disability related to the President's New Freedom Initiative (e.g., emergency preparedness, services to youth with co-occurring disabilities, employment, direct care workers, services to infants who are deaf, and youth in transition).
- ✦ ADD also serves as ACF representative on the United We Ride Interagency work group triggered by the President's Executive Order to improve transportation options for older citizens and individuals with disabilities.
- ✦ ADD coordinates ACF's responses to action plan updates related to disability for the Secretary and President on the New Freedom Initiative and the White House Commission on Mental Health, and coordinates the preparation of information about services to individuals with disabilities from unserved and underserved populations (e.g., homeless, Native Americans, Hispanics).
- ✦ ADD, in conjunction with the Child Care Bureau, Head Start, and the Office of Special Education Programs in the U.S. Department of Education is working to increase access to and participation in early care and education programs for children with disabilities.
- ✦ ADD promotes, among its grantees, awareness of and participation in public campaigns initiated by the Secretary related to women's health and the Medicare Prescription Card. In FY 2004 ADD expanded an existing grant to the Arc of the United States so that it could develop a website in plain English on the prescription drug card program. Funding for this website came through an interagency agreement, in which the Centers for Medicare and Medicaid Services transferred \$12,000 to ADD.

Chapter 7: New Freedom Initiative Activities

Olmstead Decision



On June 22, 1999, the Supreme Court held in its landmark Olmstead decision that Title II of the Americans with Disabilities Act (ADA) requires States, whenever possible, to place qualified individuals with mental disabilities in community settings rather than in institutions.



Since then, each State has worked to address the Olmstead Decision. For example, in 2002 a Task Force was established in Virginia to focus on Olmstead related activities. Virginia's DD Council took an active role in helping with initiatives to obtain consumer input into the work of the Olmstead Task Force and report and funded the research initiative to gather and analyze data in support of Olmstead report recommendations. The Council developed formal recommendations and submitted them to the Secretary of Health and Human Resources regarding "next steps" in implementing the Olmstead plan. The Council is a member of Virginia's Olmstead implementation team.

In Iowa the Council has participated in Olmstead related activities since the first focus groups were held throughout the state. The Council participated in the development of the State plan and continues to participate in the Olmstead Real Choices Consumer Task Force. The Governor's Executive Order 27 names the Olmstead Real Choices Consumer Task Force as a resource state agencies can tap as they identify and prioritize barriers to community living and develop plans for effective, efficient use of their resources in support of ADA goals. In response to the Executive Order, State agencies, with help from the Real Choices project, are providing a self-assessment of their effectiveness in promoting community living for people with disabilities. State agencies have designated specific staff to coordinate Olmstead-related activities and have provided preliminary plans to the Office of the Governor.

New Freedom Initiative

On February 1, 2001, within two weeks of taking office, President George W. Bush announced his New Freedom Initiative (NFI), one of his first major acts in office. This initiative is aimed at eliminating barriers that restrict Americans with disabilities seeking to participate in their communities through its four key components.

1. Increasing access to assistive and universally designed technologies:
 -  Increase Federal investment in assistive technology research and development; and
 -  Increase funding for low-interest loan programs to purchase assistive technologies.

2. Expanding educational opportunities for Americans with disabilities:
 -  Increase funding for the Individuals with Disabilities Education Act; and
 -  Focus on reading in early grades.

3. Integrating Americans with disabilities into the workforce:
 - ✚ Provide resources to help small businesses comply with the Americans with Disabilities Act (ADA); and
 - ✚ Promote awareness and utilization of Disabled Access Credit to assist small businesses in complying with the ADA
4. Promoting full access to community life:
 - ✚ Signing of an Executive Order 13217, on June 18, 2001, for swift implementation of the Olmstead Decision in a manner that respects the proper roles of the Federal government and States. The Executive Order articulated NFI goals to address barriers to full integration:
 - a) Integrate Americans with disabilities into the workforce;
 - b) Promote comprehensive array of community-based services and supports;
 - c) Promote safe, decent housing and homeownership;
 - d) Promote integration into and sustained participation in the workforce;
 - e) Increase access to assistive and universally designed technology;
 - f) Expand transportation options; and
 - g) Promote full access to community life.

DD Activities Supporting the New Freedom Initiative

Colorado UCEDD

The Colorado Youth WINS (Work Incentive Network of Supports) Youth Transition Process Demonstration (YTPD) was funded by the Social Security Administration. The overarching goal of the demonstration project was to remove major barriers and disincentives to work for youth, aged 14-25, who receive, or who are likely to receive payments through programs such as Supplemental Security Income (SSI) or Child Disability Benefits (CDB). The project, which promoted economic self-sufficiency and career advancement for disabled youth, utilized a two-prong approach to achieve this system goal:

1. A Transition Team located in each selected community and housed at the local workforce center provided specialized and intensive transition services and training to youth and their families; and
2. A mix of federal waivers (SSA and U.S. Department of Labor) applied to participating youth to eliminate or greatly reduce many of the current regulatory barriers to employment.

Florida Council

The Florida *Shake-A-Leg Miami Program* developed an innovative, family-centered mentoring program for children with disabilities. Assistance was provided to high school students in an inclusive environment. The program served 532 participants and exceeded the target number of participants.

Illinois UCEDD

The Partner for Inclusive Employment (PIE) coalition was created as a partnership between the Institute on Disability and Human Development (the Illinois UCEDD) and the Westside Jobs Collaborative to address the issue of a 70% unemployment rate among people with disabilities. P.I.E. coalition members came from government agencies, non-profit groups, advocacy organizations, and corporate entities. The focus of this grass-roots effort was to develop and

implement an industry friendly protocol for people with disabilities in the job market. The P.I.E. model was a Job-Match Fair where job-seekers and employers are both pre-screened, which promoted successful matches between the two. P.I.E. was nominated as one of the finalists for the Midwest region's Council of State Governments' Innovations Award.

Iowa UCEDD

The Iowa Department of Human Services (DHS) subcontracted their Real Choices Systems Change grant to the Iowa UCEDD. The project included policy analysis, research (e.g. clinical screening/assessment protocols for level of care decision-making), training, and information sharing initiatives. The UCEDD worked with the Olmstead Task Force to amend Iowa's existing waivers to add self-directed services that would allow individuals to "cash out" and use resources with more flexibility and with greater consumer control.

Maryland Council

The Maryland Council received a Medicaid Infrastructure Grant to assist with operational aspects of the Medicaid Buy-In Program Implementation. The federal grant was also used to assist Maryland in planning for a statewide system of Personal Assistance Services to support people with disabilities in competitive employment. The Council, along with the Maryland Coalition for Work Incentives Improvement, advised the State about the needs of people with disabilities and the urgency for the program. The Maryland Coalition for Work Incentives Improvement also worked to provide information to people with disabilities and their families about the Ticket to Work Program that began in November 2003. The Coalition drafted and distributed "Let's Talk Ticket" fact sheets.

Minnesota UCEDD

The Minnesota UCEDD carried out a two-component study on assistive technology. The first component was the development of a bibliography summarizing research on which "cognitive technologies" were being used, or could potentially be used, by persons with intellectual and/or developmental disabilities. The second component of the research involved interviews and surveys of public officials in State MR/DD agencies and reviews of State budgetary documents and published material on the methods of financing assistive technology for persons with intellectual and/or developmental disabilities. The study explored mounting a state-by-state, nationwide study of the financing of AT, including State agency Medicaid programs, public school special education programs, and State vocational rehabilitation agencies.

Missouri Council

The Missouri Council partnered with the Department of Mental Health and the UCEDD to obtain an Independence Plus Grant that will offer support in studying the state's Medicaid waiver and to expand services that support increased independence and choices when the next waiver is written. Staff and Council Members have also been active in the Real System Change efforts to develop and implement a curriculum to inform individuals in habilitation centers and nursing homes of their rights to obtain community services and supports. The Council has also encouraged and supported the Department of Mental Health's efforts to close down some beds in State institutions where the buildings were aging and deteriorating and significant numbers of residents had shown interest in community services. Council members have provided leadership in the Department of Mental Health's system redesign, encouraging them to build and support a

stronger network of community options and to provide greater opportunities for independence and choice.

New York Council

The New York Council collaborated with the State Department of Labor and the State's workforce development authorities to facilitate access for people with disabilities to One-Stop services and supports. The Council also supported the Office of Mental Retardation to develop self-employment as a viable option for day services and employment, including self-employment. Over 30 individuals were given assistance to establish their own business enterprises. This project also worked with the State vocational rehabilitation agency to implement a self-employment demonstration pilot. The Council, in collaboration with the Department of Health, the State Office for the Aging, and the State Education Department's Independent Living Programs, funded six Independent Living Centers to implement a local community transition process for people with disabilities in nursing home placements, or at risk of such placements.

Texas UCEDD

The Texas Center for Disability Studies (UCEDD) managed the Texas Assistive Technology Partnership. Services of the project included providing: information and advice to individuals and organizations about a wide range of assistive technology (AT) issues; training and technical assistance to AT professionals and others who help people with disabilities access and use technology; assistance to policymakers at all levels of the service delivery system to assure that technology access is incorporated into public policies for education, employment, community services and supports, health care and telecommunications, as required by laws like the ADA and IDEA; and statewide research on technology trends and consumer experience and satisfaction with technology access.