The American Dream Belongs to Everyone:

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

Fiscal Years 2005-2006

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.

The Administration on Developmental Disabilities (ADD) is built on this belief, and in partnership with our grantees, we work to make that dream accessible to Americans with developmental disabilities. We believe that if the rights of any segment of society are denied, all people's rights are imperiled.

Historically, people with developmental disabilities have often been treated as second class citizens—segregated in educational settings, deprived of personal autonomy, left out of public policy, and not fully included in their communities. Fortunately, this is changing. The voices of people with developmental disabilities are being heard, and changes in policy are a testament to the power of those voices. ADD is committed to ensuring that those voices continue to be heard—and understood. We are dedicated to the ongoing fight for the personal and civil rights of individuals with developmental disabilities.

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

ADD carries out its mandate through the direction given to us in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The law states:

> *"The purpose of this title (Title I, P.L. 106-402(b)) 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"…*

This legislation exists to address a problem: that historically, individuals with disabilities have often been isolated and segregated from the rest society. Individuals with disabilities experience discrimination every day. Manifestations of discrimination include archaic policies and practices that do not fully meet the needs of Americans with developmental disabilities as well as facilities and programs that have not been modified to permit inclusion of people with disabilities. Individuals with developmental disabilities may experience inferior services, programs, activities, benefits, jobs, or other opportunities.

In order to combat this discrimination, ADD directs four grant programs authorized by the DD Act. The four ADD grant programs are: University Centers for Excellence in Developmental Disabilities (UCEDDs), State Councils on Developmental Disabilities (Councils), State Protection and Advocacy Agencies (P&As), and Projects of National Significance (PNS).

ADD grantees in each State work cooperatively with other grantees and with individuals, businesses, and communities to form statewide networks of support that are tailored to positively impact the specific needs people with developmental disabilities within a particular State, city, or community. For example, the needs of individuals with developmental disabilities in rural Arkansas may be significantly different from the needs of individuals in midtown Manhattan. Because ADD funding supports at least three grantees in every State, grantees are able to meet the specific needs of the people and communities with whom they are most familiar.

ADD’s grantees reach out to individuals with developmental disabilities and their families in a variety of ways. The DD Act directs grantees to assist individuals with developmental disabilities by providing support in one or more areas, including: child care, education and early intervention, health, employment, housing, transportation, and recreation. In addition, ADD grantees are directed by the DD Act to sponsor projects in quality assurance to protect the civil and human rights of people with developmental disabilities, protect them from abuse and neglect, and ensure that they have access to high quality services and supports.

People with developmental disabilities and their families influence how grantees use the funds they receive from ADD. As required by the DD Act, grantees to consider the suggestions, knowledge, experience, and opinions of individuals with developmental disabilities to shape the standards by which programs and policies operate.

ADD and its grantees are also empowered by two initiatives of President George W. Bush related to individuals with disabilities. First, President Bush launched the New Freedom Initiative on February 1, 2001. The New Freedom Initiative is intended 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. These 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 Executive Order 13127 in which he directed Federal agencies to address the decision in the Olmstead case (*Olmstead v. L.C.*, 527 US 581 (1999)). In that decision, the Supreme Court held that the Americans with Disabilities Act requires States to place qualified individuals with mental disabilities in community settings rather than institutions whenever possible.

This report tells stories about ADD's grantees and how they have changed lives – through assisting individuals with developmental disabilities to advocate for themselves and through ensuring access to education, fostering integration into communities, embracing new technologies, and providing opportunities.

Highlights include:

- As a result of grantees' efforts, children with developmental disabilities and their families have access to better child care options. The Arkansas UCEDD supports the "Welcome the Children" project in order to ensure that quality child care programs are available to Spanish-speaking families affected by disabilities.

- Grantees worked to ensure that the educational needs of children with developmental disabilities were met as the child progressed from pre-school through elementary and secondary school and into adulthood. One example involves "Carl," an 11-year-old Navajo boy with developmental disabilities who was attending a public school in an extremely segregated setting. Carl's parents requested the help of the Arizona P&A, and through their advocacy, Carl received comprehensive independent evaluations and is now placed in the regular classroom for a majority of the school day.

- Grantees supported programs that helped individuals with developmental disabilities lead healthy lives. For example, the Texas Council funded several projects that allowed parents to train pediatric residents on the delivery of long-term care to children with chronic illness or disabilities. The Houston Project trained 43 pediatric residents and 13 new parent teachers. In San Antonio, 25 pediatric residents and two parent teachers were trained.

- As a result of grantees' work, people with developmental disabilities were able to obtain or maintain employment opportunities consistent with their interests, abilities, and needs. The Alaska UCEDD supports the Self-Employment Training Grant program**,** designed to help individuals with developmental disabilities find success and fulfillment in self-employment.

- Grantees worked to increase the availability of accessible, reliable transportation. The Pennsylvania Council developed and supported the Persons with Disabilities Transportation Program. This service provides transportation for individuals with disabilities, especially in rural areas where other transportation options are minimal.

- Grantees increased the inclusion of people with developmental disabilities in community activities, public events, social gatherings, and other everyday diversions. New Hampshire's P&A is working to improve the restaurant experience for diners with disabilities. The Rolling Gourmet offers diners with disabilities the ability to review restaurants and have their reviews publicized for other diners to consider when choosing a restaurant.

- Grantees helped improve the quality of life for individuals with developmental disabilities. In Vermont**,** a Family Support project funded by a PNS grant empowered families to train other families to be self-advocates. Local parents who have encountered the service system first-hand were hired on a part-time basis to assist other parents in navigating the service system. Peer navigators also provide guidance, comfort, and encouragement to families in crisis. A statewide management team, which includes family members, assists the peer navigators with identifying resources and locating services.

I am proud to lead the Administration that oversees these efforts, and I believe that the achievements of these grantees have done much to advance the civil and personal liberties of individuals with developmental disabilities, helping to secure the rights and improve the lives of the larger community. Through the efforts of ADD's grantees in Fiscal Years 2005 and 2006, individuals with developmental disabilities received child care and early intervention services that addressed their needs early, providing a foundation for a better life. They received quality educational services in classrooms with their neighbors and peers. Programs and other support were made available to help them live healthier lives, pursue careers that interested and excited them, and have access to transportation that allowed them to travel to the places they wanted to go. They were able to enjoy recreational and social activities, and become contributing members of their communities.

They received services that not only helped them as individuals, but supported their families as a whole. I believe that by empowering individuals and families to make choices and advocate for themselves, we improve their quality of life, both in the present and in future generations.

I am pleased to present this report as a record of the achievements of ADD's grantees. This report documents and celebrates the efforts of ADD's grantees to secure choices and control for Americans with developmental disabilities and their families, and to support these individuals in the pursuit of their dreams.

/s/
Patricia A. Morrissey, Ph.D.
Commissioner
Administration on Developmental Disabilities

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Executive Summary

The Administration on Developmental Disabilities (ADD) is committed to the idea that the American dream belongs to everyone. Our mission, and the mission of our grantees, is to help Americans with developmental disabilities in their pursuit of the American dream.

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. Through education, advocacy, and the implementation of diverse projects, ADD grantees help individuals with developmental disabilities receive quality care and education, protect their health, excel in the careers of their choice, travel freely, live independently, participate in activities they find fulfilling, and make informed choices about the kinds of services and supports they receive.

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 them in health, 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.

As required by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), the Fiscal Year 2005-2006 report is based on the analysis of individual grantee reports submitted annually to this department. This report reflects the achievements of ADD’s four grant programs:

- University Centers for Excellence in Developmental Disabilities (UCEDDs);
- State Councils on Developmental Disabilities (Councils);
- Protection and Advocacy Systems (P&As); and
- Projects of National Significance (PNS).

Each type of grantee has a specific role to play and each complements the others, strengthening the reach and power of their respective State DD Network. Because each grantee has a distinctly different focus, their individual statistics and achievements should not be compared directly to one another. Data reflected in these pages are from individual grantees. The DD Act directs grantees to spend funds on initiatives recommended by people with developmental disabilities, family members and advocates. The law does not require grantees to engage in activities in each area of emphasis, thus the data reflects what people in a State consider important.

The information highlighted below is a representative sample of the activities undertaken by ADD's grantees in Fiscal Years 2005 and 2006. For each grant program, we 1) highlight in an area of emphasis how a specific grantee had a positive impact on the lives of people with developmental disabilities and 2) provide national data for the same area of emphasis.

Please note that these numbers, and other statistics throughout this report, are measures of persons served by each grantee in specific issue areas. The DD Act directs grantees to spend funds on issues that individuals with developmental disabilities, families, and advocates have asked the grantees to address. Grantees have the flexibility to focus on one or more areas of emphasis listed in the DD Act: employment, health, education and early intervention, housing, transportation, child care, recreation, and quality assurance. Public input from individuals with developmental disabilities is the basis of each grantee's annual planning process: how many areas to invest in, the amount invested, and what to do with the ADD funs received. Thus, given that any grantee's program focus is subject to change each year, ADD does not promote or endorse comparisons among grantees, programs, or across years for individual grantees or across grantees.

The outcome measures shown in these pages are a representative sample of outcome measures reported in the grantees' annual Program Performance Reports.

UCEDDs EMPLOYMENT

The **Illinois** UCEDD created the **Partner for Inclusive Employment (P.I.E.) Coalition** to address the issue of a high unemployment rate among people with disabilities. P.I.E. coalition members come from government agencies, non-profit groups, advocacy organizations, and corporate entities. The focus of this grass-roots effort is to develop and implement an industry-friendly protocol for people with disabilities in the job market. The P.I.E. model is a Job-Match Fair where job-seekers and employers are both pre-screened, promoting successful matches between both. The program was nominated as a finalist for the Midwest region's Council of State Governments' Innovations Award.

THE NATIONAL PICTURE

- In Fiscal Year 2006, **113,195** people participated in Nationwide UCEDD projects aimed at helping individuals with developmental disabilities to acquire, retain, or advance in employment in integrated settings in a community. Because UCEDDs only recently initiated their current system of data collection, comparative statistics are not available for Fiscal Year 2005.

Councils CHILD CARE

In Louisiana, the Council funded **Partnerships For All Children Together (Project PACT)**. This project was designed to enhance and expand the capacity of child care providers to support and include young children with disabilities within community child care environments in the Greater New Orleans area. Project PACT uses a community-building process designed to establish and maintain long-term relationships across child care providers and administrators, early intervention specialists, early intervention system administrators, and families. General knowledge workshops are offered free to any interested family member, child and family care providers, and early intervention specialists. The project also provides long-term, intensive support to a selected group of child care providers that have enrolled children with disabilities. Project PACT coordinates on-site follow-up to support families, child care providers, and early intervention specialists in addressing the individual needs of young children with disabilities.

THE NATIONAL PICTURE

- In Fiscal Year 2005, **3,092** families of children with developmental disabilities across the Nation benefited from expanded availability of affordable, appropriate child care with accessible facilities. In Fiscal Year 2006, **2,636** people were reached.

P&As EDUCATION

"Maggie's" mom contacted the **Alabama** P&A because she was concerned about her daughter's education. Maggie was nine years old at the time, and has autism. At the time her mother contacted the P&A, Maggie had been taken out of school and was being home schooled because her mother objected to Maggie's educational placement -- a self-contained classroom and access to non-disabled peers only for lunch and gym. Maggie's mom wanted her daughter educated in a regular education classroom. She believed Maggie could handle such a placement and would benefit academically and socially from more interaction with the larger school community. The P&A represented Maggie at an Individualized Education Program (IEP) meeting, advocating for an appropriate educational placement with supports. As a result of the P&A's intervention, Maggie has returned to school and is receiving a significant amount of time on a daily basis in the regular education classroom. She receives only math and language arts instruction in the self-contained class, and the remainder of her day is spent in an inclusive environment, interacting with her peers.

THE NATIONAL PICTURE

- In Fiscal Year 2005, P&As worked with parents, educators, school administrators, and policy makers Nationally to ensure that **11,736** students with developmental disabilities gained or maintained access to appropriate educational opportunities in their local areas. In Fiscal Year 2006, **12,242** people were reached.

Projects of National Significance

In **New Mexico**, a Family Support 360 program has partnered with a Native-American nonprofit organization to provide a comprehensive array of culturally appropriate services to families who have a child with a developmental disability. Project staff with laptops travel to four Pueblos, work with tribal leaders, and visit families in need at their own homes. A steering committee comprised of families, tribal members, and key agencies oversees the implementation of the four centers. This project recognizes the sensitive need to balance tribal sovereignty with State and Federal laws.

THE NATIONAL PICTURE

- In Fiscal Years 2005 and 2006, PNS grants funded 21 Family Support 360 programs as well as 15 Youth Centers and several data collection projects.

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 in the services and opportunities available to individuals with developmental disabilities. We look forward to working with our partners and grantees to continue to meet the challenges that lie ahead, and to create a bridge to a better way of life for all Americans.

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.

Chapter 2: Collaboration, gives examples of ADD collaboration among ADD's grantees.

Chapters 3, 4, and 5 provide profiles of grantee programs and an overview of outcome statistics, structured around ADD's areas of emphasis.

Additionally, the report provides information regarding Projects of National Significance (*Chapter 6*) and Accountability (*Chapter 7*).

Chapter 8: Emergency Preparedness gives an overview of ADD's grantees efforts to ensure that the disability community is informed and protected in the event of an emergency.

Chapter 9: Technical Assistance and Interagency Activities provides information about the technical assistance ADD offers its grantees and discusses ADD's participation in interagency committees.

Chapter 10: 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 this report is not a comprehensive reflection of all the support which ADD and its grantees provide, it is a comprehensive sampling 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 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:

- University Centers for Excellence in Developmental Disabilities Education, Research, and Service;
- State Councils on Developmental Disabilities;
- Protection and Advocacy Systems; 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.

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 three programs outlined below.

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs): ADD administers a discretionary grant program to provide 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, original research, 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.

UCEDDs are uniquely positioned to facilitate the flow of disability-related information between the community and the academic world. This network of independent yet interlinked Centers represents a tremendous national resource for addressing issues relating to persons with disabilities and their families, including:

- Interdisciplinary preservice, preparation, and continuing education;
- Research;
- Information dissemination; and
- Community services, which include training, technical assistance, direct services and model demonstrations.

ADD awards core funds to each UCEDD to support the operation and administration of the Center. In turn, UCEDDs are required, to the extent possible, to utilize the ADD funds as infrastructure support to leverage additional public and private funds to successfully implement the mandated core functions (Section 154(a)(3)(F)). Section 154(a)(3)(C) of the DD Act states the UCEDDs must "use the funds made available through the grant to supplement, and not supplant, the funds that would otherwise be made available for [core function] activities." Thus, ADD funding is used to support the organizational foundation of the UCEDD, which allows the Centers to pursue other sources of support to carry out core function activities. UCEDDs will leverage funding from a variety of sources to carry out core function activities, including federal, State, and local agencies as well as private foundations, donations, and fee for services.

Activities of UCEDDs include: providing interdisciplinary training for professionals, researching developmental disabilities, and offering training by and for people with developmental disabilities and their families.

In Fiscal Year 2005, ADD had $31.5 million available for grants to 64 UCEDDs. In Fiscal Year 2006, ADD had $33.2 million available and funded three new UCEDDs.

State Councils on Developmental Disabilities (Councils): Councils, appointed by Governors, 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 activities and initiatives to improve services that enable persons with developmental disabilities to achieve their maximum potential and participation in their communities, thereby leading independent and fulfilling lives. These efforts focus on systems change, capacity building, and advocacy – having discussions, testing ideas, and educating others so that the services and supports available to people with developmental disabilities work to their benefit.

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 the opportunities for individuals with developmental disabilities;
- Supporting the inclusion of individuals with developmental disabilities in communities; and
- Eliminating barriers to full participation in community life.

In Fiscal Years 2005 and 2006, $72.5 million and $71.8 million, respectively, was available to support 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 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. 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.

In Fiscal Year 2005, $38.1 million was available in grants from ADD for the P&As. In Fiscal Year 2006 the amount was $37.9 million.

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 2005 and 2006, ADD made available $11.5 million and $11.4 million, respectively, to support PNS discretionary grants.

ADD's Areas of Emphasis

In order to advance their shared mission, ADD's grantees may do work in any of eight distinct issue areas, referred to as ADD's *areas of emphasis*:

- Child Care,
- Education and Early Intervention,
- Health,
- Employment,
- Transportation,
- Housing,
- Recreation, and
- Quality Assurance.

Through programs that target each of these areas of emphasis, the grantees increase the ability of individuals with disabilities to achieve their maximum potential and to participate fully in their communities, thereby leading independent and fulfilling lives. Based on the individual needs of their States, the grantees chose which areas of emphasis on which to focus in any given year.

Child Care

One of the first challenges that parents of a child with developmental disabilities face is locating accessible, affordable child care staffed with appropriately trained professionals. Through programs that facilitate research, education, training, and system change, grantees are improving the ability of child care and early education systems to meet the needs of children with disabilities in a nurturing, inclusive environment.

Education and Early Intervention

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. All three types of ADD grantees work extensively to provide support in these areas.

Each child with developmental disabilities has different circumstances and needs, and ADD's three types of grantees meet those needs in different ways. *UCEDDs*, as mandated by law and by virtue of being affiliated with 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. *Councils* work to educate parents, educators, and the community about inclusive education issues. *P&As* focus substantially on educational issues, and work to ensure that students receive an appropriate education in an inclusive setting. Historically, the majority 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.

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.

Health

Obtaining quality health care services can present challenges for people with developmental disabilities. Individuals may require support when filling out insurance forms, filing claims, or making medical decisions. They may need assistance in the sometimes overwhelming process of securing transportation to and from health care services or finding a qualified medical professional with the training to work effectively with individuals with disabilities. Through the initiatives of grantees, people with developmental disabilities are receiving medical services that meet their needs, thereby improving not only their health, but the quality of their lives.

Housing

While the classic symbol of the American Dream is to obtain a home of one's own, finding a home can be a significant challenge for individuals with disabilities. Safe, independent, and accessible housing provides individuals with freedom and self-sufficiency. Independent living opens doors and allows individuals to achieve independence and become part of a community; providing people with developmental disabilities living options other than in nursing homes and group settings. ADD encourages programs which give individuals with developmental disabilities community-based alternatives to institutional living. Grantee programs work to help people find accessible, affordable housing in their communities, thereby increasing their independence.

Employment

Participation in the work force is key to participating in society. Locating and maintaining employment is one of the most important steps individuals can take towards personal and financial independence. Through grantee-sponsored programs, people with developmental disabilities receive the support they need to achieve independence and fulfillment in careers of their choice.

Transportation

A person's ability to find and maintain employment, consult his or her choice of a health care professional, choose a place to live, and participate in community activities is dependent on transportation to and from these locations. 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. Grantees work to increase the availability of accessible transportation, thereby allowing individuals with disabilities to get to work, medical appointments, and other activities that provide a degree of personal freedom that would not be possible otherwise.

Recreation

People use recreational activities to relieve stress, connect with friends, be creative, or escape from their daily lives. For people with disabilities, recreation can be an important way to improve health and fitness, as well as an opportunity for community interaction. Through recreation-focused projects, grantees ensure that people with developmental disabilities make decisions about their leisure time, and pursue their interests with others.

Quality Assurance

Part of ADD's mission is to promote independence by ensuring that individuals with developmental disabilities have access to services that allow them to lead full and self-sufficient lives as a member of an integrated community. Grantees support this mission through programs that allow individuals with disabilities to participate in recreational and cultural activities, advocate for their personal rights, live where they choose, and otherwise exercise choice and control over their lives. Grantees work to protect the rights of individuals with developmental disabilities, and to improve the quality, accessibility, and flexibility of the services available to them. Through these efforts, individuals are helped in the short and long term, and 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 grantees.

New Freedom Initiative:

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, Department of Labor, and the Department of Transportation.

Chapter 2: DD Network Collaborative Projects and Activities

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) requires ADD work to ensure that people with developmental disabilities and their families receive the services and supports they need and participate in planning and designing those services. The DD Act established eight areas of emphasis for ADD programs; employment, education and early intervention, child care, health, housing, transportation, recreation, quality assurance, and formal and informal community supports. ADD meets the requirements of the DD Act by supporting the following three programs: University Centers for Excellence in Developmental Disabilities Education, Research, and Development (UCEDDs); State Councils on Developmental Disabilities (Councils); and Protection and Advocacy Systems (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. The DD Network partners are designed to fit together like the pieces of a puzzle; together they create a cohesive net of opportunities and supports that ensures that no individual is left behind. Through collaboration, the partners bring their unique and complementary roles and capabilities to the table and coordinate their resources to achieve common goals and support systems change.

With their respective roles and skills, the DD Network partners may focus on different elements of the same goal(s) or different goals, but the collective results they achieve contribute directly and positively to the ability of individuals with developmental disabilities to live in and contribute to their communities.

ADD grantees individually and as State DD Networks also cooperate with other local, State, and national organizations to maximize their ability to provide the varied opportunities, services, and supports to individuals with developmental disabilities and their families.

Collaboration can take many forms. ADD has shared information about collaboration with its grantees. In its strongest form, collaboration encompasses interdependent systems and a shared vision. Partners make decisions jointly and initiate strategic planning to identify shared goals, outcomes, and resources.

ADD fully supports its grantees in their efforts toward full collaboration, and believes that a collaborative network that underwrites opportunities, services, and supports is the best way to achieve full independence, inclusion, and support for individuals with disabilities in every State.

The programs profiled in the following pages serve as just a few examples of the collaborative achievements of DD Networks in Fiscal Years 2005 and 2006.

In **Alaska**, the DD Network works together with a variety of stakeholders to increase the employment rate of Alaskans with disabilities. One specific example is the development and implementation of a statewide benefits planning and assistance system, which includes outreach, training and technical assistance, direct service provision and quality assurance.

As a direct result of this partnership, the following outcomes were achieved in FY 2005 and 2006:

- Continued implementation of policy by the Division of Vocational Rehabilitation requiring that all vocational rehabilitation consumers on public assistance receive benefits analysis and, if needed, benefits counseling;
- Information and referral contacts were made available to 388 individuals;
- Through 43 overview training sessions held across the State, 413 individuals with disabilities, family members, service providers, State agency staff, advocates and school district personnel had access to appropriate training;
- Skills gained by training participants indirectly benefited 4,142 individuals with disabilities;
- 40 people were certified as benefits counselors; and
- A cadre of 25 active benefits counselors is available statewide.

In **New Jersey**, the DD Network formed the Cultural Competence Collaborative in order to enhance the capacity of disability services to address the increasing cultural diversity in the State. The Network developed a series of Cultural Awareness Days (based on the model of The Boggs Center DD Lecture Series), planned in collaboration with leaders from various ethnic communities, to ask them to teach the disability community about their cultural communities in New Jersey. The Network also formed the *Latinos and Disabilities Planning Task Force*. The Task Force created a Latinos and Disabilities listserv and sponsored several conferences.

In **Oklahoma**, the DD Network grew concerned about the ability of individuals with disabilities to respond quickly and effectively in the face of an unexpected disaster. Hurricanes Katrina and Rita, as well as wildfires in Oklahoma, highlighted the urgent need for improved disaster preparedness for individuals with disabilities. As a result, the DD Network, operating together as the Redlands Partners, developed a plan to increase the awareness of community members with disabilities and to distribute needed disaster preparedness information. Additionally, the Redlands Partners, on an ongoing basis, provide and encourage others to disseminate information to community resource people and first responders who serve as points of contact and assistance for people with disabilities in Oklahoma.

The ***Texas*** *Community Integration Project (*TCIP) is a collaborative project of the Texas DD Network that assists people with disabilities of all ages. TCIP works to help move people with disabilities out of institutions, such as nursing facilities or State schools, and into homes in the community. The project demonstrates how people who wish to live in the community can do so safely and successfully, and has increased the numbers of individuals who actually move. In addition, project staff facilitate improvements in the process through which people living in institutions can access community support services. Private and governmental entities recognize the expertise of project staff and have requested their assistance when nursing homes have closed.

Originally a project working only in the San Antonio area, the Council and its DD Network expanded the project to five additional sites: Houston, Waco/Temple, Corpus Christi, El Paso, and Dallas. In Fiscal Year 2006, the project provided extensive supports that allowed 49 people to move from congregate settings to their own homes. In addition, 150 other people received the information and support that helped them move from a nursing home to a community home.

In **Kentucky,** the DD Network collaborated on various projects over the past several years. This collaboration led the three ADD grantees to develop a joint brochure and web site (www.kyddnetwork.org). They not only share their collaboration but demonstrate the link among the three grantees and how they support each other on their mutual goals. The three grantees also put out a joint newsletter.

One of the many collaborative initiatives undertaken by the Kentucky DD Network is the *Preservice Health Training Project.* Obtaining quality health care services for themselves or their family can present difficulties for some people with developmental disabilities, and finding a talented medical professional who is trained to work with people with disabilities can often be a challenge. Therefore, the DD Network developed a collaborative project to help overcome some of these challenges by expanding the pool of trained professionals and improving health care for people with developmental disabilities.

The DD Network is formatting cross-disciplinary training modules that can be incorporated into existing course work in medicine, allied health, and nursing programs throughout Kentucky. A core team of medical and nursing school faculty as well as individuals with disabilities and their family members are helping to design a set of ‘virtual patients’ modules for medical students in Kentucky. The web-based, interactive modules feature virtual patients with developmental disabilities. Students being instructed through these modules are required to choose how best to provide care to the virtual patients. In addition to the modules, the faculty at the universities receive manuals and other materials that they can use in the classroom.
This project has drawn national attention, resulting in several presentations which have led at least seven universities outside of the State of Kentucky to express an interest in using the Preservice Health Training Modules.

The Building Leadership Series (BLS) is a collaborative workshop project of the **Indiana** Developmental Disabilities Network. In FY 2006, 20 self-advocates completed three two day workshops over a three month period. Self-advocates are people with developmental disabilities who advocate for themselves and teach others to do the same. All workshops are co-trained with staff from the DD Network and self-advocates. The training includes a mix of interactive activities, video, discussion, role play and lecture. Workbooks accompany each topical area. Selected participants are able to receive a workshop attendance stipend, meals and overnight lodging. Support staff, where needed, also receive compensation, meals and lodging. Participants have commented on how much they learned and committed to personal action steps upon arriving back home. New friendships developed and personal growth was evident for all participants.

In **Georgia**, the three grantees joined forces to create the *Children's Freedom Initiative*. The goal of this initiative is that no child in Georgia will have to live in an institution. The initiative is centered on the belief that children belong with loving families and complies with the Supreme Court's Olmstead decision which held that Title II of the Americans with Disabilities Act (ADA) requires States, whenever possible, to place individuals with mental disabilities in community settings rather than in institutions. Currently, it is estimated that 140 – 150 of Georgia's children are living in nursing homes and State hospitals. The Georgia DD Network is taking steps to change that.

"John" was one of the many children helped by the *Children's Freedom Initiative*. John loves country music, fireworks, go-cart rides, and Veggie Tales videos. By 2005, however, John had been living in an institution for six years- half of his young life. Fireworks and go-carts, along with other favorite family activities, were only available on John's occasional visits home. Music and videos were played in his room in a nursing home where most of the other residents were senior citizens. John loved being outside, but did not often get the opportunity to go out. He spent his days lying in bed, or occasionally sitting in a chair in the nursing home hallway.

John's mother wanted to bring him home. However, she couldn't afford the services that John would need. The State would pay for John's nursing home care, but not for the supports that would allow him to receive the care he needed to live his life at home with his family.

As part of the *Children's Freedom Initiative*, the DD Network worked cooperatively to bring together a diverse group of stakeholders at a summit to "ensure that children who live in facilities are given the chance to live with permanent, loving families" and to "imagine a future where no child will live in an institution."

During the 2005 legislative session of the General Assembly, House Resolution 633 was introduced to look into this issue. This resolution resulted in the creation of an oversight committee. The non-legislative members of the committee are persons with disabilities, family members, and representatives from the DD Network.

In conjunction with this project, the P&A and the Council jointly funded "Longing For Home," the powerful video/DVD about the initiative. In addition, UCEDD-affiliated graduate student Katie Bailey interviewed six families whose children were or are now institutionalized in Georgia and wrote stories for a publication called *From Loving Arms*. UCEDD staff disseminated over 1000 copies of this publication. A picture of John was featured on the cover.

The Georgia legislature approved funds to allow all of the children in Georgia's state-administered institutions to go home. Next year, the DD Network will work with the legislature to tackle the issue of children in private facilities & nursing homes.
With the help of the *Children's Freedom Initiative* and the P&A's advocacy efforts, John at last went home to live with his family in February 2006. He has a swing in his backyard, and is receiving good support from his school. Through encouraging flexibility in the law, and by working together in a manner that capitalized on all their strengths, the DD Network was able to improve the lives of families across the State.

Chapter 3: University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs):

University Centers for Excellence in Developmental Disabilities (UCEDDs) are uniquely positioned to facilitate the flow of disability-related information between the community and the academic world. The network of independent yet interlinked UCEDDs represents a tremendous national resource for addressing issues relating to persons with disabilities and their families.

There is at least one UCEDD program in each State and Territory, with some States having multiple centers. UCEDDs engage in a variety of activities and serve as liaisons between academic environments and service delivery systems, positively affecting the lives of individuals with developmental disabilities and their families. This is accomplished through the implementation of four core functions that frame the UCEDD program:

- Interdisciplinary presence, preparation, and continuing education;
- Research;
- Information dissemination; and
- Community services, which include training, technical assistance, direct services, and model demonstrations.

Activities of UCEDDs include: providing interdisciplinary training for professionals; researching developmental disabilities; and offering training by and for people with developmental disabilities and their families.

The following is just a small sample of UCEDD activities in Fiscal Years 2005 and 2006, framed around ADD's areas of emphasis: child care, education and early intervention, health, employment, transportation, housing, recreation, and quality assurance. Because UCEDDs only recently initiated their current system of data collection, comparative statistics are not available for Fiscal Year 2005.

Child Care

Outcome Statement: In Fiscal Year 2006, **44,924** people participated in UCEDD projects that allow the families of children with developmental disabilities to have access to appropriate, accessible child care services.

The **Arkansas** UCEDD supports the **Welcome the Children** project in order to ensure that quality child care programs are available to Spanish-speaking families affected by disabilities. The Spanish-speaking community in Arkansas has grown rapidly in recent years, and child care providers, early childhood educators, and other professionals have been greatly affected by this population growth. However, most child care programs have received little training to assist them in adapting their services to work more effectively with Spanish-speaking children and their families.

Welcome the Children uses proven materials to provide training to early childhood professionals and others who work with Spanish-speaking children, with and without disabilities. Part of the projects goal is to train child care workers to recognize early signs of developmental disabilities, so that appropriate early intervention can begin while the child is young. Two seven-hour training modules have been developed. Module 1, *Cultural Diversity*, covers recognition and acceptance of cultural and linguistic diversity. Module 2, *Second Language Development and Assessment in Early Childhood*, covers the first language and second language acquisition process for young children, how to assess children for language difference vs. language delay, and strategies for working with families to reinforce classroom activities.

To ensure that these training materials will be available statewide, Welcome the Children is developing the capacity of local trainers to provide these training sessions to professionals in early childhood programs. This is being accomplished through the development of community teams that consist of volunteer local trainers and other individuals who provide expertise and ideas to assist the trainers.

The **Indiana** UCEDD supports the **Healthy Child Care Indiana** project, a partnership of over 15 entities working to ensure the availability of safe and healthy child care and education for all children. Indiana has experienced the highest incidence of death in the U.S. for children attending child care and education programs. Goals of the Partnership include: developing a system to increase the effectiveness of informal professional development activities, development and provision of a statewide child care health consultant project, and working to increase the inclusion of the National Health and Safety Standards and other nationally recognized standards in child care and education rules and regulations.

Resources developed by the Partnership include a Health Resources guide to programs serving young children and their families, a child care health consultant training manual and training program, a State-wide web-based calendar of training events for early care and education professionals, a report that compares Indiana's child care rules with the National Health and Safety Standards, a report about the provision of professional development for the early care and education field, and a report on providers interest and need for child care health consultation.

Education and Early Intervention

Outcome Statement: In Fiscal Year 2006, **371,720** people participated in UCEDD projects supporting the increased availability of inclusive and appropriate education for people with developmental disabilities.

ADD's grantees work to ensure that developmental disabilities are identified as early as possible in a child's life, thereby ensuring that treatment and services begin early.

The **South Dakota UCEDD** organizes **early intervention services** on the South Dakota Native American Reservations. This creates local access to comprehensive and culturally appropriate systems of health and developmental services to identify developmental concerns from birth through five years of age and to provide linkage to appropriate services.

The UCEDD has broken traditional barriers by taking the services to the families on the reservations instead of expecting these families to travel long distances to have their children evaluated for developmental delays.

Programs like South Dakota's are crucial because they give a child a head start. Once a child is actually diagnosed with a developmental disability, ADD's grantees work to ensure that the child receives a high-quality inclusive education. 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 become an active, valued member of their communities throughout their lives.

Historically, when being educated, children and young adults with developmental disabilities were segregated from their peers who were not disabled. 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 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.

The **Vermont** UCEDD partnered with the Vermont State Department of Education to address the use of paraprofessionals in an integrated educational setting. The **Paraeducator Support Demonstration 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 across the Nation, in any classroom from preschool through high school.

Often, one of the largest gaps in educational services provided to students with developmental disabilities is in the transition from the school environment into the community and the working world. **Montana's** UCEDD implemented a project designed 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, an approach that better matches students to jobs, increasing job satisfaction and retention while reducing the cost and duration of outside supports.

Health

Outcome Statement: In Fiscal Year 2006, **524,703** people participated in UCEDD projects that allowed individuals with developmental disabilities to acquire the knowledge and skills to gain access to appropriate health services.

The **Oregon** UCEDD works to combat violence against women with disabilities, which has been identified as a serious health issue. In addition to domestic violence issues, women with disabilities face an increased risk for abuse by caregivers or personal assistants. Unfortunately, this problem has remained well-hidden, and many women with disabilities are unable to access the resources they need to end violence. The goals of the **Oregon Violence Against Women with Disabilities Technical Assistance Center** include increasing awareness about violence against women with disabilities and building the capacities of various community organizations to provide an accessible, coordinated, community response to violence against women with disabilities.

Key elements include:

- An Advisory Council that brings together leaders from various organizations to shape a response and oversee the activities of the Center;

- On-site peer mentor-based training and technical assistance to facilitate strategic planning;

- Flexible “mini-grant” funding to support the education/training needs of rural communities;

- A clearinghouse of resources related to ending violence against women with disabilities, including video tapes, public service announcements, curriculum, and protocols for identifying and reporting abuse; and

- Comprehensive dissemination of information and materials through statewide video conferences, an interactive web site, and a State conference on ending violence against women with disabilities.

Housing

Outcome Statement: In Fiscal Year 2006, **524,703** people participated in UCEDD projects that increased their ability to live where and with whom they chose.

The **New Hampshire** UCEDD partnered with a national organization on inclusion to ensure that individuals with disabilities have access to “accessible” community-based housing. The Center for Housing and New Community Economics (CHANCE) is designed to improve and increase access to integrated, affordable, and accessible housing coordinated with, but separate from, personal assistance and supportive services. CHANCE's purpose is to offer alternatives to approaches that segregate, congregate, and control people with disabilities.

The UCEDD works in all aspects of CHANCE in partnership with ADAPT, a national organization that focuses on promoting services in the community for people with disabilities.

The development of community housing and services for people with disabilities has been a major national policy direction for the past 20 years. Unfortunately, the administrative structures supporting community services typically promote congregate and agency controlled approaches to housing and personal assistance services. While the number of people living in institutions and large facilities has decreased, the vast majority of individuals residing "in the community" live in residences owned and controlled by someone else.

Through this initiative, the UCEDD collaborates with a broad coalition of people and organizations concerned with housing, economics, personal assistance services, and advocacy. The coalition includes people with disabilities and their families, as well as people from Federal, State, and local agencies. Collaboration between the private and public sectors is encouraged and facilitated.

Employment

Outcome Statement: In Fiscal Year 2006, **113,195** people participated in UCEDD projects aimed at helping individuals with developmental disabilities acquire, retain, or advance in employment in integrated settings in a community.

The **Alaska** UCEDD supports the **Self-Employment Training Grant** program, designed to help individuals with developmental disabilities find success and fulfillment in self-employment. Individuals who are under-employed or unemployed frequently express a desire to be self-employed; yet they are often discouraged and dismissed by traditional funding sources. Risk is a major factor that prevents people from pursuing self-employment. Common barriers include:

- Counselors, caseworkers, and other service providers who tend to be unfamiliar with entrepreneurship and sources of business assistance;

- Local administration and management issues, such as high worker caseloads, limited awareness on the part of caseworkers, and the need for additional caseworker training; and

- A 'work first' philosophy which discourages participation in any activity that potentially delays employment entry.

Self-employment can be of particular value as an employment option when individuals have recurring illnesses, transportation issues, and difficulty with supervisory interactions or working at a particular time of the day. Self-employment, particularly home based micro-enterprises, offers more flexibility and autonomy.

The Alaska program develops self-employment training curriculum and materials for dissemination to Job Centers, One Stops, local and State boards, and consumers. The program also increases Job Center and One-Stop capacity to utilize self-employment as a Statewide option for consumers.

The **Illinois** UCEDD created the **Partner for Inclusive Employment (P.I.E.) Coalition** to address the 70 percent unemployment rate among people with disabilities. P.I.E. coalition members come from government agencies, non-profit groups, advocacy organizations, and corporate entities. The focus of this grass-roots effort is to develop and implement an industry-friendly protocol for people with disabilities within the job market. The P.I.E. model is a Job-Match Fair where job-seekers and employers are both pre-screened, which promotes successful matches between the two. The program was nominated as one of the finalist for the Midwest region's Council of State Governments' Innovations Award.

In **Minnesota**, the UCEDD is increasing literacy in order to enhance employment opportunities for American Indians with developmental disabilities. The **Literacy as the**

Path to Employment (LPE) project is a comprehensive and collaborative model to improve the literacy levels, future employment, and earnings of American Indian adults with disabilities. The project seeks to measure the effectiveness of implementing the Wilson Reading System (WRS), a proven curriculum for adults with disabilities, within the context of Minnesota's American Indian communities. The ultimate goal is that of empirically examining the impact of WRS in improving the literacy and employment outcomes of American Indian adults with disabilities.

The project works directly with the American Indian communities to ensure the cultural appropriateness of strategies and approaches used. The project team achieves success by:

- Incorporating American Indian cultural perspectives within the implementation of the WRS;
- Providing extensive training and technical assistance to staff on the WRS program;
- Employing new and innovative strategies to engage adult American Indians in improving their literacy skills to access, secure, and maintain successful employment;
- Developing approaches of integrating WRS into current literacy programs;
- Researching, in collaboration with the Federal contractor, the effectiveness of the WRS system and its impact on improving the employment outcomes of American Indians with disabilities;
- Systematically conveying the importance and value of client literacy development through workshops, state/regional meetings, and informational materials; and
- Disseminating project information and results to Minnesota's Workforce Centers, high schools, adult and postsecondary education programs, and American Indian community organizations.

Transportation

Outcome Statement: In Fiscal Year 2006, **8,500** people participated in UCEDD projects designed to increase the capacity for inclusion of people with developmental disabilities in community activities, public events, and social gatherings.

The State of **Connecticut** is committed to designing and implementing a State Action Plan for responsive, comprehensive, coordinated community transportation systems for people with low income, older adults, and people with disabilities. To be truly successful, a transportation coordination initiative must take into account the needs of those who use the system. The Connecticut UCEED works with transportation partners to ensure that the interests of people with disabilities are represented in the action plan. The UCEDD serves a pivotal role in facilitating information gathering and developing consensus around transportation priorities. The UCEDD will:

- Support a series of Regional Forums with disabled consumers of transportation services;
- Implement a day-long Transportation Institute with consumers, State legislators, State policy makers and State agency representatives; and
- Assist with the development of Technical Advisory Committees that will help the State in the development and implementation of a State Human Services Transportation Action Plan.

The **Alabama** UCEDD, in partnership with the DD Network, has identified accessible, reliable transportation as one of the greatest needs for people with disabilities in the State. The **Van Fair** project addresses this need not only by providing transportation, but also by providing specific training in self-advocacy. The goals of this project are as follows:

- To provide accessible transportation to work, appointments, school, shopping, recreation, and other needs for people with disabilities living within a 50 mile radius of the Civitan International Research Center;
- To provide Statewide training to individuals with disabilities, their family members, policy-makers, and others regarding the need for accessible transportation in Alabama, barriers to accessible transportation, and solutions to the barriers; and
- To collect and disseminate information regarding the use of accessible transportation through the project, demographics of the users, the numbers of specific requests for different needs.

Activities include scheduling rides on a first-come, first-served basis; providing transportation and advocacy training statewide to a total of twelve faith communities, disability agencies and organizations, and community and volunteer services; and to develop a brief survey containing information regarding the utilization of this project, the demographics of the users, and other significant information that can be used in planning and systems changes.

The expected outcomes of this project include, but are not limited to: greater inclusion in the community for people with disabilities; reliable, accessible transportation for people with disabilities living in Central Alabama; more competency in advocating for better statewide accessible transportation; and current, specific data regarding transportation needs and solutions, to be disseminated to legislators, policy-makers and consumers, in an effort to provide better planning, funding, and implementation of statewide systems changes in accessible transportation.

Recreation

Outcome Statement: In Fiscal Year 2006, **8,939** people participated in UCEDD projects that helped to increase the capacity for inclusion of people with developmental disabilities in community activities, public events, and social gatherings.

The **Tennessee** UCEDD partnered with Full Circle Art, a group of independent artists, to hold inclusive workshops for youth and adults. Together they collaborated to create art, which culminated in an exhibit "Common Ground." The workshops included drumming, movement, and dance.

Additionally, for several summers, the UCEDD has collaborated with national and local disability organizations to hold day camps focused on building specific skills, including recreation and art. The Frist Center for the Visual Arts has been an annual partner for **Explorers Unlimited Academic Camp** for students with Down Syndrome. The Frist Education staff provides art instruction, which each year is related to a major exhibit and culminates in a field trip to the Frist Center to view the exhibit.

Music instruction also has been incorporated into camp curricula, taking advantage of Vanderbilt's Blair School of Music and Nashville's extensive music resources. Teens and young adults with Williams Syndrome who attend the annual Music Camp work with professional songwriters and musicians to write and record an original song, which is performed live at the Grand Ole Opry.

Quality Assurance

Outcome Statement: In Fiscal Year 2005, **217,492** people participated in UCEDD projects that helped them to be included in their communities, to live free from abuse and neglect, and to make choices for their lives.

Quality assurance activities have many purposes, one of which is to increase the community inclusion of individuals with developmental disabilities. The **Hawaii** UCEDD sponsors the **Alliance for Inclusion Advancement-Hawaii** (AIA-HI), the purpose of which is to engage persons with disabilities age 14 and over in service and volunteerism. AIA-HI has created two Local Inclusion Collaborative Networks (LINCs) on O'ahu and the Big Island of Hawaii to facilitate this development.

AIA-HI has worked for several years with Martin, who has cerebral palsy. After years of volunteering in various capacities, for many organizations, Martin has become an employee at the local Center for Independent Living and was recently elected President of the first advocacy committee for those with developmental disabilities, called the Self Advocacy Advisory Committee (SAAC).

The **Delaware** UCEDD aims to facilitate community inclusion for people with disabilities through a program called **Community Connectors**. Since its inception in 2003, Community Connectors has partnered with adults with disabilities, helping them pursue personal interests and become involved in their communities. Twenty-five people participated in the program during Fiscal Years 2005 and 2006.

The project's main objectives are three-fold: to provide support to help individuals become an active community participant; to support participants in identifying, developing, and attaining personal life goals; and to monitor and evaluate the progress of life enrichment activities for program participants.

Community Connectors is built on two programs: the Individual Program and the Group Program. With support from a staff of graduate and undergraduate students from the University of Delaware, participants in the Individual Program create personal goals, make plans to achieve those goals, seek out opportunities of interest, and engage in activities. They then meet with staff two to four times per month to share progress and successes, or brainstorm solutions to challenges they may have encountered.

For people who want a less structured experience, the Group Program provides a wonderful opportunity to socialize, build friendships, and gain new experiences. Twice a month, adults with and without disabilities join together at a variety of events – from watching movies and football games to volunteering and pottery classes.

Chapter 4: State Councils on Developmental Disabilities

State Councils on Developmental Disabilities are appointed by governors and funded by ADD to promote and build advocacy, systems change, and capacity building in the eight areas of emphasis so that individuals with developmental disabilities can lead full lives in their communities. Councils advocate for the establishment of public policy that helps individuals with developmental disabilities to gain increased control over their lives. Each of the 55 Councils - one in each State, the District of Columbia, and four U.S. Territories - work to increase the independence, productivity, and community integration of all people with developmental disabilities.

Council members include individuals with developmental disabilities, family members, advocates, and State agency representatives. This diverse membership uniquely positions the Council as an objective observer and analyzer of State services, trends, and resources. From these observations, Councils develop a five-year State Plan designed to show new ways to improve the delivery of services so that individuals with developmental disabilities have the opportunity to exercise their individual rights and obtain their personal goals. In order to carry out the State Plan and their respective missions, Councils utilize varied activities, including:

- Involving and supporting people with disabilities and family members in leadership roles;
- Educating communities to welcome individuals with developmental disabilities;
- Informing policymakers about disability issues;
- Funding projects to show new ways for people with disabilities to work, play, and learn; and
- Seeking information from the public and from State and national sources.

By partnering with individuals with developmental disabilities and their families, as well as with organizations that pursue similar goals, Councils build coalitions that effectively change public policy and service delivery. Thus, Councils are valued as collaborators and catalysts for innovative ideas that positively impact the lives of people with developmental disabilities.

The following is just a small sample of Council activities in Fiscal Years 2005 and 2006, framed around ADD's areas of emphasis: child care, education, health, employment, transportation, housing, recreation, and quality assurance.

Child Care

Outcome Statement: Due to the work of Councils in Fiscal Year 2005, **3,092** families of children with developmental disabilities benefited from expanded availability of affordable, appropriate child care with accessible facilities. In Fiscal Year 2006, **2,636** people were reached.

In Louisiana, the Council funded **Partnerships for All Children Together (Project PACT)**. The project was designed to enhance and expand the capacity of child care providers to support and include young children with disabilities within community child care environments in the Greater New Orleans area. Project PACT uses a community-building process designed to establish and maintain long-term relationships across child care providers and administrators, early intervention specialists, early intervention system administrators, and families.

Training modules were developed and tested in the first year of the project and updated as necessary. General knowledge workshops are offered free to any interested family members, child and family care providers, and early intervention specialists. The project also provides long-term, intensive support to a selected group of child care providers that have enrolled children with disabilities. Project PACT coordinates on-site follow-up to support families, child care providers, and early intervention specialists in addressing the individual needs of young children with disabilities (e.g., adapting activities and materials, embedding individual instructional goals into ongoing activities, and using naturalistic teaching strategies).

Following Hurricane Katrina in 2005, several of the child care centers involved in the project were no longer able to operate. However, the project continued with the remaining centers and added new ones. In 2006, Project PACT began sharing the curriculum developed by the project and providing support to other organizations interested in replicating this process in other areas of the State.

Education and Early Intervention

Outcome Statement: In Fiscal Year 2005, Councils helped to enhance the knowledge, capabilities, and self-advocacy skills of **19,803** students with developmental disabilities and their families, in order to ensure the schools they attend are providing inclusive, appropriate, and local educational opportunities. In Fiscal Year 2006, **33,003** students were reached.

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. Placing all students together teaches understanding and acceptance to younger generations, which in turn may build a foundation for community inclusion in the future.

In order to encourage and promote proactive and innovative inclusive education strategies, the **New Jersey** Council on Developmental Disabilities sponsors a **Fellowship Program in Inclusive Education**. The Fellowship Program was created to encourage, acknowledge, and expand promising practices in including children with disabilities in all aspects of the public education system. Any individual or group who encourages the inclusion of students with disabilities in all areas of school life is eligible. Fellows must embrace the concept that children with disabilities have the right to be educated in the least restrictive environment. They must be committed to making that concept a reality for their students. Nominees must demonstrate a commitment to the identified practice or concept. The utilization of fellowship awards must be explicitly described.

In **North Dakota**, the Council provided funding for a project that helped families to provide information and one-on-one emotional support to other parents raising children with disabilities or special health care needs. This network also provided training to medical, education, and other professionals as well as to child care providers on issues pertaining to raising children with special needs. 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.

Health

Outcome Statement: In Fiscal Year 2005, Councils helped **25,180** individuals with developmental disabilities by educating health professionals on the needs of people with developmental disabilities, teaching self advocacy, and encouraging facility accessibility conversions. In Fiscal Year 2006, **12,271** individuals were reached.

The **Texas** Council funded several projects that allowed parents to train pediatric residents on the delivery of long-term care to children with chronic illness or disabilities. The Houston Project trained 43 pediatric residents and 13 new parent teachers. In San Antonio, 25 pediatric residents and two parent teachers were trained. The Driscoll Children's Hospital in Corpus Christi trained 46 residents in all components of the program, presented information on the program to a medical school in Dallas, and is also training dental assistants.

Employment

Outcome Statement: In Fiscal Year 2005, Councils expanded the availability of job training, equal employment information, inclusive work environments, and job placement for **3,838** people with developmental disabilities. In Fiscal Year 2006, Councils reached **4,582** people with developmental disabilities.

The **Nevada** Council sponsors the **Nevada Business Leadership Network** (BLN), an employer-led initiative working to establish quality employment opportunities for Nevada citizens with developmental disabilities. The BLN increases employer awareness, appreciation of, responsiveness to, and hiring of people with disabilities by:

- Facilitating employer leadership development and expanding its steering committee comprised of area employers;
- Conducting public education activities (mentoring and training for both employers and job seekers) to improve attitudes/competencies;
- Providing technical support to individual employers to improve recruitment efforts and hiring results; and
- Partnering with community rehabilitation providers and school districts.

The **Tennessee Employment Consortium** (TEC) was established through a Challenge Grant from the Council. TEC is comprised of stakeholders from across the State, and includes family members, employment services providers, the Tennessee Division of Rehabilitation Services, the University of Tennessee Center on Disability and Employment, The Arc of Tennessee, People First of Tennessee, and the Tennessee Microboard Association.

The work of the TEC had specific success related to the number of individuals who achieved community employment through Consortium activities. In Fiscal yeas 2005 and 2006, TEC activities helped 63 individuals to find meaningful jobs in their communities.

The training implemented by TEC for job coaches was also productive.

Training was implemented on several fronts with positive outcomes:

- Job Coach Training (JCT) was provided to 1,219 job coaches
- Thirty-five trainers received Job Coach Train-the-Trainer training and were approved to deliver JCT
- Twenty-five new job coaches were hired
- Eighty-eight job developers received Job Development Training
- More than160 people participated in Project Income, a training targeted to people with disabilities and family members about employment and the benefits of employment

Transportation

Outcome Statement: In Fiscal Year 2005, Councils increased flexible, affordable transportation options for **15,766** individuals with developmental disabilities, increasing their personal freedom. In Fiscal Year 2006, Councils reached **14,642** individuals with developmental disabilities.

In **Nebraska**, the Council worked in collaboration with the State DD Network to improve transportation options for individuals with developmental disabilities. Transportation had been identified by all grantees as a high priority, as Nebraska is a very rural State with few communities having access to public transportation. The concern was not only about access, but also about the rising cost of transportation services and the lack of flexibility for consumers. In addition, statutes required that all transportation paid for by Nebraska Health and Human Services must be provided by commercial carriers, such as taxi companies or bus services.

Therefore, the Council funded the Munroe-Meyer Institute (Nebraska's UCEDD) to hold several statewide video-conferences on **Transportation: Exploring Solutions**. These conferences included the major stakeholders in the State such as the Public Service Commission, which regulates transportation; the Department of Roads, which oversees public transportation systems; the Health and Human Services System, which is the payer of much of the transportation for people with disabilities; and consumers and advocates. These conferences provided opportunities for the parties to speak to each other and discuss perceived barriers. The DD Network decided to approach a State senator to discuss their concerns with him including any needed change in State law which might improve transportation services. Representatives of the Council, the P&A, and the UCEDD developed a survey which identified a number of concerns including the lack of choice by individuals because of the requirement that they must use a taxi for their transportation. Based upon these concerns, the DD Network, along with other disability advocates, agreed to try to make a small change to the current statute by adding language to allow non-legally responsible relatives to be reimbursed for eligible transportation services.

Recognizing that there would be vocal opposition by the taxi lobby, advocates came together to organize strong testimony at the bill hearing. The senators were so impressed by the testimony that they amended the bill to include not only family but friends as well to be potential transportation providers. The bill was passed. Representatives from all three Network agencies were present when the Governor signed the bill into law.

This change will give individuals with disabilities more control over who provides them transportation. It will also result in cost savings to programs including Medicaid. State senators were able to see that disability advocates were not just asking for more funding but also coming up with solutions that give individuals more choice as well as result in a cost savings.

The **Pennsylvania** Council developed and supported the **Persons with Disabilities Transportation Program**, which provides transportation for individuals with disabilities, a service which is particularly important in rural areas where other transportation options are minimal. Nearly 9,000 individuals have registered for the service and more than 400,000 trips have been taken. Forty-five percent of all trips are made for work. Forty-seven percent of regular users were able to get or keep a job because the transportation program was available.

Housing

Outcome Statement: In Fiscal Year 2005, Councils made housing more accessible for **2,400** people with developmental disabilities by participating in deinstitutionalization efforts, and by ensuring that those with independence can continue to maintain it. In Fiscal Year 2006, Councils reached **1,557** individuals with developmental disabilities.

The **Virginia** Council's **Transportation and Housing Alliance** (THA) grant to the Thomas Jefferson Planning District Commission brought stakeholders and advocates together with experts in planning, housing, and transportation. Alliance members developed the THA Toolkit, which localities can use to assess needs and plan transportation and housing for people with disabilities in coordination with land use. The toolkit provides localities and Planning Districts with new opportunities for coordinated needs-based planning and growth. The use of the toolkit is being promoted by the Virginia General Assembly's Disability Commission as a means by which localities can meet comprehensive planning requirements specified in the Code of Virginia §15.2-2223. Revisions to this Code section, which will be effective in July, 2007, include a requirement that localities determine and plan for the current and future needs of residents who are elderly or are people with disabilities. The toolkit is also being tested by the Virginia Housing and Development Authority as a possible new market study assessment, which is required of developers that apply for low income housing tax credits.

In the **District of Columbia**, the Council has taken steps to inform and involve the community regarding accessible housing. Two community forums were held as part of the D.C. Council **Quality Assurance Advocacy** initiative. Leadership representatives from the DC Housing Authority, DC Department of Housing & Community Development, DC Housing Finance Agency, University Legal Services, DC Office on Human Rights, Affordable Housing Alliance, and a private developer served as panelists and addressed over 124 individuals regarding the process for utilizing housing services and alternatives. Discussions focused on accessible and affordable housing and specific questions related to housing and how to make appointments for follow-up if necessary. As a result of these forums, one self advocate with developmental disabilities was able to get the “right” resources communicating to bring to fruition the installation of a much needed elevator in his home.

The **Wisconsin** Council supported the development of **Movin' Out**, originally a group of families who wanted home ownership for their sons and daughters. Since 1997, Movin' Out has helped more than 700 people with disabilities purchase or renovate homes for accessibility, safety and home maintenance needs. "Sue," met with a Movin' Out Housing Counselor to develop a plan. The first step was figuring out how she could save money without jeopardizing her SSI and Medicaid benefits. Movin' Out referred Sue and her family to an attorney who helped them to establish a trust to protect her income. Sue worked hard for three years and made sacrifices in order to save enough money for a down payment. Whenever her friends went out for a movie, Sue stayed home and put away the amount of money she would have spent. Sue and her counselor met with a mortgage lender and although she qualified for three down payment assistance programs, it still wasn't enough for a down payment. Finally, working with the city of Madison, Sue traded her Section 8 rent voucher for a voucher that could be used to offset her mortgage. Sue located a condo in a location that works well for her, and is a proud new homeowner.

Recreation

Outcome Statement: In Fiscal Year 2005, Councils facilitated the inclusion and participation of **8,305** individuals with disabilities in events or social gatherings they chose. In Fiscal Year 2006, Councils assisted **9,167** individuals to participate in recreation.

Access to community recreational opportunities for people with developmental disabilities continues to be a priority for the **Idaho** Council on Developmental Disabilities. Council funds were awarded to a project to develop Idaho's first universally accessible playground. Children of all abilities and ages, as well as adults, have been playing on "The Grand Voyage" at **Adventure Island Playground**. Located in Meridian's Settler's Park just outside of Boise, Adventure Island makes available exploratory and physical play opportunities. In its present state, the playground is approximately 75 percent complete while a community volunteer planning team continues to raise the remaining necessary funds.

SPLORE, a Salt Lake City, Utah, nonprofit organization, was awarded a grant by the **Utah** Developmental Disabilities Council for the second year of a pilot program providing inclusive outdoor recreation experiences to children with disabilities in Utah elementary schools. The pilot program, called the **Experience Your Abilities** Program, creates opportunities for elementary age students with disabilities to develop social relationships with their peers without disabilities by participating in inclusive outdoor recreation activities together.

The Experience Your Abilities Program helps the public school system to provide a positive educational experience, both academically and socially, to students of all abilities. The program opens the door for inclusive social interactions between students with disabilities and students without disabilities. By participating in safe, fun and challenging outdoor recreation activities together students are able to have a shared experience and find a commonality with one another. Evaluations from the first year show the program is highly effective in fostering healthy social relationships, higher self-concept, sensitivity to the needs of others and positive behavioral changes. Activities included hiking, indoor and outdoor rock climbing, snowshoeing, cooperative games, adaptive cycling, equestrian activities, and exploration of local nature centers.

The **Iowa** Council funded **Community Change** Projects. Community teams led by people with developmental disabilities could write proposals to apply for seed money to make the change they want to see in their community. The purpose was to increase the leadership skills of people with developmental disabilities as well as to increase community integration.

Davenport, Iowa is located on the Mississippi and Rock rivers. Many lifestyle choices and recreation opportunities in the area involve water sports. People with mobility limitations do not have the same opportunity to participate in one of the most popular water sports; water skiing. The Davenport Team (comprised of two people with developmental disabilities, a physical therapist, a Recreation Therapist and an outdoor outfitter) used the seed money from the Council to purchase three ski cages and one sit-ski. They leveraged additional money for a weekend-long adaptive waterskiing clinic. Fifteen skiers with disabilities participated. Fifty volunteers were trained to assist. The event was held in coordination with a local ski club that spent a day learning how to adequately support persons with disabilities. Three of the skiers with disabilities skied in the ski club show Sunday after receiving training.

“Craig” is a 40 year old with a developmental disability. He had a strained relationship with his 11-year-old son. Craig learned how to ski the first day and brought his son with him on the second day of skiing. The two spent the day growing closer as they enjoyed the water. At the end of the day Craig’s son wanted to enroll in a free kids ski clinic.

After 25 years of living with paraplegia, “Jackie” attended the ski clinic to glide over the water, feel the spray against her face and “experience the rush of physical exertion.” She didn’t make it the first time but tried again. “I amazed myself.” Her mother and relatives were there to watch with tears in their eyes.

Quality Assurance

Outcome Statement: In Fiscal Year 2005, Councils empowered **79,139** individuals with developmental disabilities to make choices and have control over their lives through training in leadership and self-advocacy. In Fiscal Year 2006, Councils assisted **72,806** people.

The **New York** Council provides funding to the **Partners in Policymaking** training program. The New York State program provides 40 people with developmental disabilities or their families with hands-on training in the areas of community building, advocacy, the legislative process, policymaking, inclusive education, housing and employment from experts in the field. Participants develop significant skills so that they can better advocate for themselves and family members.

"Kate" is the proud parent of four sons ranging in age from 17 to 24 years old. She entered the Partners in Policymaking program to hone her advocacy skills for two of her sons who have developmental disabilities. She says, "My knowledge-base grew through Partners and I have been more effective at all levels of advocacy." Kate has recruited several members of her community to pursue the Partners in Policymaking training.

Thanks to exposure to the legislative process and public speaking through the Partners in Policymaking program, Kate has secured legislative funding for Family Support program enhancements in her area.

The **Indiana** Council designed the project **Count Us IN** to increase the numbers of people with disabilities engaged in the electoral process while also reaffirming the significant contribution people with disabilities can make to the electoral process. To energize people with disabilities, several educational seminars were conducted which covered voting rights, participation and volunteer opportunities. The American Association of People with Disabilities provided consultation and technical assistance through out the project. Booklets and voting guides were developed to familiarize people with disabilities about the voting process. Booklets were also published that targeted County and local election officials regarding access issues and disability awareness. Additionally, a number of presentations were made before various advocacy groups and providers of services.

Chapter 5: Protection & Advocacy Systems

ADD funds Protection & Advocacy Systems (P&As) in each U.S. State and Territory, and in one Native American Consortium, to uphold and advance the civil and human rights of people 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 systems 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.

The following pages contain a small sampling of P&A activities conducted in Fiscal Years 2005 and 2006, framed around ADD's areas of emphasis: child care, education, health, employment, transportation, housing, recreation, and quality assurance.

Child Care

Outcome Statement: In Fiscal Year 2005, P&As expanded appropriate, inclusive child care opportunities for **67** children with developmental disabilities and their families. In Fiscal Year 2006, P&As reached **63** people.

In **Illinois**, the P&A successfully advocated for a change in the hiring process for child care professionals and other care providers. The P&A became involved when staff investigated a company that provided services to adults with developmental disabilities, in order to determine whether the company was employing a direct care worker against whom there was a finding of child abuse. During the investigation, the P&A determined that while both the child care system and the system of adult services require certain background checks for potential employees, which include searching their own data bases for abuse/neglect findings, neither system accesses the abuse data base of the other system. This resulted in a substantial gap in each system's ability to prevent the employment of individuals who have abused vulnerable people. Because many direct care professionals work within both systems, the P&A immediately called upon the affected State agencies to develop a process to access data bases in both systems. The P&A continues to supervise this process, which is ongoing.

Education and Early Intervention

Outcome Statement: In Fiscal Year 2005, P&As worked with parents, educators, school administrators, and policy makers to ensure that **11,736** students with developmental disabilities gained or maintained access to appropriate educational opportunities in their local schools. In Fiscal Year 2006, **12,242** people were reached.

"Carl" is an 11-year-old Navajo boy with developmental disabilities who was attending a public school, but in an extremely segregated setting. Carl's parents requested the help of the **Arizona** P&A in obtaining thorough and appropriate evaluations of their son and then advocating for a more inclusive educational placement with the proper supports and services. The P&A was preparing for the administrative process when the school expressed an interest in negotiating the matter. Through the P&A's advocacy, Carl received comprehensive independent evaluations and is now placed in the regular classroom for most of the school day. The P&A also assisted Carl's parents in developing a more positive and constructive relationship with the school staff.

"Maggie's" mom contacted the **Alabama** P&A because she was concerned about her daughter's education. Maggie was nine years old at the time, and she has autism. At the time her mother contacted the P&A, Maggie had been taken out of school and was being home schooled because Maggie's mother objected to Maggie's educational placement -- a self-contained classroom with access to non-disabled peers only for lunch and gym. Maggie's mom wanted her daughter educated in a regular education classroom. She believed Maggie could handle such a placement and would benefit academically and socially from more interaction with the larger school community. The P&A represented Maggie at an Individualized Education Program (IEP) meeting, advocating for an appropriate educational placement with supports. As a result of the P&A's intervention, Maggie has returned to school and is spending a significant amount of time daily in a regular education classroom. She receives only math and language arts instruction in the self-contained class and the remainder of her day is spent in an inclusive environment, interacting with her peers.

"Mateo" has autism. His family speaks only Spanish, and he was eight years old when his parents contacted the P&A in **California**. Mateo's parents were unable to effectively advocate for him in the IEP process because of their inability to speak English, and because Mateo's school district did not provide adequate interpreter services. Mateo remained in a special class despite his parents' efforts to integrate him. The P&A represented Mateo at his IEP meetings and secured a regular education class placement at his neighborhood school, the services of a Least Restrictive Environment (LRE) facilitator, extensive curriculum modifications and accommodations, a behavior plan, and the assignment of a one-on-on aide for six hours each day. Mateo is now doing well in his community school.

Health

Outcome Statement: In Fiscal Year 2005, P&As increased access to affordable health care for **1,340** individuals with developmental disabilities by providing advice, advocacy training, legal intervention, or other forms of assistance. In Fiscal Year 2006, P&As reached **1,531** people.

"Joe" is 3½ years old and lives on the Turtle Mountain reservation in **North Dakota** with his parents. The Turtle Mountain Reservation sits just south of the Canadian border. The reservation population is 8,307, of which over 96 per cent are American Indians. It is estimated that almost 19 percent of these individuals have a disability. Twenty-eight percent of the families live below the poverty line. Unemployment is close to 15 percent as compared to the four per cent unemployment rate for the State as a whole.

The North Dakota P&A hired a full-time disabilities advocate to start in its new office in Belcourt, a town on the reservation, in July 2005. The new office was the result of people with disabilities and family members, who live on the reservation, asking for more advocacy services. This was combined with the fact that Turtle Mountain, the smallest reservation in the State geographically, is the largest in population (approximately 8,300 individuals). This new disabilities advocate was able to help Joe receive the medical care he needs.

Joe's primary diagnosis is cerebral palsy and, accordingly, his doctor prescribed a supine stander (otherwise known as a standing frame) to facilitate Joe's neuro-developmental and orthopedic needs. Payment for the supine stander was denied by Medicaid. Joe's doctor referred his family to the P&A. The P&A provided legal representation and filed an appeal on behalf of Joe. The P&A commenced negotiations with Medicaid's legal counsel. The negotiation process brought to light a number of concerns. As a result, the supine stander was found to be medically necessary, and the preauthorization request was approved. Not only did Joe receive the needed standing device, the case resulted in significant change in Medicaid policy. Upon a showing of medical necessity, Medicaid will now pay for standing frames for consumers who are need of such equipment.

Employment

Outcome Statement: In Fiscal Year 2005, P&As supported **426** people with developmental disabilities in obtaining or maintaining employment consistent with their interests, abilities, and needs. In Fiscal Year 2006, **P&As assisted 343** people.

The **Alaska** P&A assisted "Marco" in an employment discrimination case. Marco, who is deaf, was terminated from his position with a civilian military contractor. During the termination process, the contractor never provided an interpreter. Therefore, Marco did not understand why he was being terminated, and was unable to defend himself, or to discuss his employment situation. Moreover, the employer thought the Americans with Disabilities Act did not apply to him as a military contractor. After a series of negotiations, the P&A helped Marco to get his job back, with back pay.

Transportation

Outcome Statement: In Fiscal Year 2005, P&As helped **133** people with developmental disabilities locate the solutions necessary to get where they needed to go. In Fiscal Year 2006, P&As assisted **130** people.

In St. Cloud, **Minnesota**, three high school students wanted to participate in a rite of passage anticipated by teenagers across the country – learning to drive a car. The three students, who are deaf, called local driver's education schools to sign up for classes. They requested a sign language interpreter, an accommodation that all of the schools refused to provide. The students and their parents contacted Minnesota's P&A and sued the schools, charging that they violated federal and State human rights laws by refusing to provide interpreters. The schools then agreed to settle the case and provide interpreters not only for these particular students, but for any students with hearing impairments who wish to take driver's education in the future.

Housing

Outcome Statement: In Fiscal Year 2005, P&As assisted **408** individuals in obtaining or retaining a residence, living where and with whom they chose. In Fiscal Year 2006,P&As helped **484** people.

"Maria" is 42 years old, with severe developmental disabilities. When the **Kentucky** P&A staff first met Maria, she was living in a institution, a 400 bed facility that had been riddled with problems over the past few years. The Office of the Inspector General issued more than 20 citations in 2005 and 2006, and the facility received notice that its funding would be terminated. Maria had lived at the facility for 16 years. When the staff first visited her, she was wearing soiled clothing, sitting on the couch rocking back and forth. Facility staff reported that Maria is pleasant and friendly, except when being directed to do something she does not like. She then becomes agitated and may bite others. Some of the barriers to community living presented by staff at the facility and State guardianship services included her medical fragility and risk for falls due to problems with balance. Maria had 118 minor injuries in the year prior to the P&A's intervention, including 16 incidents of aggressive behavior toward her from others. Through P&A negotiations, including attendance at transition/discharge meetings, the team agreed that Maria would benefit from supports in the community. During transition it was discovered that Maria had three sisters, all of whom have developmental disabilities, and who were currently being served in the community. In 2006, Marie moved out of the institution and into the community. Maria now shares a lovely threebedroom home with two housemates in rural Appalachia. She enjoys participating in her community and visiting with her sisters.

For several years the **Kansas** P&A has been a part of the Kansas Statewide Homeless Coalition's Summit on Housing and Homelessness. P&A staff attend meetings of the Governor's Mental Health Planning Council's subcommittee on Housing and Homelessness. Coordinators help with credit checks, background checks, section 8 applications, transition from the Rescue Mission, and other housing issues. In addition, P&A advocacy staff work with Independent Living Centers and local housing authorities to find housing for homeless clients/consumers when those issues are part of a disability discrimination case.

The **South Carolina** P&A staff learned that “Gwen” was about to be moved to a more restrictive setting because of a change in her health status. Gwen liked the residence in which she lived; she didn’t want to leave. The P&A staff worked with Gwen and suggested possible alternatives to her local provider, which was concerned about being neglectful by not moving Gwen to a more restrictive setting. The P&A helped find solutions to better support Gwen in her current environment, and she was able to remain in the home of her choosing.

Recreation

Outcome Statement: In Fiscal Year 2005, P&As facilitated participation or inclusion in order for **63** individuals to be able to enjoy activities they chose. In Fiscal Year 2006, P&As helped **41** individuals access recreation.

From first dates to birthday dinners, restaurants are often a central part of celebrations and social interaction. However, when people with disabilities talk about not being able to get into a restaurant, they’re not always discussing the difficulty of getting a reservation on a Friday night. From parking to restroom access inaccessible establishments can create barriers that prevent diners from enjoying a family celebration or the best filet mignon in town.

New Hampshire’s P&A, is working to improve the restaurant experience for diners with disabilities. **The Rolling Gourmet** offers diners with disabilities the ability to review restaurants and have their reviews publicized for other diners to access when choosing a restaurant. It has proved to be a popular program, and 175 New Hampshire restaurants have been rated so far.

The interactive guide to restaurant accessibility allows patrons to rate a restaurant in multiple categories, including:

- Parking
- Getting into the restaurant
- Inside access
- Restroom access

- Accommodations
- Overall experience

Not only is this a guide for accessible dining, it also serves as incentive for restaurants to improve their ratings.

Quality Assurance

Outcome Statement: In Fiscal Year 2005, P&As secured or maintained quality assistance for **5,879** people with developmental disabilities, increasing their safety or personal welfare, and maintaining their personal authority. In Fiscal Year 2006, P&As reached **6,084** people.

Quality assurance activities are undertaken by the grantees to ensure that individuals are able to live free from abuse and neglect, that they can personally make the choices that affect their lives, that they are included in their communities, and that they have access to high quality services and supports. Due to the nature of their work, P&As most often provide legal services on behalf of individuals with developmental disabilities, protecting their rights, freedom, and safety.

The **Vermont** P&A represented a 19-year-old woman who is deaf, and who has developmental disabilities and mental illness. “Jane” had been adopted from a Russian orphanage when she was a young child. Jane left her adopted home after it was revealed that she, along with other deaf adopted children in the home, had been sexually assaulted by the adoptive father over a number of years. The adoptive father was incarcerated and Jane did not want to have anything to do with her adoptive mother. She had never attended school and had not learned American Sign Language or any other standardized communication system. Jane was briefly committed to the psychiatric unit of a local hospital, and thereafter was essentially homeless. Her adoptive mother had petitioned to be appointed as temporary guardian. Although communication was challenging, Jane was able to let the P&A know that she did not want her mother to be her guardian. The P&A defeated her mother's request for a temporary guardianship and, at Jane's direction, provided advocacy for her to attend an out-of state-deaf school and treatment program. Prior to her departure to attend the program, Jane indicated that she was interested in having a guardian to protect her interests and ultimately, in the absence of any other person willing to act as guardian, the Probate court appointed her mother as limited guardian with the power to enroll Jane in the out-of-state Deaf School and to maintain her enrollment. The P&A provided advocacy to maintain Jane’s private health insurance, which was funding her schooling out of state. In addition, advocacy was provided, through treatment coordination meetings, so that Jane could return to Vermont and live in a community-based setting, but not with her adoptive mother.

The **Wyoming** P&A received several incident reports in which persons with developmental disabilities were being injured while being restrained. The P&A challenged the provider, which used these actions and its policies that seemed to encourage restraint. The P&A obtained materials from the Training and Advocacy Support Center and from the National Association of State Mental Health Program Directors regarding alternatives to the use of restraint techniques. This information was shared with the provider. As a result of P&A advocacy, the provider began following crisis de-escalation procedures prior to physical interventions. The provider informed the P&A that they were seeking “best practices for dealing with disruptive behavior with the least restrictive means possible.” The P&A engaged in follow-up and learned that the provider was no longer teaching restraint as a means of crisis intervention. Client behavior plans are showing significantly less use of restraint techniques and more use of positive behavioral supports.

“Paulo” has Asperger’s Disorder, and he lives in a psychiatric medical institution for Children in **Iowa**. His finger was broken during a restraint. Under the Children’s Health Act of 2000, the facility notified Iowa P&A. Advocates investigated the situation and determined that the restraint was excessive. The P&A recommended that the facility research more appropriate methods to deescalate crisis situations and that restraints such as this have been banned in other facilities. As a result of the investigation, the facility increased mandatory training to all staff regarding reducing restraint and seclusion. They updated their policies regarding restraint procedures.

The **Massachusetts** P&A provided financial and organizational support to MASS, (Massachusetts Advocates Standing Strong), the statewide self-advocacy organization for individuals with cognitive disabilities, to combat instances of sexual exploitation and other forms of mistreatment. Too often trainings are geared to service providers and State officials, rather than the individuals with cognitive disabilities themselves. In contrast to that approach, the focus of this series of training events was to heighten the awareness and understanding of people with cognitive disabilities. The P&A and MASS contracted with a self-advocacy organization in Maine, to conduct a series of regional train-the-trainers events. The slideshow-centered presentations were very well-received and resulted in a core of MASS members who are interested in expanding the trainings to an even greater number of people with disabilities.

The **Tennessee** P&A provided 153 scholarships to persons with disabilities and their family members in order for them to attend the Annual Mega Conference. As a result of the scholarships the P&A provided, these attendees were empowered and trained in self-advocacy skills in the areas of special education, access, community integration, employment, abuse/neglect and other issues, and learned significant and effective tools in order to achieve positive changes in their own lives as well as the lives of other Tennesseans with disabilities.

Chapter 6: 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 support helps individuals with developmental disabilities and their families stay together and participate 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 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. PNS funding in Fiscal Years 2005 and 2006 was for Family Support 360 projects, youth centers, and data collection activities.

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.

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, help in coordinating services, or aid in finding 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 unit 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.

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.

One of the strengths of the Family Support 360 approach is the ability of one-stop centers to adapt to the unique needs of the communities they serve. The following are examples of several approaches or models that have shown successful early results.

Culturally-Sensitive Mobile Services Model

In **New Mexico**, the UCEDD, which received the Family Support 360 grant, has partnered with a Native-American nonprofit organization to provide a comprehensive array of culturally appropriate services for families who have a child with a developmental disability. Project staff with laptops travel to four Pueblos, working with tribal leaders and visiting families in need at their own homes. A steering committee comprised of families, tribal members, and key agencies oversees the implementation of the five centers. This project recognizes the sensitive need to balance tribal sovereignty with State and Federal laws, as services are being provided to Native-Americans with developmental disabilities and their families.

Faith-Based Model

In **Minnesota,** the State Council on Developmental Disabilities, which received the Family Support 360 grant, has teamed up with a local church to address the needs of unserved and underserved families in one of Minneapolis' poorest neighborhoods. An open house promoted the availability of the services and resources of the center to both families and providers. Interpreter services are provided to Somali and Spanish speaking families.

Family Navigators Located with Local Programs Model

In **Colorado**, family navigators are located in the same office as the staff of a program that works with Temporary Assistance for Needy Families (TANF) recipients. Navigators provide support to families, as well as ongoing comprehensive training to case mangers to improve overall services to families of individuals with disabilities. Resources available to families and TANF case workers include assistance with case reviews, parent support networks, advocacy with the public school system, advocacy for inclusive child care, and follow-up services to help families meet their desired outcomes.

Local Peer Navigators Model

In **Vermont,** local parents who have encountered the service system first-hand were hired on a part-time basis to assist other parents in navigating the service system. Peer navigators also provide guidance, comfort, and encouragement to families in crisis. A statewide management team, which includes family members, assists the peer navigators with identifying resources and locating services. The State Agency of Human Services oversees the project. The peer navigators are hired, trained, and supervised through a sub-contact with the UCEDD.

Some individual accomplishments of the Family Support 360 programs in Fiscal Years 2005 and 2006 included:

- Jean P. Snoddy, Director of Colorado Family Support 360 was appointed by the Governor to the Colorado State Board of Human Services.

- Alaska's Stone Soup Group (SSG) became a certified Care Coordinating agency for the State of Alaska, which included receiving their own Medicaid billing number and authorization. This was a "first step" (and project goal) toward building sustainability for SSG to provide ongoing care coordination and support for families that may be Medicaid billable.

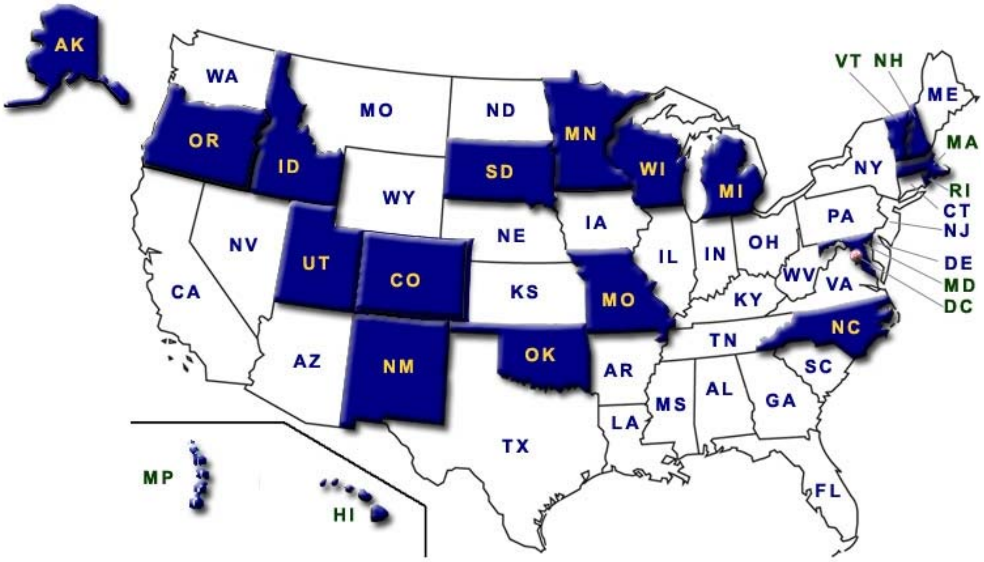
- A team of Idaho Department of Health and Welfare staff and the family support coordinator refined the process of supporting families to allow only one contact person (the family support coordinator) to talk with families and connect them to the correct resources.

- New Hampshire began to convene a Transportation Cooperative, which included a Peterborough area State representative.

- Oklahoma partnered with the Community Action Project, an organization that created an electronic resource searching tool for individuals and families in Oklahoma called the “Benefits Eligibility Systems for Oklahomans” (BESO). The BESO system allows the Family Support Coordinators to enter a family’s data into the system and be prompted to services the individual or family may be eligible to receive.

Family Support 360 Program Map

The highlighted States/territories on this map represent the locations of Family Support 360 programs.



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. These grants continued to be active in Fiscal Years 2005 and 2006. Centers will help youth and individuals with developmental disabilities on national and local levels.

Youth Centers address the unique challenges that youth with developmental disabilities face, including locating and maintaining appropriate housing, excelling in careers of their choice, and making informed decisions about their lives, education, and personal care. By reaching these young adults early, these programs can impart skills that will increase their independence and personal freedom throughout their lives.

Youth information, resource, and training centers educate youth with developmental disabilities about the value of graduating and encourage emerging leaders with developmental disabilities to seek and maintain employment.

For purposes of this program, the term "youth" is defined as individuals with developmental disabilities between the ages of 13 and 17 while "emerging leaders" refers to individuals with developmental disabilities between the ages of 18 and 30 with the desire and interest to engage in community leadership and policymaking activities.

As a result of the activities undertaken by these Centers, young people with developmental disabilities have increased opportunities to graduate with a standard high school diploma and to obtain and retain paying jobs as well as work on additional goals important to young adults.

The Youth Centers focus on diverse populations, are located in either rural or urban locations, and partner with local organizations in order to offer youth with developmental disabilities new opportunities as they transition from adolescence to adult life as contributing members of their communities.

Some of the Youth Center achievements in Fiscal Years 2005 and 2006 include:

- **Inclusion Research Institute (IRI)** – The DC Self-Advocacy Empowerment Center has established three Empowerment groups that have been meeting and working on advocacy efforts: The Sharpe Health School - 14 youth; the College Student and Young Professionals Group - 11 emerging leaders; and the National Children's Center group - 7 emerging leaders. A fourth Empowerment group is being established at the Cesar Chavez Public Policy Charter High School.

- **Institute for Educational Leadership (IEL) – National Consortium on Leadership and Disability-Youth (NCLD- Youth) –** NCLD-Youth has been developing and revising their various workbooks and curricula, a legislative guide and submitted their draft curriculum on disability culture/history to a group of youth reviewers. They continue to work with a graphic designer/web master who is developing a selection of clip art with disability themes. IEL continues to collaborate with various youth groups and programs for youth.

- **Iowa Department of Human Services – Self Advocacy and Leadership for Youth with Disabilities (SALYD)** is currently interviewing for a full time director, now has office space and will move in soon. Iowa's website is up and running at http://www.salyd.org. The "side" SALYD-- a potential program branch of the organization to conduct outreach, host social events and other activities to increase youth participation and youth knowledge about programs and opportunities-- is being considered.

- **The Maryland Developmental Disabilities Council – Youth Empowerment Alliance (YEA)** The YEA project has completed three modules for their trainings. Recently they attended the TASH conference and are implementing training programs for youth and emerging leaders that will be similar to one another. Prince Georges County is considered the pilot site for the youth leadership advisory committee meeting.

- **Independence, Productivity, Self-Determination, Integration and Inclusion's** (**IPSII Inc.) IPSII, Pathways: The Road to Leadership –** IPSII has developed youth-friendly web-based materials in English and in Spanish. They have the unique opportunity to work with the Family Support 360 project within the same neighborhood. They are seeking to expand collaboration. The emerging leaders are now taking more active leadership roles in the advisory meetings. Pathways have developed a leadership training program for non-readers.

- **Family Voices – Kids As Self Advocates (KASA)** has been working on a white paper that will include data from questions that discuss views of youth on Standardized testing. KASA has also developed a manual on how to get youth involved in leadership roles of organizations and agencies.

- **WA Protection and Advocacy System (WPAS) - School to Work** – WPAS is working with five school districts, each having weekly advocacy clubs that are student led. They continue to receive requests from school districts. Upcoming events include a parent meeting where emerging leaders and youth will make presentations about the experience.

On-going Data Collection and Information Dissemination

In Fiscal Years 2005 and 2006, ADD funded four National projects to examine and provide information about financial commitments and programmatic trends in developmental disabilities services and supports. Each of the four projects has a different focus described in the remaining pages of this chapter.

The State of the States in Developmental Disabilities

The *State of the States in Developmental Disabilities* is a comparative nationwide longitudinal 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:

- Analyzes developmental disabilities financial and programmatic trends in each State and the District of Columbia;

- Identifies trends and innovations in the financing of family support, supported living, and supported employment in the States;

- Is conducting a special study of Medicaid spending for special education; and

- Conducts 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.

The project contributes reliable knowledge about the status of services for people with developmental disabilities from a State and national perspective.

State of the States in Developmental Disabilities: 2004 – 2007, A Nationwide Study of Financial and Programmatic Trends

This project extends 17 years of research, describing day and employment services for individuals with developmental disabilities. The project:

- Assesses the effectiveness of State Developmental Disabilities and Vocational Rehabilitation agencies in promoting full inclusion of individuals with developmental disabilities through employment and other community activities;
- Assesses the employment and economic status of individuals with developmental disabilities on a State and National basis;
- Describes and promotes effective State and local policy and practices that enhance access to integrated employment at both the systems and individual consumer levels;
- Maintains www.statedata.info, an interactive website that provides accessible charts and tables illustrating service system investment in employment services;
- Demonstrates the use of the Geographic Information System (GIS) Technology to illustrate patterns of investment in service system outcomes;
- Provides online access to a catalog of best practices in State and local policy that promotes access to integrated employment; and
- Provides online access to best practices in job support for individual job seekers, family members, and advocates using individual stories.

A number of products will be produced by this project, including journal articles, research reports, fact sheets, and guides for consumers and family members.

The National Residential Information System Program: Ongoing Data Collection and Information Dissemination on Residential Services for Persons with Developmental Disabilities

This project continues more than 20 years of analysis of annual State and national statistics on residential services for people with developmental disabilities (DD), including State and non-State institutional settings as well as community and home-based residential services. The project:

- Utilizes a large multi-State database on individuals with DD to examine the associations between personal characteristics, living arrangements, financing and support models, State systems and other factors on the achievement of inclusion, self-determination, satisfaction, and outcomes;

- Conducts State policy and program surveys on key topics in residential and other community services; and

- Maintains clearinghouses of information and resources on consumer-controlled housing, the direct support workforce, and community living outcomes.

The project also disseminates information through a variety of formats, which include, among others, annual reports; the *IMPACT, Policy Research Brief, and Community Services Reporters newsletters;* the *QualityMall.org* website; and the "Trends and Milestones" feature in *Mental Retardation*. The activities carried out through this project provide timely and accurate information about residential services in the United States and on effective, innovative policy development and implementation.

The Medicaid Reference Desk: A Web-Based Information Resource for Adults and Children with Developmental Disabilities, Families, Service Brokers, Service Providers, and Policymakers

The Medicaid Reference Desk Project is maintaining and expanding an interactive website to provide people with developmental disabilities, their families, and the general public with timely, accurate State and national level information on Medicaid services. The project serves as a nationwide resource by providing research, translation, and audio/video recording of comprehensive Medicaid information for each State and Territory. The website presents information in plain English that is understandable to readers with varied ability levels to read. The project, primarily through its website:

- Provides current State-specific Medicaid services information, including printable resource sheets, in everyday language;

- Offers a cognitively accessible, person-centered planning module that will allow a person with a developmental disability and/or family member to produce a "proposed list" for the service coordinator in his or her State;

- Disseminates information about the project to a variety of audiences through an online annual briefing book and printable brochures; and

- Showcases an expanding collection of stories that communicate in everyday language the constructive experiences of people with developmental disabilities benefiting from Medicaid funding to create options and choices in their lives.

Chapter 7: Accountability

The Administration on Developmental Disabilities (ADD) uses its Monitoring and Technical Assistance Review System (MTARS) 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 the 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 grantees within the State;
- Technical assistance needs; and
- Innovative practices.

During the MTARS process, 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 their State 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 the 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.

MTARS Team Structure

The MTARS team structure was revised in Fiscal Year 2005. Generally, the MTARS Team is comprised of the following people:

- ADD Central Office Program Specialists
- Regional Office Program Specialist for DD
- Council Peer Reviewer
- P&A Peer Reviewer
- UCEDD Peer Reviewer
- Individuals with developmental disabilities/family members
- Fiscal Reviewer

The MTARS Team is managed by the *Team Coordinator*, who is an ADD staff person.

ADD divides the larger MTARS Team into three Program Teams. The use of program teams makes it possible for reviewers to focus on one program and accomplish more during the site visit. The Program Teams are:

1) DD Council Program Team
2) P&A Program Team
3) UCEDD Program Team

Each of the Program Teams consists of a minimum of three people, including a/an:

1) ADD and/or Regional Office staff person
2) Peer
3) Individual/family member

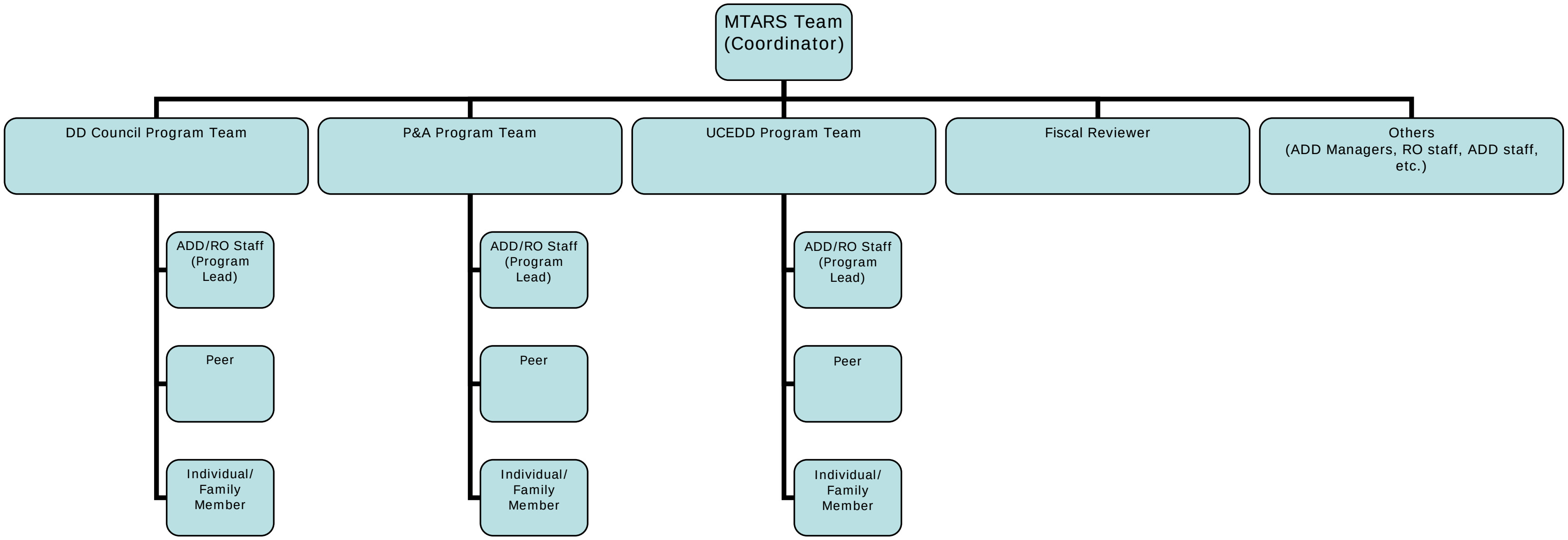
The ADD/Regional Office Staff person serves as the *Program Lead* for the team.

The fiscal reviewer functions independently of the Program Teams. They schedule with the grantees a time during the site visit week to visit the program to conduct the fiscal review. They meet with staff responsible for fiscal-related matters. They typically spend one day at each program.

The Review Team members presented above is the norm. However, there may be instances when additional people accompany the team. For example, an ADD manager may participate in MTARS. There may be additional ADD and/or Regional Office staff who participate in the review. In addition, individuals with developmental disabilities may request to bring a personal support person on the site visit. The personal support person is not an active participant. See the Figure on the next page for a overview of the MTARS team configuration.

In Fiscal Years 2005-2006, New Hampshire, Delaware, Maryland, Illinois, New mexico, South Dakota, and California underwent an MTARS review.

MTARS Team Configuration



Chapter 8: Emergency Preparedness

This chapter of ADD's *Report to Congress, the President, and the National Council on Disability* highlights the work done by ADD and its grantees in Fiscal Year 2005 and 2006 to address emergency preparedness, and will discuss the work that remains to be done. It provides an overview of:

1. Emergency Preparedness and Individuals with Disabilities
2. The ADD Response after Hurricanes Katrina and Rita
3. Information about *The Working Conference on Emergency Management and Individuals with Disabilities and the Elderly,* sponsored by HHS in June 2006 in collaboration with the U.S. Department of Homeland Security (DHS) and other agencies, especially the Administration on Aging and the Office on Disability, in which ADD provided central coordination, management, and financial responsibility.

Emergency Preparedness and Individuals with Disabilities

In August and September of 2005, Hurricanes Katrina and Rita made landfall in Louisiana, uprooting lives across the Gulf Coast. Major damage to the coastal regions of Louisiana, Mississippi, and Alabama made Katrina the most destructive and costliest natural disaster in the history of the United States. These storms highlighted our Nation's need to improve emergency preparedness—not just in relation to natural disasters, but also in order to be able to respond effectively in other kinds of emergencies, such as the pandemic flu or terrorist attacks. The storms also illustrated the extreme vulnerability of certain segments of our population, including individuals with disabilities and the elderly.

The needs, unique situations, and knowledge of people with disabilities, including developmental disabilities, must be more effectively integrated throughout the emergency management process. While all Americans face difficulties during emergencies, these difficulties are often increased for people with disabilities and their families.

ADD recognizes that while Federal involvement in emergency management is crucial, community organizations and State and local governments are largely the primary first responders in a disaster. In order to effectively incorporate the needs of the disability community into emergency planning at all levels, we must not only plan *for* individuals with disabilities, we must include the disability community *itself* in all stages of planning. . ADD and its grantees firmly believe that the following three steps must be incorporated into emergency preparedness at all levels:

1. People with experience working with the disability and aging communities *must* be involved in all phases of emergency management: planning, response, and recovery. Members of these communities themselves should be involved as well, and must have defined roles in shaping response strategies and solutions.

2. Individuals and organizations involved in emergency management, and individuals and organizations focused on disabilities or aging must develop a plan for working together. The time to build solid relationships with other organizations is before the waters start to rise. By starting *now* to encourage collaboration between organizations, we can become familiar with each other's operations, and discover ways that our services and planning techniques can complement each other.

3. Resource mapping is crucial. Everyone should spend time on documenting the availability and location of the resources that will be needed in the event of a disaster -- supplies, equipment, vehicles, housing. During Hurricane Katrina, there were hundreds of accessible buses located within a few hundred miles of the disaster area that went unused because responders didn't know where they were or how to get permission to use them. In order to have access to the resources needed in a disaster, we must know where those resources are and how to quickly access them when they are needed.

ADD and Grantee Response after Hurricanes Katrina and Rita

In the wake of Hurricanes Katrina and Rita, both ADD and its grantees played important roles in response and relief. Some of these efforts are highlighted below.

ADD Response

ADD's decisions and responses were influenced by what its grantees in the affected States told ADD staff in a series of conference calls on September 7 and 8, 2005.

Recognizing the need to support grantees as well as Federal and State entities in the response and recovery effort, ADD partnered with a variety of organizations and agencies in order to provide technical assistance and guidance regarding strategies for responding to the needs of evacuees with disabilities, including those with developmental disabilities.

In the months after the hurricanes, ADD partnered with and gave guidance and technical assistance to the Department of Homeland Security, the Federal Emergency Management Agency, the Red Cross, the Administration for Children and Families, Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, the Administration on Aging, the Department of Agriculture, the Office on Disability, the Department of Education, the Interagency Committee on Emergency Preparedness for Individuals with Disabilities, and State officials in Louisiana, Mississippi, and Texas.

Most importantly and effectively, ADD engaged and worked through its grantees in Louisiana, Mississippi, Texas, Alabama, and Tennessee.

In the months following the hurricanes, ADD conducted three site visits. For the first site visit, ADD representatives served as part of a cross agency team, and traveled to Baton Rouge, Louisiana; Jackson, Mississippi; and Austin, Texas. There, they met with ADD grantees, State officials, local entities, Red Cross personnel, and FEMA representatives.

This visit laid the groundwork for ADD grantees to work with State agencies and the Red Cross in assisting people with disabilities in the response and recovery effort. During the second visit, staff were deployed to Louisiana (Baton Rouge and Lafayette) as part of a broader ACF team. Both staff members monitored the services provided in the shelters, met with State and FEMA officials, and coordinated activities with grantees.

Finally, ADD conducted a two-day visit to Tennessee where she discussed issues related response and recovery efforts.

ADD Gulf Coast Grantees' Responses

The following is an overview of ADD grantees' activities in the months following hurricanes Katrina and Rita. It is by no means a comprehensive account, nor does it address emergency preparedness and hurricane relief activities initiated more than six months after the hurricanes.

Many grantees went above and beyond the call of duty to help the victims of the hurricanes, particularly in the areas where the most demand was felt -- Louisiana, Mississippi, and Texas. Those grantees worked around the clock to ensure that the needs of persons with disabilities were met. Many of the grantees' staff members were themselves displaced. The Louisiana UCEDD offices in New Orleans were completely wiped out and the P&A offices in New Orleans were badly damaged.

Louisiana Grantees

The Louisiana Developmental Disabilities Council responded rapidly to assist individuals with developmental disabilities affected by the storm. Two days after the hurricane hit, essentially every staff person at the Council became engaged in assisting people. The Council collaborated with the ARC of Louisiana, local ARCs, Families Helping Families, the Down Syndrome Association, the Advocacy Center, and the Department of Health and Hospital's emergency response team to identify, locate, and directly assist people to get the supports they need. Flexibility was critical, allowing the Council to immediately provide resources and support where and how it was critically needed by individuals with developmental disabilities and their families.

Examples of how the Council assisted evacuees with disabilities:

- The Council assisted 7 year old "Doug," a boy with Down Syndrome, and his family by personally arranging private transportation from the Baton Rouge Red Cross shelter to Lake Charles LA.

- The Council provided bus tickets from Baton Rouge to Dallas for a family with a child with severe disabilities being transitioned from a Red Cross shelter because the infirmary was being closed.

- The Council provided transportation to "Lily," a young woman with cerebral palsy and her large family from a Red Cross center to a church that will meet her special needs in

> privacy and dignity. The young woman was no longer able to stay in the Red Cross shelter because of her specific needs.

The Advocacy Center (the Louisiana P&A) was also actively engaged in helping evacuees with disabilities. Together with other organizations in the State, Advocacy Center staff went out in teams to work in shelters and identify people with disabilities in need of assistance. Staff worked with a housing task force to raise awareness of the need of people with disabilities affected by the storm. They visited temporary housing sites where FEMA was staging trailers and mobile homes. The Advocacy Center staff worked closely with FEMA and other State agencies to ensure that evacuees with disabilities were provided with accessible trailers and mobile homes. In order to best meet the needs of those impacted by the hurricane, the Advocacy Center developed a "Katrina Unit," which provided specific information about disaster relief to seniors and people with disabilities. The Katrina Unit also provided referrals and short-term assistance, and fielded a large number of calls related to the need for accessible housing. Additionally, the Advocacy Center put together a packet for victims of the hurricanes that provided information on issues such as FEMA and other public benefits, housing, and transportation.

The Louisiana UCEDD, The Human Development Center (HDC), is part of the School of Allied Health Professions (SAHP) within the Louisiana State University Health Sciences Center (LSUHSC). Of the 40 full-time staff members, 29 were unable to return to their homes directly after Hurricane Katrina. More than a dozen staff lived in the hardest-hit areas of New Orleans.

Despite this, HDC made significant contributions to the hurricane response effort in Louisiana. In the days after the hurricane, HDC faculty and staff worked side-by-side with their ADD Network partners in shelters to provide services and supports to displaced constituents and to obtain information from them to be used for strategic planning and resource allocation. In addition, staff members provided leadership in developing and implementing plans to ensure availability and access to community housing for displaced citizens with disabilities, and the elderly. Finally, HDC documented, and continues to address, what worked, what did not work, what is needed, and lessons learned from the perspective of persons with disabilities and their families. HDC intends to use this information to develop recommendations and training materials that persons with disabilities, their families, and the agencies/providers/ personnel that support them can use to ensure a higher level of "emergency preparedness" exists within the disability community in the future.

Mississippi Grantees

The Mississippi UCEDD – the Institute for Disability Studies (IDS) **-** provided extensive case management services and outreach to evacuees. In addition to providing general advocacy services, UCEDD staff went into the shelters and provided recreational and academic support to children, and mental health support to adults. Nine licensed social workers on staff provided case management services in the community. Each social worker carried an average caseload of 35 families. A 1-800 phone number was established for families to call for information and referrals, and more than 500 families were helped through this hotline. UCEDD staff also developed a Hurricane Disaster Resource Directory to distribute to the evacuees at local shelters and to other displaced families across the State. The directory, which included phone numbers for Federal, non-profit, and faith based organizations providing help to evacuees, was also distributed to local agencies and schools. In addition, housing placement and counseling services were provided to evacuees.

The Mississippi P&A rented a mobile unit to provide outreach to evacuees across the State. As a result, they were able to identify and provide advocacy services to evacuees with disabilities. Additionally, the P&A held multiple press conferences to raise awareness regarding the needs of individuals with disabilities who were impacted by the storm.

The Mississippi Council sponsored several initiatives. Among other activities, Council representatives assisted families with housing needs, trained and then served as helpline operators, assisted individuals with equipment needs, and worked to help displaced college students with disabilities so that they could continue their education.

Texas Grantees

Texas received a large percentage of evacuees after Hurricane Katrina devastated Louisiana, and then faced the need to provide additional services within the State when Hurricane Rita struck Texas.

The Texas Developmental Disabilities Council received approval to expand their "Texas Community Integration Project" grant. This grant goes to the Texas P&A, and in its original form was intended to help fund the P&A’s efforts to help transition people out of institutional settings. In the wake of Hurricanes Katrina and Rita, the grant was expanded to specifically target Katrina/Rita evacuees who were in danger of institutionalization. The Council also expanded its web site, adding 15 pages of resources for evacuees. Additionally, Council representatives provided input to the Texas governor’s task force focusing on emergency response for people with disabilities.

The Texas UCEDD visited the shelter in San Antonio regularly to provide outreach services to people with disabilities. They assisted individuals to help them find more permanent solutions post-Katrina. They assisted many families, most particularly those who are relocated to the San Antonio area and needed to access special education services.

The Texas P&A, Advocacy, Inc., was also instrumental in reaching out to the evacuees, even though their Beaumont offices were significantly damaged. Initially, P&A staff went into shelters with two major goals: to assist in identifying individuals with disabilities to ensure their needs were identified and met; and to get an overview of the process in place to ensure that identification and access to services and supports happened routinely. Through shelter visits across the State, P&A staff responded to needs related to housing, assistive technology, transportation, medical services and mental health needs, Medicaid, emergency food stamps, protective services, family unification, special education, legal services, employment, child care, and case management.

Hurricane Response by Grantees located outside the Gulf Coast Area

While the gulf coast grantees were "in the trenches," providing daily services to individuals with disabilities affected by the hurricanes, grantees across the Nation also stepped in to provide relief and assistance wherever they were able. The following is an overview of some of the hurricane response activities throughout the country.

It is by no means a comprehensive account, nor does it address emergency preparedness and hurricane relief activities initiated more than six months after the hurricanes.

Arkansas P&A. The P&A sent a team out to shelters, left sign up sheets and posters, and shared information about P&A advocacy with agencies.

Arkansas UCEDD. The UCEDD developed resource lists for individuals working as crisis intervention staff. Included was information such as:
- A list of disability providers across the State;
- A list of aging providers (similar list of community-based providers who serve individuals who are elderly including those with disabilities);
- A list of local school district special education coordinators;
- A list of independent living centers;
- A list of organizations that respond to disability specific groups; and
- A list of locations where assistive technology is available or where durable medical equipment can be accessed.

These resource lists seemed to be the highest need and were disseminated via the National Association of Social Workers.

District of Columbia Council: Efforts provided by the District of Columbia as a unit. Grantee actions and staff assignments were part of the overall services provided by the DHS as mandated by the District's Emergency Management Plan. Those services included shelter, social services, health and mental health, housing and generally accommodating their immediate needs.

District of Columbia P&A: The P&A provided information and advocacy services at the DC Armory, a shelter housing several hundred Katrina evacuees.

District of Columbia UCEDD: UCEDD sent teams to San Antonio, Dallas, and Austin and coordinated with a team in Houston around children's mental health issues.

Idaho P&A: The P&A provided one senior advocate to the Louisiana P&A to assist in their efforts for four weeks.

Iowa Council: The Governor of Iowa positioned State agencies, along with private resources to accommodate 5000 evacuees initially. Preparations were made eventually for 1000 evacuees and resources were on stand-by. In the end, 19 evacuees came to Des Moines. Two of those were elderly with disabilities and were taken immediately to the hospital for care. One woman with a disability received assistance to find employment. This was accomplished through State agencies that provide direct services.

Iowa P&A: The P&A worked in concert with the Iowa Department of Human Services to be sure that accurate assessments were taking place on behalf of evacuees with disabilities arriving in Iowa, provided direct assistance in linking those evacuees with services for immediate needs, e.g., shelter, food, clothing, etc., and assisted evacuees with disabilities to continue meeting their programming needs through the transfer of waiver, Medicaid, Medicare revenue for which they were eligible. The director and staff of the P&A were present when the initial evacuees arrived in Des Moines.

Kansas Council: The Council sent funds to Louisiana Families Helping Families, funded by the LA council. Funds were used to assist evacuees with disabilities and their families to find their own apartment/house.

Kansas UCEDD: The UCEDD worked closely with a family/parent support group in New Orleans (Pyramid Partners), which is a support and advocacy group for parents of children with developmental disabilities. Through one of the UCEDD centers this grantee established a Pyramid family relief fund and worked immediately with the co-directors of Pyramid to begin to trace Pyramid members.

Missouri Council: The Council sent funds to Louisiana Families to Families to support the DD Council's efforts to identify evacuees with disabilities and provide them with services and supports.

Nebraska DD Network Combined: The three Nebraska grantees informed Red Cross and other emergency service of what the DD Network did and how to reach them. A check with Health and Human Service verified that no one who came to Nebraska was institutionalized. Faculty and staff members provided counseling services to those arriving in Omaha and temporarily placed at the Omaha Civic Center. People needing psychotropic drugs were identified and medications provided. The Council participated in a cross-disability group to identify issues prior to the arrival of the evacuees. They produced a list of resources and shared that with the local Red Cross and the media to insure people were aware of how to contact needed resources. Agencies including the three network agencies met to coordinate across disabilities, inform responders about people with disabilities and facilitate referrals as needed.

Ohio UCEDD: The UCEDD took care of the medical needs of a family with twins with Spina Bifida.

Pennsylvania Council: The Council sent funds to Louisiana.

Tennessee UCEDD: The UCEDD offered assistance to multiple State and local agencies, churches and other organizations involved in Katrina relief. Faculty and staff provided volunteer services on an individual basis in several areas including intake assistance and sorting of donations.

Tennessee P&A: The P&A worked to meet the needs of individuals with disabilities staying in local shelters, and to make those shelters as comfortable as possible for everyone staying there. Efforts included providing TTY and interpreter services as well as coordinating mental health professionals' visits to various shelters.

Utah P&A: The State received 570 evacuees. Three P&A staff with expertise in legal issues, short-term technical assistance, consumer issues, and systems went to Camp Williams to observe, monitor, talk with evacuees and work with Utah's Departments of Health and Human Services to ensure the safety, well-being and basic service needs of people with disabilities and their families.

Vermont UCEDD: The UCEDD contributed to goods taken down by about 40 trucks from Vermont to Mississippi. It sent supplies (wheelchairs, walkers, etc.) to the Mississippi Independent Living Council.

West Virginia Council: The Council gave funding to the West Virginia P&A for their work with evacuees with disabilities in West Virginia.

The Working Conference on Emergency Management and Individuals with Disabilities and the Elderly

- I In June 2006, ADD collaborated with the U.S. Department of Homeland Security (DHS) to present the *Working Conference on Emergency Management and Individuals with Disabilities and the Elderly*. ADD sponsored the conference in cooperation with the Administration on Aging (AoA), Office on Disability, Family and Youth Services Bureau, Children's Bureau, Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), the Social Security Administration (SSA), and DHS' Office for Civil Rights and Civil Liberties.

This conference was unique both because of its content and its structure. This first of its kind conference was exceptional, and included presentations by key national leaders on the complex issues facing the disability and aging populations in the face of natural or man-made disasters. Senior officials from both HHS and DHS made keynote presentations and were joined by colleagues from other Federal agencies. Top experts from State and local governments and the private sector also addressed this conference.

The unique structure of the conference brought together Governor-appointed teams from each State to connect emergency management officials with key leaders from the disability and aging communities. These teams worked together during the conference to identify ways to integrate their work within their jurisdictions' emergency management framework. Senior officials from each of the Federal Emergency Management Agency's Regions were present, which facilitated cooperative planning among State and Federal officials. This team structure allowed for identification and implementation of measurable outcomes and tracking systems in the States.

Conference Participants included 217 delegates and 191 non-delegates for a total of 408 attendees in the general assembly. This does not account for the additional speakers, topic discussants, facilitators, and others there in administrative capacity. Governors from 44 States sent delegations.

Topics of the Emergency Management Conference included:

- Day 1: Estimating populations and the viability of registries.
- Day 2: Accessible transportation and communication.
- Day 3: Coordination and restoration of services.

The goals of the conference for State delegations were to:

- Connect representatives from homeland security, emergency management, special needs, aging and disability with each other,

- Have an opportunity to work together and lay out how to strengthen the capacity of their States to assist target populations in an emergency or disaster,

- Take their consensus-based ideas back to their Governors, and

- Work together for the adoption and implementation of these ideas statewide.

The goals for Federal agencies and national organizations:

Just as State delegations and Regional Groups worked through how to address specific topics, meetings of Federal and national groups each afternoon allowed these Government agencies to work through the challenge of determining how to facilitate these activities by working together at the national level.

Key findings of the Conference:

The key findings of the conference are issues repeatedly identified by State delegates, discussants, and speakers. The findings have implications for the Federal government, and indicate priority areas where efforts can be focused in further integrating disability and elderly issues into emergency plans. While many of these issues are consistent with what has already been observed by other entities/reports and are already being addressed by DHS, HHS, and other agencies, this conference further demonstrated the benefit of the cross-pollination of ideas, actions, and meaningful outcomes across agency and State lines.

Key Findings Related to Guidance and Policy

- Develop a federal term, definition, or model to signify “special needs populations” that can be used as a guide for State and local authorities in emergency planning. The definition should be based on a functional model rather than a medical model, and be flexible and adaptable to accommodate State/local planning.

- Increase planning support to the local level. Use toolkits, planning templates, best practices, and models.

- Develop national standards and reimbursement policy for special needs shelters (i.e., medical needs shelters) for State and local authorities.

- Develop clear guidance and best practices related to the creation, maintenance, and use of registries.

- Clarify how HIPAA applies to registries in emergency situations.

- Ensure that Medicaid waivers that allow for State-to-State services are part of emergency plans.

- Allow Medicaid reimbursement funds to follow the person. In some States there are Medicaid protocols which allow the funds to follow the person across agencies in State, but no such provisions which provide reimbursement coverage across States.

Key Findings Related to Preparedness and Planning

- Integrate disability and senior organizations and agencies into emergency management programs. Reach out to non-traditional disaster agencies, organizations and individuals from within these networks.

- Improve communication and coordination among Federal, region, State, Tribal, and local agencies in the emergency management, disability, and aging fields.

- Prioritize planning for people with disabilities and the elderly in emergency management.

- Include people with disabilities, the elderly, and caregivers in communication plans and public information campaigns.

- Involve the disability and elderly communities in drills and exercises.

- Work with public and private insurance programs about access to prescription drugs and policies that put limits on the supply of these drugs.

Key Findings Related to Research and Development

- Conduct more research in the area of emergency planning for people with disabilities and the elderly. For example, this would help identify models for issues such as registries, sheltering, evacuation, etc.

- Maintain the conference website [www.add-em-conf.com].

- Increase funding and flexibility in funding streams for planning around disability and elderly issues.

- Use existing systems for sharing resources, such as the Emergency Mutual Aid Compact (EMAC), and incorporate this into planning for people with disabilities and the elderly. This will allow States to share resources during emergencies/disasters.

- Increase funding for accessible temporary and long-term housing post-disasters.

The delegates to the conference made a commitment to submit quarterly progress reports for at least one year. These reports, and additional conference information and resources, are available at http://www.add-em-conf.com/.

Chapter 9: 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 a grantee wants to tackle 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 2005 and 2006, ADD funded several contracts that provided technical assistance and/or training to grantees, and to ADD as a whole, including the following:

- The National Association of Councils on Developmental Disabilities (NACDD) provides technical assistance to State Developmental Disabilities Councils;
- The National Association of Protection and Advocacy Systems/Training and Advocacy Support Center (NAPAS [Currently the National Disability Rights Network]/TASC) provides technical assistance to State Proection and Advocacy Agencies;
- The Association of University Centers on Disabilities (AUCD) provides technical assistance to University Centers for Excellence in Developmental Disabilities;
- EST-Technologies provides provides logistical support to ADD, including for the Emergency Management Conference;
- BETAH provides technical assistance to Family Support 360 projects and Youth Centers;
- Z-Tech Corporation maintains the ADD input into Online Data Collection System (OLDC), maintains ADD's website, and produces all of our publications ; and
- Westat is designing ADD's independent evaluation of Councils, P&As, and UCEDDs.

Other sources of technical assistance that may be arranged directly by ADD may come from or through any of 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

The ADD Technical Assistance Contract with the National Association of Councils on Developmental Disabilities (NACDD) helps to improve performance, compliance and program outcomes across the network of State Councils. Self-advocates, family members and Council staff work collaboratively to produce a variety of products including a Council member guide for self-advocates and family members, workshops on Council leadership, and a fiscal guide for Council staff and members.

The contract utilizes a variety of methodologies for communication and sharing of information. These include listservs, topic specific conference calls, a national face-to-face conference, on-line tutorials, and printed materials. In addition, the contract focuses on communities of practice in the areas of Council membership, fiscal policies and procedures, and data collection.

The contract also maintains an on-line library of systems change strategies, legislative advocacy, support to self-advocates, and demonstration projects, as well as organizational and operational practices. This information is generated by the Councils themselves.

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.

In fulfillment of its obligations, the contractor undertook the following activities: governance (with input from the P&A Community), publications for the P&As, trainings, needs assessments, website and listserv management, reporting assistance, and professional development.

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

Through the contract with the Association of University Centers on Disabilities (AUCD), UCEDDs are provided regular updates and information about issues pertinent to developmental disabilities. AUCD, a membership organization that supports and promotes a national network of university-based interdisciplinary programs, has serves as a technical assistance contractor for ADD for 20 years. The purpose of the current TA contract is to improve program performance, statutory compliance, and program outcomes across the national network of UCEDDs. ADD staff also provides technical assistance on an individualized basis. In addition, technical assistance visits are conducted to address individual program needs.

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 (FS 360) grantees. BETAH continued to provide these services in Fiscal Years 2005 and 2006. The training and technical assistance is designed to share knowledge, promote collaboration and understanding, build skills and facilitate collaborative problem solving amongst the FS 360 grantees. This is done through the FS 360 website, conference calls, the annual Technical Assistance Institute, Regional Trainings, research and appropriate materials. BETAH also facilitates linkages between FS 360 projects and 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 2005 and 2006, information was gathered, through Program Performance Reports, from 118 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.

Independent Evaluation

In September 2005, ADD awarded a contract to Westat to conduct Phase I of an independent evaluation of the State DD Network. It is aimed at providing feedback to ADD to help improve the effectiveness of its programs and policies. It will also serve as a decision-making tool for ADD to promote accountability to the public. Phase I of the independent evaluation project involves the development of measurement tools for the study and a pilot study. ADD is conducting the independent evaluation based on feedback from the Program Assessment Rating Tool (PART).

The focus of Westat's work in the first year was on developing DRAFT performance standards for each ADD grant program (Councils, P&As, and UCEDDs), as well as for collaboration. To do this, Westat convened working groups for each of the ADD grant programs (DD Councils, P&As, and UCEDDs), as well as a collaboration working group to gather information for developing the draft performance standards. Through the working groups, Westat compiled a large amount of information on the ADD grant programs and on collaboration.

When completed, the independent evaluation will be a high quality, unbiased evaluation to demonstrate actual impact on the well-being of individuals with developmental disabilities and their families that can be attributed to grantees.

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 2005-2006.

- 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 June 2006, ADD collaborated with the U.S. Department of Homeland Security (DHS) to present the *Working Conference on Emergency Management and Individuals with Disabilities and the Elderly*. ADD sponsored the conference in cooperation with the Administration on Aging (AoA), Office on Disability, Family and Youth Services Bureau, Children's Bureau, Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), the Social Security Administration (SSA), and DHS'Office for Civil Rights and Civil Liberties.

The Office on Disability (OD) advises the Secretary of HHS on disability issues and is charged with leading the HHS New Freedom Initiative (NFI). The broader mission of the Office is to oversee the implementation and coordination of disability programs, policies, and special initiatives. The OD heightens the interaction of programs within HHS and with Federal, State, local government entities and private sector, non-government partners, and supports plans and initiatives designed to tear down barriers facing people with disabilities, preventing them from full participation and contribution in community life. The Office on Disability facilitates numerous interagency and interdepartmental initiatives for which ADD is a partner, including the New Freedom Initiative Work Group which meets monthly providing timely disability based information and to track the efforts of different HHS agencies on projects supporting the NFI. Other initiatives for which the ADD and OD partner in include: addressing the needs of children and youth with co-occurring developmental disabilities and emotional/substance abuse disorders; the HHS department-wide medical home initiative for persons with disabilities to support an integrated and coordinated disability based medical home program; emergency preparedness addressing the health and human service needs of persons with disabilities during and after an emergency; the Office on Disability’s comprehensive service system initiative addressing young adults with disabilities; and the December 2007 Ninth International Congress on Children and Youth with Special Needs.

Chapter 10: New Freedom Initiative

The New Freedom Initiative, one of President George W. Bush's first major acts of office, is an embodiment of the philosophy upon which ADD is built: *The American Dream Belongs to Everyone.*

The New Freedom Initiative was set into motion with the goal of tearing down the barriers to equality that face many of the 54 million Americans with disabilities. It is an important step in ensuring that all Americans with disabilities can participate more fully in the life of their communities and of our country.

This initiative supports States' efforts to meet the goals of the *Olmstead v. L.C.* Supreme Court decision (see below) issued in July 1999 that requires States to administer services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

New Freedom Initiative

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.

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; and
f) Expand transportation options.

ADD believes that the intent and philosophy of the New Freedom Initiative must be incorporated into the daily actions, programs, policies, and attitudes of this Nation. All of ADD's activities and the activities of its grantees support the New Freedom Initiative. Through enduring commitment to these goals and ideals, we will continue to break down barriers, and increase the ability of Americans with disabilities to participate more fully in the life of their communities and of our country.