



# **Biennial Report to Congress, the President, and the National Council on Disability**

***Fiscal Years 2009 and 2010***

*Prepared by*

Administration on Developmental Disabilities  
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## Executive Summary

Throughout its history, the Administration on Developmental Disabilities (ADD)<sup>1</sup> has sought to enable individuals with developmental disabilities across the United States and its territories to live their best, most fulfilling lives. Among other responsibilities, ADD oversees four grant programs authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The DD Act also requires the Secretary to submit a biennial report on the goals and outcomes for these programs. This report identifies the goals and outcomes of ADD's programs during fiscal years 2009 and 2010.

ADD's four grantee programs established by the DD Act are responsible for advancing the mandate to provide individuals with developmental disabilities with the information, skills, opportunities and support to make informed choices and decisions about their lives; live in homes and communities where they can exercise their full rights and responsibilities as citizens; pursue meaningful and productive lives; and contribute to their families, communities, states, and the nation.

These four grantee programs are:

- **State Councils on Developmental Disabilities (Councils)**, which work at the state level to advance the interests of individuals with developmental disabilities and promote policies and practices that fully meet the needs of all Americans. Councils are composed of individuals with developmental disabilities, family members, advocates and state agency representatives, and often focus on empowering individuals with developmental disabilities through activities that teach self-advocacy skills and support self-determination.
- **Protection and Advocacy Systems (P&As)**, which work to protect individuals with developmental disabilities from abuse and neglect by empowering them and advocating on their behalf. P&As are dedicated to the ongoing fight for the personal and civil rights of individuals with developmental disabilities. They provide legal support and other advocacy services (including mediation, counseling, conflict resolution, and litigation) to traditionally unserved or underserved populations to help them navigate the legal system to achieve resolution and foster systems change.
- **University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs)**, which are affiliated with universities and represent an expansive national resource for addressing issues, finding solutions and advancing research related to the needs of individuals with developmental disabilities and their families. The UCEDD program is framed by four core functions: interdisciplinary pre-service preparation and continuing education of students and fellows; research; information dissemination; and community services, which include direct services, training, technical assistance, and model demonstrations.
- **Projects of National Significance (PNS)**, which are often short-term endeavors focusing on issues that are important to the developmental disabilities community, and ensuring that services meet the needs of people with developmental disabilities. PNS funds have supported families, increased community living options, developed quality assurance standards, assisted with family leadership development, and increased opportunities for self-advocate involvement in system change initiatives. PNS funds have also supported long-term data collection projects that help policymakers, service providers, individuals with developmental disabilities and their families make the most informed policy and individual care decisions.

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<sup>1</sup> During Fiscal Years 2009 and 2010, the Administration on Developmental Disabilities (ADD) was responsible for administering the programs and activities contained in this report. ADD has since been reorganized as the Administration on Intellectual and Developmental Disabilities (AIDD) within the Administration for Community Living. ADD is referenced throughout the report to reflect the work of the agency responsible for leading the programs and activities undertaken during FY 2009 and 2010.

The first three of these grantee programs operate at the state level and comprise a Developmental Disabilities network in their respective states. The fourth grantee program, Projects of National Significance, focuses on nationally recognized and emerging needs. They support the development of national and state policy that enhances the independence, productivity, inclusion and integration into the community for people with developmental disabilities.

Through the grantee programs, technical assistance and interagency collaboration, ADD worked during FY 2009 and FY 2010, as it has in the past, to embody the core values of the DD Act — self-determination, independence, productivity and inclusion and integration in all facets of community:

- **Self-determination** is represented by successful self-advocacy trainings and conferences, and the activities of the National Youth Leadership Network and the National Training Initiative for Self-Determination to encourage individuals with developmental disabilities and their families to advocate for equal rights and inclusion. For example, in 2009 ADD grantees launched the National Gateway to Self-Determination website, which gives self-advocates, professionals, policy-makers and the general public access to current best practices in enhancing self-determination for people with intellectual and developmental disabilities. The website also features videos of self-advocates telling inspirational stories and explaining the definition of self-advocacy.
- **Independence** is represented by strides made in the areas of community living and housing through victories in the court system and the successful implementation of universal design concepts. It is also advanced in the area of health care as a result of a settlement agreement that upholds the *Olmstead v. L.C.*<sup>2</sup> decision in Georgia hospital settings, which allows individuals with developmental disabilities to receive public health care services in the most integrated settings appropriate to their needs. In addition, independence is represented in education by programs that increase opportunities for educational advancement in university settings. For example, the Learning Academy at the University of South Florida (USF) is a two-year, four-semester transitional experience designed to help students with Autism Spectrum Disorder achieve a life of opportunity, independence and success.
- **Productivity** is exemplified by programs that encourage gainful, meaningful employment and development of job skills. In the past two fiscal years, those Councils whose work included an emphasis on employment reported that they have assisted more than 7,000 Americans with disabilities to either maintain or obtain jobs of their choice.<sup>3</sup> Productivity was also supported through strides made in securing access to technology that enables individuals to participate equally in activities. In FY 2009, 54 of 56 state and territory assistive technology programs provided 37,833 assistive technology device loans, 38 percent of which were loaned directly to individuals with disabilities.<sup>4</sup>
- **Integration and inclusion** are represented by quality assurance and community activities that promote supports and services that make it possible for individuals with developmental disabilities to participate in society. These values are also represented in the National Residential Information System Project and State of the States in Developmental Disabilities, two projects that analyze current conditions for Americans living with developmental disabilities. In addition, Family Support 360 projects provide opportunities to create one-stop centers to assist unserved and underserved families of individuals with developmental disabilities, improve community

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<sup>2</sup>*Olmstead v. L.C.* is a Supreme Court ruling made in 1999 that requires states to eliminate unnecessary segregation of individuals with disabilities in the delivery of public services, and to ensure that individuals with disabilities receive public services in the most integrated setting appropriate to their needs. <http://www.ada.gov/olmstead/index.htm>

<sup>3</sup> See Appendix.

<sup>4</sup> Braddock, D, et al. The State of the States in Developmental Disabilities 2011. Coleman Institute for Cognitive Disabilities at the University of Colorado Boulder. 2011. p. 29.

capacity to support these families, and encourage systemic change. In FY 2010, Family Support 360 projects served 3,823 youth and 4,471 families.<sup>5</sup>

ADD is also involved in technical assistance that supports its mission and mandate. These technical assistance activities help grantees tackle a problem that crosses state lines or respond to the needs of clients, and make efficient use of funding. Technical assistance activities include trainings and conferences, information dissemination, website maintenance and other support. In FY 2009 and FY 2010, ADD provided training and technical assistance to its grantee programs through contracts with a number of organizations:

- The Information and Technical Assistance Center for Councils on Developmental Disabilities (iTACC), operated under contract by the National Association of Councils on Developmental Disabilities, provides technical assistance to state Councils. Through iTACC, Council members, staff and executive directors quickly access information and resources by visiting the iTACC website or submitting information requests. In FY 2009, iTACC staff received and completed 119 requests for information and resources.
- The Training and Advocacy Support Center (TASC), operated under contract by the National Disability Rights Network, provides technical assistance to state P&As. For example, TASC staff members provide consultation via e-mail and phone on disabilities law, organizational management, and board management. In addition, TASC staff responded to more than 800 programmatic issues per year in areas such as abuse, neglect, and compliance with the Americans with Disabilities Act.
- The UCEDD Resource Center, operated under contract by the Association of University Centers on Disabilities (AUCD), provides technical assistance to UCEDDs. For example, AUCD developed, launched, maintained and updated the UCEDD Resource Center website, which provides a variety of resources for UCEDDs, including grants management documents, annual report requirements, guidelines for onsite technical assistance visits, and archives of events, meetings, and webinars.
- BETAH Associates provides technical assistance to PNS family support grantees. This contract promotes knowledge sharing, builds skills, and facilitates problem-solving among grantees. As part of these efforts, in 2010 BETAH held the Family Support 360 Technical Assistance Institute, an event that received positive ratings from grantees regarding its effectiveness.

In FY 2009 and FY 2010, ICF International provided technical assistance for online data collection, statistical and analytical reports, and the development and maintenance of the ADD Internet and intranet sites, as well as publication, production and information dissemination support, including the development of this report.

ADD undertook a number of partnerships and collaborative efforts, including work with the U.S. Department of Education, U.S. Department of Housing and Urban Development, Interagency Autism Coordinating Committee, and with the Office of Child Care, Office of Head Start, and the Office of Child Abuse and Neglect in the Administration for Children and Families.

While much work has been done to improve the lives of individuals with developmental disabilities, ADD is looking toward the future. A series of listening sessions, conferences and other events have taken place to better inform the development of ADD policy in the years ahead. ADD's mission and the DD Act's mandates remain the primary focus, driving ADD's and its grantees' work across the United States and its territories, with the paramount goal of enabling successful lives for individuals with developmental disabilities.

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<sup>5</sup> Compiled from year-end reports from all FS360 grantees.

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## Introduction: ADD and the DD Act

The Administration on Developmental Disabilities (ADD) is dedicated to ensuring that individuals with developmental disabilities and their families are able to fully participate in and contribute to all aspects of community life in the United States and its territories.

ADD's work supports approaches that shape attitudes, raise expectations, change outdated or broken systems and empower individuals with disabilities to pursue the lives they imagine for themselves. To that end, ADD provides financial and leadership support to organizations in every state and territory in the United States. These bodies assist individuals with developmental disabilities of all ages and their families obtain the support they need to achieve all aspects of a life envisioned and defined by the DD Act.

### *DD Act: Ensuring Access and Support*

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) ensures that individuals with developmental disabilities and their families have access to community-based services and supports to promote opportunities for independence, productivity and inclusion through culturally competent programs established and authorized by the law.

The DD Act establishes four grant programs that are overseen by ADD: State Councils on Developmental Disabilities (Councils); State Protection and Advocacy Systems (P&As); University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs); and Projects of National Significance (PNS).

These grantees ensure that individuals with developmental disabilities have access to opportunities and the necessary supports to be included in community life, have interdependent relationships, live in homes and neighborhoods of their choosing, and make contributions to their families, communities, states and the nation. Individuals with developmental disabilities influence the grantees and their actions through public forums and other methods, helping grantees determine what areas to invest in and how to use their ADD funding. Each grantee has its own process for choosing these areas. Some grantees, such as Councils and UCEDDs, use public forums to assess the needs of individuals with developmental disabilities, while P&As perform work that is client-initiated, which means that someone approaches them with a problem or issue that needs solving on a case-by-case basis.

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

### *Meeting National Policy Goals*

ADD's work significantly relates to the current policy efforts in place to enhance the lives of the estimated 5 million Americans with developmental disabilities.<sup>6</sup> ADD has been working on strengthening health care and supports, increasing employment opportunities, expanding educational opportunities, protecting civil rights, promoting access to community living, and supporting the development and use of accessible technologies.

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<sup>6</sup>National Aggregated Data from 2010 Council State Plans.

## **Visions for the Future**

The number of individuals with developmental disabilities who have been served through the system has risen steadily for the past ten years, with nearly 600,000 served in 2009, up from slightly more than 420,000 in 1998.<sup>7</sup> While this is a significant number when compared to the estimated 5 million people living with a developmental disability in the United States, there is still a long way to go before all individuals are receiving the services they need to rightly participate in American life.

Beginning in 2010, ADD has undertaken a number of efforts to collect feedback from the stakeholders it serves. This feedback, gathered through online submissions and a series of nationwide listening sessions called Envisioning the Future, will be evaluated, analyzed and incorporated into a strategic framework that will help shape future ADD policy directions.

Additionally, ADD embarked on a 6-year contract through Westat to identify network achievements and explore new performance measurement criteria. The first phase of the contract began in September 2005 and ended in September 2008, and the second phase began in October 2008.. Moving forward, ADD will review and incorporate performance measurement recommendations into the Government Performance and Reporting Act reporting structure and revise performance progress reports.

## **Biennial Report (FY 2009 and FY 2010)**

The Biennial Report to Congress, the President and the National Council on Disability is a requirement of the DD Act. This report presents an overview of achievements by ADD's grantees during FY 2009 and FY 2010 as reported by the grantees in their annual reports to ADD. These achievements were reached using funding from ADD, state and local communities and other sources, and reflect the core values of the Administration: self-determination, independence, productivity, integration and inclusion in all facets of community.

This report offers examples of successful implementation of each of the core values as they have been achieved by ADD grantees, as well as through training and technical assistance programs and interagency collaboration.

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<sup>7</sup> Braddock, et al., Coleman Institute and Department of Psychiatry, University of Colorado. 2011. Accessed July 25, 2011. <https://www.cu.edu/ColemanInstitute/stateofthestates/UnitedStates.pdf>

## Chapter 1: The Developmental Disabilities Network

Developmental disabilities grant programs authorized by the DD Act include three state- and territory-based programs that collaborate with each other as well as with other entities in their respective states: Councils, P&As and the national network of UCEDDs. In each state<sup>8</sup>, these programs form a developmental disabilities network (DD network) that is uniquely positioned to meet the diverse needs of individuals with developmental disabilities in that state. A fourth program, Projects of National Significance (PNS), is directed toward current and emerging needs of individuals with developmental disabilities. These nationwide projects work across the DD networks.

While each grantee within the DD networks serves specific, sometimes disparate purposes, these entities were established with overlapping goals that facilitate collaboration and interconnectivity among the different units. Because of its structure, each grantee within a state's DD network is able to work cross-functionally to effectively and efficiently fulfill the mandates of the DD Act and its core values: self-determination, independence, productivity, integration and inclusion in all facets of the community.

### Councils

There are 55 Councils in the United States, its territories, and the District of Columbia. Councils are independent, self-governing organizations that work at the state level to advance the interests of individuals with developmental disabilities and promote policies and practices that fully meet the needs of all Americans.

Councils are committed to the advancement of public policy that helps individuals with developmental disabilities gain more control over their lives. They are composed of individuals with developmental disabilities, family members, advocates and state agency representatives. In part because of their diverse membership, Councils analyze and improve systems, services and trends within a state, and ensure that the voices of people with developmental disabilities and their families are heard.

**Empowerment through self-advocacy.** Councils often focus on empowering individuals with developmental disabilities through activities that teach self-advocacy skills. These activities include:

- Delivering trainings that enable people with communication impairments to communicate (known as facilitated communication).
- Providing workshops that teach individuals with developmental disabilities how to advocate for their rights and holding leadership academies that teach them how to mentor other individuals.
- Supporting the growth of local self-advocacy organizations.
- Providing programs that teach young people advocacy and activism strategies to help them influence policies that affect their choices (e.g., education and employment).

By empowering individuals and their families to advocate not only for themselves, but also to seek long-term solutions through systems change, Councils are creating an environment of self-sufficiency, self-determination, inclusion, and acceptance, both today and for future generations. (For details on self-advocacy efforts funded by Councils, see *Chapter 3, Self-Determination*.)

**State-level planning and goal implementation.** To serve their communities, Councils design 5-year state plans that address new ways of improving service delivery so that individuals with developmental disabilities have the opportunity to exercise their rights and reach their personal goals. To carry out the state plans and their respective missions, Councils work with different groups in many ways to achieve the following goals:

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<sup>8</sup> In this context, "state" refers to the 50 States, the United States territories, and the District of Columbia.

- Involve and support people with disabilities and family members in leadership roles (by law, more than 60 percent of a Council's membership must consist of individuals with developmental disabilities or their family members).
- Educate communities to welcome individuals with developmental disabilities.
- Inform policymakers about disability issues.
- Fund projects to show new ways for people with disabilities to work, play and learn.
- Seek information from the public and from state and national sources.

For example, the Massachusetts Council partnered with the Arc of Massachusetts, an advocacy organization for people with intellectual and developmental disabilities, to form a coalition of statewide cross-disability organizations called the Massachusetts Alliance for 21<sup>st</sup> Century Disability Policy partnership (MA21). This coalition worked to educate individuals, families and policymakers on the principles of MA21.

## Protection & Advocacy Systems (P&As)

Each P&A works to empower, protect and advocate on behalf of individuals with developmental disabilities and their families. There are 57 P&As in the United States, its territories, and the District of Columbia, and each is independent of service-providing agencies.

Protecting individuals with developmental disabilities from abuse and neglect is at the core of the P&A mission. Along with the other ADD grantees, P&As are dedicated to the ongoing fight for the personal and civil rights of individuals with developmental disabilities. P&As provide legal support to individuals with developmental disabilities, as well as other populations of persons with disabilities, to help them navigate the legal system to achieve resolution. P&As ensure that individuals with disabilities have the ability to exercise their rights to make choices, contribute to society and live independently.

**Diverse focus.** While their focus is most often legal, P&As also engage in a full range of other efforts to promote the rights of individuals with developmental disabilities. P&As often provide information and referrals, as well as training and technical assistance to service providers, state legislators and other policymakers. They also conduct self-advocacy trainings and raise public awareness of legal and social issues affecting individuals with developmental disabilities and their families.

**Working toward inclusive education.** P&As also focus on educational issues, working to ensure that students receive an appropriate education in an integrated and inclusive setting. Historically, the majority of the workload and cases handled by P&As has dealt with securing an education in an inclusive setting for children with developmental disabilities.

For example, the Connecticut P&A provided parent advocacy training for a mother whose son was not receiving the supports from the school that he needed to be successful. This training helped empower the mother and other parents in their community and taught them how to be effective advocates for their children. (For additional information on the Connecticut P&A's efforts, see *Chapter 4, Independence.*)

**Olmstead and other cases.** P&As have been involved in a significant number of landmark cases and work closely with other partners, especially Councils and UCEDDs. P&As work to implement the U.S. Supreme Court's 1999 decision in *Olmstead v. L.C.*, which requires states to eliminate unnecessary segregation of people with disabilities and ensure that they receive services in the most integrated setting.

## **University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs)**

**Addressing issues, finding solutions, and advancing research.** The 67 UCEDD grants are spread among 68 centers across the United States and its territories. UCEDDs differ from the other grantees established by the DD Act in that they are affiliated with universities. This affiliation positions UCEDDs to serve as liaisons between academia and the community.

This nationwide network of independent but interconnected centers represents an expansive national resource for addressing issues, finding solutions and advancing research related to the needs of individuals with developmental disabilities and their families. Four core functions frame the UCEDD program:

- Interdisciplinary pre-service preparation and continuing education of students and fellows.
- Research.
- Information dissemination.
- Community services, which include direct services, training, technical assistance and model demonstrations.

Examples of the UCEDDs' work include the efforts of the Washington UCEDD, which collaborates with numerous agencies to provide direct services such as job development, job placement, job training, and continued employment support (see *Chapter 5, Productivity*). In Tennessee, the Vanderbilt Kennedy Center UCEDD developed and implemented a postsecondary education program for students with intellectual disabilities at Vanderbilt University. This two-year nonresidential certification program is the first and only program of its kind in the state (see *Chapter 6, Integration and Inclusion*).

ADD awards UCEDDs a discretionary grant to public service units of universities, or public or nonprofit entities associated with universities. ADD funding is used to support the organizational foundation of UCEDDs, which allows them to pursue other sources of support to carry out various activities. UCEDDs leverage funding from a variety of sources, including federal, state and local agencies; private foundations and donations; and charging fees for services.

## **Projects of National Significance (PNS)**

Projects of National Significance (PNS) focus on nationally recognized and emerging needs, supporting the development of national and state policy that enhances the independence, productivity, inclusion and integration into the community for people with developmental disabilities.

In FY 2010, ADD awarded 59 PNS grants, 30 of which were new that year. PNS funds create grants, contracts and cooperative agreements to public and private nonprofit organizations to create opportunities for individuals with developmental disabilities to directly and fully contribute to and participate in all facets of community life.

PNS funding supports the development of national and state policies that reinforce and promote the self-determination, independence, productivity, and integration and inclusion of individuals with developmental disabilities in all facets of community life. These projects are supported by families, guardians, advocates and communities, and include family support activities, data collection, technical assistance to UCEDDs and Councils, and other projects that hold promise to expand or improve opportunities for individuals with disabilities.

**Short-term projects, long-term differences.** Projects are typically short-term (one to five years) and focus on the most pressing issues affecting people with developmental disabilities and their families. Over the years, PNS funds have supported families and caregivers, increased community living options,

developed quality assurance standards, assisted with family leadership development, and increased opportunities for self-advocate involvement in system change initiatives.

**Longitudinal data studies.** PNS funds have also supported long-term data collection projects that help policymakers, service providers, individuals with developmental disabilities and their families make the most informed policy and individual care decisions. These studies look beyond data collected by each individual grantee within their specific state and allow for an over-arching, higher-level evaluation of the conditions of individuals with developmental disabilities within the United States.

**Demonstrating and supporting emerging needs and best practices.** The projects are intended to enable more rapid responses to emerging issues by targeting an unserved or underserved area, with the intent of eventually implementing programs on a broader, national level. Examples of PNS projects include:

- Data collection and analysis to track longitudinal trends significant to individuals with intellectual and developmental disabilities and their families, such as the residential and employment service in each state. For example, the National Residential Information System Project continues more than 20 years of analysis of annual state-by-state and national statistics and analysis on residential services for people with developmental disabilities (see *Chapter 2, Supporting the Core Values of the DD Act*).
- Programs to assist youth with developmental disabilities in the transition from school to the workforce and postsecondary education opportunities. For example, the Youth Information, Training, & Resource Centers support increasing the ability of individuals with developmental disabilities to exercise greater self-choice and determination, and to engage in leadership activities in their communities (see *Chapter 3, Self-Determination*).
- Programs to develop self-advocacy and leadership skills among people with developmental disabilities. For example, the National Youth Leadership Network is run and led by young people with disabilities and promotes youth leadership, education and advocacy. NYLN advocates for youth in the areas of education, employment, independent living, health care, advocacy and disability awareness and pride (see *Chapter 3, Self-Determination*).
- Projects that create employment opportunities for individuals with disabilities. For example, the Alaska DD Council implemented START-Up/Alaska, part of the Alaska Works Initiative, to increase the self-employment of Alaskans with disabilities (see *Chapter 5, Productivity*).
- Family support activities, including those for military families, which rely on collaborative efforts and community-based solutions to reach unserved and underserved families. For example, the Alaska Family Support 360 program provides services and supports for any family member as needed, not just the member with the disability (see *Chapter 6, Integration and Inclusion*).
- Programs designed to enhance the participation of minorities in initiatives in developmental disabilities. For example, the University of Hawaii at Manoa (Hawaii UCEDD) received an emergency preparedness grant that works to increase the resilience of diverse cultural and geographic populations by training communities' most vulnerable members to be preparedness trainers. These individuals are further strengthened to assume leadership positions within their natural cultural and geographic community as preparedness resources (see *Chapter 6, Integration and Inclusion*).
- Technical assistance to enhance the Councils and UCEDD programs. For example, the Association of University Centers on Disabilities (AUCD) provides technical assistance to UCEDDs in many forms, one of which is information dissemination. In FY 2009 and FY 2010, AUCD led information dissemination efforts through multiple channels, including electronic newsletters, reports, the UCEDD Resource Center website, online discussions, and web-based audio and video broadcasts (see *Chapter 7, Training and Technical Assistance*).

## Chapter 2: Supporting the Core Values of the DD Act

*“The purpose of this title 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, including specifically State Councils on Developmental Disabilities in each State to engage in advocacy, capacity building, and systemic change activities ... protection and advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities ... [and] University Centers for Excellence in Developmental Disabilities Education, Research, and Services ... funding for national initiatives to collect necessary data on issues that are directly or indirectly relevant to the lives of individuals with developmental disabilities; technical assistance to entities who engage in or intend to engage in activities consistent with the purpose described in this subsection or the policy described in sub-section (c); and other nationally significant activities....” — Developmental Disabilities Assistance and Bill of Rights Act of 2000*

The DD Act requires that ADD and its grantees work to ensure that individuals with developmental disabilities and their families receive assistance that promotes the core values of self-determination, independence, productivity, and integration and inclusion into all aspects of community life. These four values represent a broad definition of what it means to be an American, participating fully in life in the United States, and relate directly to the four goals of the Americans with Disabilities Act: equality of opportunity, full participation, independent living, and economic self-sufficiency for all people with disabilities.

In FY 2009 and FY 2010, ADD sought, as it had earlier, to embody these values with great success, enabling individuals with developmental disabilities and their families across the United States to achieve a better quality of life. The examples that follow in this report offer a glimpse at the extensive work being done across the country by ADD grantees.

### Meeting the Goals of the DD Act

Longitudinal data are the basis for ADD’s strategic mission and provide qualitative support for ADD’s continued efforts to better the lives of individuals with developmental disabilities.<sup>9</sup> The data are collected on a national level and have been funded by Projects of National Significance more than 20 years. The data are used to identify areas of specific need, and are helping lawmakers and other stakeholders make the most educated policy and care decisions for individuals with developmental disabilities in the United States.

The comprehensive, population-level data collected from grantee annual reports embody the four core areas of the DD Act, and are used to analyze the movement of individuals with developmental disabilities from segregated environments to integrated and inclusive ones, as well as the state of employment opportunities, and the quality and availability of community services.

These longitudinal data studies are the National Residential Information System Project (RISP), State of the States in Developmental Disabilities, and Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities.

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<sup>9</sup> Data from the studies appear throughout this report and are cited to indicate the source and date of the data.

## *National Residential Information System Project (RISP)*

RISP continues more than 20 years of analysis of annual state-by-state and national statistics and analysis on residential services for people with developmental disabilities, including state and non-state institutional settings and community and home-based residential services. With the guidance of an advisory group made up of people with intellectual and developmental disabilities and their family members, the research is conducted through the Research and Training Center on Residential Services and Community Living Institute on Community Integration, the UCEDD at the University of Minnesota.

A PNS-funded project, RISP examines 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 other outcomes. It also conducts research on state policy and program outcomes relating to 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 collects data from states on the number of children and youth with intellectual and developmental disabilities living and receiving supports outside the home of biological or adoptive family members.

These data sets provide information that is not available in other national surveys for analyses of demographic, service and policy topics specific to people with intellectual and developmental disabilities. In FY 2010, for example, 55 percent of individuals with intellectual and developmental disabilities receiving publicly funded supports lived with family members, and 12 percent lived in homes of their own. An estimated 19 percent lived in congregate settings with 6 or fewer residents, 5 percent lived in congregate settings with 7–15 residents, and 9 percent lived in large public or private facilities, nursing homes, or public psychiatric facilities. Of individuals with intellectual and developmental disabilities who did not live with family members in 2010, 36 percent lived in settings with 1–3 people (including homes of their own, host homes, and small group settings), and 32 percent lived in settings with 4–6 residents.

RISP data regarding state services varies widely. In FY 2010, 10 states served 90 percent or more of all citizens with developmental disabilities who lived in congregate settings with six or fewer residents, while four states served less than 50 percent of such people in smaller settings. Furthermore, while the national percentage of people with developmental disabilities who lived in congregate settings with 1–3 residents was 36 percent, two states reported that more than 90 percent of people with developmental disabilities receiving residential supports outside of their own or family home lived in settings with three or fewer residents. Five states reported that less than 25 percent of their citizens with developmental disabilities who did not live in homes of their own or with family members lived in places with 1–3 residents.<sup>10</sup>

RISP disseminates information based on its findings through a variety of formats, including annual reports; the *IMPACT*, *Policy Research Brief*, and *Community Services Reporters* newsletters; the *QualityMall.org* website; and the “Trends and Milestones” feature in the journal *Intellectual and Developmental Disabilities* (formerly *Mental Retardation*).

The activities carried out through this project provide timely and accurate information about residential services and newly implemented policies in the United States so that policymakers, service providers, individuals with developmental disabilities and their families can make informed decisions regarding housing and community living.

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<sup>10</sup> Lakin, C., et al. National Residential Information Systems Project. <http://rtc.umn.edu/RISP/main/>

## *State of the States in Developmental Disabilities*

State of the States in Developmental Disabilities is administered by the University of Colorado, funded in part by ADD.

Established in 1982 to investigate the determinants of public spending for intellectual/developmental disabilities services in the United States, the project maintains a longitudinal record of revenue, spending and programmatic trends in the 50 states, the District of Columbia, and the United States as a whole for fiscal years 1977–2009.

The project is a benchmarking study of the states' performances as they work to implement the Supreme Court's *Olmstead v. L.C.* decision promoting community living, while seeking to recover from the recent, severe budgetary challenges of the recession and its aftermath. The study found that public spending for community services first exceeded institutional spending in 1989. By FY 2009, all but one state spent more on community services than institutional services. By the same year, 84 percent of total developmental disabilities spending was dedicated to placements for 15 or fewer people, with 19 states dedicating at least 90 percent of total resources to community services, including 3 states committing 100 percent to community services.<sup>11</sup>

With the guidance of an advisory group of people with intellectual and developmental disabilities and their family members, the project provides substantive quantitative data on community services and supports, public and private institutions, fiscal efforts in states, and demand for services and supports. The project also conducted a pilot study on family support, examining services in six states.

This project provides a significant amount of information to ADD, other federal agencies, state policymakers and other stakeholders. It enables a thorough understanding of supports and service systems in the United States, and offers both quantitative and qualitative information about the living and working status of individuals with disabilities.

## *Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities*

The Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities studies have been in place since 1988, extending research describing day<sup>12</sup> and employment services for individuals with developmental disabilities and contributing to an understanding of the factors that influence employment at the individual, service provider and state levels.<sup>13</sup>

Conducted by the Institute for Community Inclusion at the University of Massachusetts Boston, the project assesses the effectiveness of state intellectual disability and developmental disabilities agencies and vocational rehabilitation agencies in promoting full inclusion of individuals with developmental disabilities through employment and other community activities, and the employment and economic status of individuals with developmental disabilities on a state and national basis. The project also identifies “promising practices” that were used by employment specialists to find employment-related services for people with intellectual and developmental disabilities.

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<sup>11</sup> State of the States. <https://www.cu.edu/ColemanInstitute/stateofthestates/index.html>

<sup>12</sup> For this data collection project, “day services” refers to facility-based and community-based non-work services for individuals with intellectual and developmental disabilities. Community-based non-work includes services focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. Facility-based non-work includes all services that are located in a setting where the majority of participants have a disability. Neither service involves paid employment of the participant.

<sup>13</sup> StateData.info. “About StateData.info.” Accessed October 6, 2011. <http://www.statedata.info/about/about.php>

With the guidance of an advisory group consisting of individuals with intellectual and developmental disabilities and their family members, the project describes and promotes promising state and local policy and practices that enhance access to integrated employment at both the systems and individual customer levels. It demonstrates the use of Geographic Information System (GIS) Technology to illustrate patterns of investment in service system outcomes, and provides online access to a catalog of best practices in state and local policy and practice that promotes access to integrated employment, including outcome data collection tools, funding structures, and employment policies and initiatives.

It also implements <http://www.statedata.info>, an interactive website that provides fully accessible on-demand charts and tables illustrating service system investment in day and employment services and employment outcomes.

## Chapter 3: Self-Determination

Self-determination refers to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directed.

Self-determination is at the core of the DD Act. As outlined in section 102, self-determination activities are defined as:

“... activities that result in individuals with developmental disabilities, with appropriate assistance, having—  
(A) the ability and opportunity to communicate and make personal decisions;  
(B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;  
(C) the authority to control resources to obtain needed services, supports, and other assistance;  
(D) opportunities to participate in, and contribute to, their communities; and  
(E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.”<sup>14</sup>

For individuals with developmental disabilities, self-determination is an important factor in their ability to pursue their own definition of happiness and to make choices that will enable them to achieve their goals and aspirations, and protect their rights as individuals within American society. Individuals with developmental disabilities who have the degree of control they desire over their lives consistent with their capacities, strengths and needs are more likely to express satisfaction in other areas of their lives, like employment.

By providing supports and services to individuals with developmental disabilities to help them determine their own futures, ADD not only is investing in the futures of individuals immediately served, but also in the futures of Americans with disabilities in generations to come.

### *Self-Advocacy*

Individuals with developmental disabilities and their families are their own best champions. They are advocates for their family members and self-advocates, speaking up about their needs and rights, and rightly asserting themselves as vital contributors to the national conversation about the services and systems that support them. Across the United States, advocates and self-advocates are raising their voices for themselves, their peers and their family members, and they seek support in their efforts from the DD networks in their states.

In 2009, 47 Councils directly or indirectly provided \$3.3 million in funding across the states to self-advocacy organizations that were led by individuals with developmental disabilities. In 2010, 48 Councils provided \$3.8 million in funding to self-advocacy organizations.<sup>15</sup>

The following are examples of the work of the self-advocacy organizations funded by the Councils:

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<sup>14</sup> Public Law 106-402, Section 102(27)

<sup>15</sup> FY 2009 and 2010 DDC Program Performance Reports.

**Watching our words.** The Colorado Council has continued its support of Watch Our Words (WOW), a self-advocacy group of facilitated communication users. Facilitated communication enables people with communication impairments to communicate. For example, a person without a disability may facilitate communication by placing his or her hands on the hands of the person with a disability, enabling that person to use a keyboard and type responses to a set of questions.

Self-advocate members of WOW who use facilitated communication have developed agendas for monthly meetings and have designed the curriculum for and delivered trainings in facilitated communication and other topics. In FY 2009, WOW expanded the topics it offers to include trainings such as “Life through Our Eyes,” “Classroom Success,” “Developing Talents,” “Employment,” “Including People with Disabilities in Your Organization,” and “Using Assistive Technology More Effectively.” Videos featuring five vignettes of WOW members, as well as training modules, have been made available on the Colorado Council’s website, and they are downloaded an average of 60 times each month.<sup>16</sup>

The Colorado Council’s financial and training support of the self-advocacy training outreach effort by WOW is just one example of the extensive support given to self-advocacy, leadership and self-determination trainings being conducted all around the nation.

In FY 2009 and FY 2010 combined, the DD Councils collectively reported that 68,545 individuals were trained in leadership, self-advocacy and self-determination.<sup>17</sup>

**Peer to Peer Project trains self-advocates.** The Texas Council supported the Texas Advocates’ Peer to Peer Project, which provided training for individuals with developmental disabilities to learn to advocate for their own rights and interests by making decisions and choosing supports and services that allow them to live the life they want.

In the San Antonio, Corpus Christi and Lower Rio Grande Valley areas, the project conducted 12 local self-advocacy workshops for 150 self-advocates. It also held regional leadership academies for 36 individuals to learn to advocate and mentor other individuals with developmental disabilities.

The Peer to Peer Project supported the growth of new or existing local self-advocacy organizations and participated in public policy advocacy. It also provided statewide information, education, technical assistance, support, training and advocacy. The project developed a training video and manual called, “Get the Power: Self Advocacy is the Key to Independence,” to provide tools to train individuals to become better self-advocates.<sup>18</sup>

**Ensuring quality, enabling transition.** My Voice My Choice was a youth information, training and resource center designed to infuse youth self-advocacy into self-advocacy activities in Hawaii. A project of the Center on Disability Studies at the University of Hawaii (UCEDD), My Voice My Choice also collaborated with the rest of the Hawaii DD network — the State Council on Disabilities and the Hawaii Disability Rights Center.

The program emphasized education, employment and quality assurance by amplifying the voices of young people involved in the development of policies and services that affect their choices. In FY 2009 and FY 2010, the program hosted the Hawaii Youth Leadership Academy in conjunction with the annual Pacific Rim International Conference on Disabilities. The 2009 academy focused on legislative advocacy

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<sup>16</sup> Colorado Council Program Progress Report, 2010.

<sup>17</sup> The DD Act directs Councils to spend funds on initiatives recommended by people with developmental disabilities, family members and advocates. The law does not require Councils to engage in activities in each area of emphasis (employment, education, housing, health, child care, transportation, recreation, quality assurance and formal/informal community services). Therefore, the number of reporting Councils for any one area of emphasis is based on programmatic decisions affected by what people in a state consider important. Statistics are derived from FY 2009 and FY 2010 Council Program Performance Reports.

<sup>18</sup> Texas Council Program Progress Report, 2009.

and community organizing, and the 2010 academy addressed civil rights. The two academies attracted more than 100 attendees and included presentations on the basics of government and lawmaking, advocacy strategies, and activism principles and practices.<sup>19</sup>

**Person-centered planning.** In North Carolina, the “Strengthening Military Families with Children With Developmental Disabilities: OneStop for Family Support Project” is working at the state and local levels through the Family Support Network at the Carolina Institute for Developmental Disabilities and the Family Support Network of Greater Forsyth to provide support to families. This project began in 2009 and is part of ADD’s Family Support 360 for Military Families program. It builds on the implementation of North Carolina’s Family Support 360 Center Project, which started in 2004 and ended in 2009.

The OneStop for Family Support Project served 32 new families during the second half of the 2009 fiscal year, with seven continuing from the previous reporting period. The project served 50 new families in 2009 using the comprehensive One Stop process, and all these families worked intensively with Family Support Coordinators to achieve the goals developed and documented in their Family Service Plans. Since their inception in 2004, the North Carolina Family Support 360 Center Projects have provided intensive services involving a Family Service Plan to a total of 250 families.

One successful outcome came in the form of the mother of a six-year-old with autism who was attending a kindergarten readiness class at an elementary school close to their home. She called to discuss her concerns about his placement for the upcoming school year. Although the school had recommended that her son be placed in a self-contained class at a different elementary school 25 minutes from home, the mother wanted him to have the opportunity to attend a regular kindergarten class — inclusion with appropriate supports in a least restrictive environment. The Family Support Coordinator worked with the family to develop a Family Support Plan. Together, they explored strategies to use with school personnel to ensure that her son’s educational needs would be met in a mainstream kindergarten class at his current school. The Family Support Coordinator assisted the mother in arranging for TEACCH, a program for children with autism, to observe her son in his classroom and make recommendations to the teachers about strategies to help him succeed in the mainstream kindergarten setting; and the Family Support Coordinator attended the Individualized Education Program meeting with the child’s father.

The TEACCH classroom observation and report was very complimentary of the kindergarten teacher in the class the son would attend. The principal also suggested that the teacher participate in a special TEACCH training for teachers to further ensure that she was able to utilize effective strategies. The mother is very pleased with the plan that was collaboratively established and with the involvement of these groups, coordinated by the Family Support Coordinator.

### *National Training Initiative for Self-Determination*

ADD awarded to a consortium of five UCEDDs a National Training Initiative grant entitled “National Gateway to Self-Determination.” This project was awarded \$800,000 each year for five years beginning in 2008 to enable self-advocates, family members, professionals, agencies and the UCEDDs to scale up efforts that promote self-determination.

UCEDDs in Illinois, Kansas, Missouri, New York and Oregon are implementing the project to establish a sustainable, evidence-based training system to improve training programs for self-advocates and their families, professionals, policy-makers, and the general public that lead to enhanced quality of life for individuals with developmental disabilities. Since its inception, the project has developed training curricula, practice briefs, a national website, and a white paper on social capital and resource guides.

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<sup>19</sup> Center on Disability Studies at the University of Hawaii (Hawaii UCEDD) Annual Report, 2010.

In fall 2009, the project launched a website containing current best and evidence-based practices in enhancing self-determination for people with developmental and intellectual disabilities and all individuals. The website features videos on the definition of self-advocacy and why it is important, as well as inspiring stories by self-advocates.<sup>20</sup>

In November 2008, the project held a workshop that introduced participants to the conceptual framework and beliefs that will guide the development of a National Gateway to Self-Determination. The workshop provided an overview of initiatives planned to help scale up support for self-determination on the national level. Workshop participants engaged in facilitated discussions regarding available resources and gaps, implementation strategies and UCEDD partnerships and sustainability.

Staff from the Kansas and Missouri UCEDDs collaborated with People First organizations in their states and the SABE board of directors to plan and coordinate the SABE National Self-Advocacy Conference in September 2010. SABE presented self-determination as its vision for the future to more than 900 self-advocates from across the country. As a major sponsor of the conference, the National Training Initiative was able to make self-determination a key feature of the agenda. Highlights included presentations on self-determination and building social capital, and advocates led the way by telling their own stories.<sup>21</sup>

### *Supporting Youth*

ADD recognizes the importance of supporting youth with developmental disabilities and empowering them to empower themselves. Through PNS projects, ADD supports youth grantees that develop the self-advocacy and self-determination skills for young people with developmental disabilities.

The Youth Information, Training, & Resource Centers is a PNS project that supports increasing the ability of individuals with developmental disabilities to exercise greater choice and self-determination, and to engage in leadership activities in their communities. These projects are conducted at the state and national levels, with 2 grants supporting national grantees and 19 grants supporting state grantees and the District of Columbia.<sup>22</sup>

In FY 2009, the Youth Center grantees reported holding nearly 500 trainings to more than 3,400 people and giving nearly 400 presentations to approximately 34,000 participants. Grantees also developed and disseminated more than 37,000 materials covering 49 different topics.<sup>23</sup>

The projects reported having 282 youth and emerging leaders from unserved and underserved populations and partner representatives, representing all 21 grantees' locations, as active advisory committee members, and 14 of 21 projects reported that they have employed more than 56 youth and emerging leaders.<sup>24</sup>

**National Youth Leadership Network.** The National Youth Leadership Network (NYLN) is run and led by young people with disabilities. NYLN promotes youth leadership, education and advocacy. NYLN advocates for youth with disabilities in the areas of education, employment, independent living, health care, advocacy and disability awareness and pride. Additionally, NYLN established the first youth-led National Youth Information Center, which emphasizes outreach to young people with underrepresented disabilities, culturally diverse youth and other areas of need.

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<sup>20</sup> <http://www.aucd.org/ngsd>

<sup>21</sup> National Training Initiative for Self-Determination Year-End Report, 2009.

<sup>22</sup> The state grantees are Arizona, Arkansas, California, Florida, Hawaii, Illinois, Minnesota, Mississippi, Missouri, Montana, New Hampshire, New Mexico, North Carolina, Oklahoma, Oregon, Utah, Virginia and Washington, and the District of Columbia. The national grantees are the Institute for Educational Leadership and the National Youth Leadership Network.

<sup>23</sup> Youth Information, Training & Resource Centers Grantee Accomplishments Report, September 2009.

<sup>24</sup> Youth Information, Training & Research Centers Grantee Goals and Accomplishments Report, 2009.

NYLN hosted the “Reap What You Sow: Harvesting Supports Systems Institute” in Raleigh, N.C., July 29–30, 2010. At the institute, more than 140 participants from 25 states were introduced to a new curriculum that teaches people how to build a support system that promotes their personal power. Attendees participated in training sessions on the curriculum’s tools, how to lead groups and how to create learning spaces where people can feel comfortable and included. The institute was sponsored by ADD, the North Carolina Council and other advocacy organizations.

The full “Reap What You Sow” curriculum<sup>25</sup> was made available to the public in spring 2011 and includes interactive elements such as games and videos, as well as a political education component that focuses on personal examples of self-advocacy and the history of ableism, or discrimination against individuals with disabilities.<sup>26</sup>

Through this curriculum and the training sessions provided at the institute and by the National Youth Information Center, NYLN has significantly contributed to the capacity of youth with disabilities to advocate for themselves and their rights.

**San Diego State University Research Foundation Center for Emerging Leadership.** This San Diego-based grantee works to improve the community inclusion for youth (ages 13–17) and emerging leaders (ages 18–30) with developmental disabilities through a replicable “Empowerment Model of Peer Mentorship” that ensures that youth and emerging leaders are trained in self-advocacy skills and as mentors, that parents are trained to promote self-advocacy, and that youth and emerging leaders are involved in community leadership roles.

In FY 2009, the Center for Emerging Leadership had three peer mentors who helped educate 60 individuals in self-advocacy skills, attended monthly People First business and workgroup meetings and continued to create and present monthly training workshops to their fellow mentors and ambassadors. These mentors are also employed by the San Diego State University Research Foundation.

In addition to the valuable self-advocacy training provided by their peers, the Center hosted four “Free Saturday Workshops” for parents, covering topics like supported employment and supported home living. Since the beginning of the project, the Center has exceeded its goal by having nearly 100 parents and family members attend the workshops.<sup>27</sup>

**University of Missouri, Youth LEAD.** Similar to the Center for Emerging Leadership, the University of Missouri, Youth LEAD (Leadership, Education and Advocacy for Youth with Developmental Disabilities) project supports the development of peer mentors and the engagement of youth and emerging leaders in greater roles within their communities.

In FY 2009, the project recruited 15 emerging leaders and peer mentors who received peer mentor, Internet safety and technology training.

The project formed a youth congress consisting of more than 70 percent youth and emerging leaders that is responsible for working the videos for the website, discussing project sustainability and planning for future meetings, and providing input on the second Urban Leadership Academy. The Academy hosted 40 unserved and underserved youth and emerging leaders from diverse racial backgrounds with disabilities within the greater Kansas City area. The program saw a 60 percent increase in the number of participants compared to the previous year, and covered topics ranging from self-advocacy and disability pride to communication skills and disability history and culture.

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<sup>25</sup> <http://www.nyln.org/resources-3/reap-what-you-sow-curriculum/>

<sup>26</sup> National Young Leadership Network Progress Report, 2010.

<sup>27</sup> Youth Information, Training & Resource Centers Grantee Accomplishments Report, September 2009.

Additionally the program held inclusion training for 70 individuals, set up a website and Facebook page and doubled its recruitment goal.<sup>28</sup>

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<sup>28</sup> Ibid.

## Chapter 4: Independence

At its core, independence for individuals with developmental disabilities is about the ability to determine one's own future and access the appropriate supports necessary to make those plans a reality. Because this may not be possible for all individuals, independence becomes about living interdependent lives with the supports one needs and finding the most self-sufficient ways to participate in daily life in the United States.

ADD's grantees support and foster independence for individuals with developmental disabilities through efforts to improve community living and housing, education and financial independence initiatives, and emergency preparedness planning.

### *Community Living: Upholding Olmstead*

The ability to live how and where one chooses is one of the greatest markers of independence for an individual with developmental disabilities. To live on one's own in a home of one's choosing can be a major part of an individual's personal dreams.

June 2009 marked the 10th anniversary of the landmark U.S. Supreme Court decision *Olmstead v. L.C.* On June 22, 1999, the Supreme Court ruled that under the Americans with Disabilities Act (ADA), unjustifiable isolation and segregation of a person with a disability is discrimination. The court ruled that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."<sup>29</sup> The court also explained that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."<sup>30</sup>

Since the *Olmstead* decision, many individuals have successfully transitioned to community settings. At the same time, waiting lists for community services continue to grow, and many individuals who would like to receive home- and community-based services are not able to obtain them. They are not able to live outside the institutional setting in homes of their choosing, which severely limits their independence.

Progress was made, however, in January 2009, when the state of Georgia entered into a settlement agreement with the U.S. Department of Justice that addresses an investigation of seven Georgia hospitals. The Justice Department found that these hospitals had violated the ADA and the *Olmstead* decision in their treatment of individuals with mental illness and developmental disabilities. The settlement agreement expanded community mental health services so that the state can serve individuals with mental illness and developmental disabilities in the most integrated setting appropriate to their needs. This agreement protects the civil rights of individuals with mental illness and developmental disabilities and ensures that they will be able to receive the services they need to live full lives in the community.

In addition, in the past two years, P&As across the United States have reported that complaints of abuse, neglect, discrimination, and human and civil rights violations have been remedied for approximately 18,000 Americans.<sup>31</sup> This work, in addition to the Georgia settlement, is a major triumph in the effort to support the independence of individuals with developmental disabilities.

**Moving into the community.** Cindy's story provides an excellent example of what can happen when someone is given the chance to live more independently. For decades since she left the Macon School for

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<sup>29</sup> *Olmstead v. L.C.*, 527 U.S. 581, 600 (1999)

<sup>30</sup> *Olmstead v. L.C.*, 527 U.S. 581, 601 (1999)

<sup>31</sup> See Appendix.

the Blind, Cindy, 58, lived in group homes, state hospitals and nursing facilities. She was estranged from her family and was often overmedicated. The Georgia P&A, the Georgia Advocacy Office, Inc., visited Cindy in the facility where she had lived for eight years. She had nothing in her room except the bed. The Georgia Advocacy Office reconnected Cindy with her brother and introduced her to the independent living center in her area. The P&A helped her find a home in the community and helped her connect with citizen advocacy. She now has a citizen advocate who serves as her ally in the community.<sup>32</sup>

Through the work of P&As and the other grantees in the DD network, individuals with disabilities are now, more than ever, able to exercise their right to choose housing that is appropriate to their needs and wants. Over the past two years, P&As around the nation reported that because of their efforts, more than 1,000 individuals with developmental disabilities live in homes of their choosing.<sup>33</sup>

**Accessibility and independence through universal design.** Universal design is an approach to architectural design that incorporates products, building features and other elements that can be used by people of all ages and abilities and enables them to live in their homes more independently for a longer time. The Delaware Council formed a Universal Design Coalition to educate the public, administrators and legislators on the benefits of building homes based on universal design principles. The coalition includes the Delaware Council, state government service providers, advocacy organizations, advisory councils, and an independent living center as well as builders and construction companies.

The Council has supported the development of materials for public awareness campaigns about universal design, including a brochure, a video and a website. The video, titled *Universal Design in Housing*, appeared on the governor's website for a week and is now hosted on the state's YouTube channel.<sup>34</sup> The website, [www.universaldesigndelaware.com](http://www.universaldesigndelaware.com), is managed by Green Diamond Builders, a company that builds using universal design concepts. The site provides information on the benefits to all people when universal design is applied to building homes.

The Council and the state chapter of the American Association of Retired Persons (AARP) are also working on an awareness campaign to educate the public, especially people with disabilities and older individuals, on the benefits of living in a home built with universal design features, such as a no-step entry, wider entrance doors, first floor bathrooms and wider hallways. If a home is built using these features, it is less expensive than remodeling a home to add those same features later. As part of the campaign, the Council, the Center for Disabilities Studies (the Delaware UCEDD) and both the national and Delaware chapters of AARP presented at a statewide conference for architects.

### *Education*

As is true for the general population, education is a key determinant in success for individuals with developmental disabilities. Regardless of whether an individual has developmental disabilities or not, the pathway to independence — the ability to choose one's own future — is most often based on the ability to receive an education. Individuals with intellectual disabilities have some of the lowest rates of employment and education, but there is a growing movement to develop programs that open the doors to postsecondary education for individuals with developmental and intellectual disabilities.

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<sup>32</sup> Georgia Advocacy Office, Inc. (Georgia P&A) Program Progress Report, 2009.

<sup>33</sup> The DD Act authorizes P&As to investigate incidents of abuse and neglect. 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. Because participation in the areas of emphasis are driven by client needs (employment, education, housing, health, child care, transportation, recreation, quality assurance and formal/informal community services), P&As may not necessarily participate and report for each area of emphasis. As a result, the number of individuals reported as having been served is considerably smaller than that of the other grantees within a state's DD network. This does not, however, lessen the impact. Given the direct relationship between P&A work and the legal system, P&A work is essential to driving systems change by establishing legal precedents for the rights of people with developmental disabilities. Statistics are derived from FY 2009 and FY 2010 Council Program Performance Reports.

<sup>34</sup> State of Delaware. "Universal Design in Housing." Accessed July 22, 2011. [http://www.youtube.com/watch?v=fLginqA\\_Cgg](http://www.youtube.com/watch?v=fLginqA_Cgg)

According to data compiled by ThinkCollege.net, a project supported by ADD grant funds to the Institute for Community Inclusion at the University of Massachusetts Boston, data from the national vocational rehabilitation database show that youth with intellectual disabilities who participate in postsecondary education were 26 percent more likely to leave vocational rehabilitation services with a paid job and earn a 73 percent higher weekly income.<sup>35</sup>

There are approximately 6,000 students with intellectual disabilities currently attending college, an experience that can make a tremendous difference in gaining employment.<sup>36</sup> The change is beginning to occur: during the past eight years, the number of college programs available for students with intellectual disabilities has grown from four to more than 250, spread across 36 states and two Canadian provinces.<sup>37</sup>

**Learning Academy supports furthering education.** The Learning Academy at the University of South Florida (USF) is a two-year, four-semester transitional experience designed to help students with Autism Spectrum Disorder achieve a life of opportunity, independence and success. The academy is a program of the Louis de la Parte Florida Mental Health Institute in the USF College of Behavioral and Community Sciences and funded as part of the Florida Center for Inclusive Communities (Florida UCEDD). It works to build and enhance skills that will prepare students for the world of work or to further their education in a college or university setting, with the provision of support and services that will facilitate success and provide the building blocks for future personal and professional goal attainment.

Students interested in seeking employment or continuing their education are eligible to apply regardless of whether their focus is employment or higher education. The Learning Academy graduated its first class in August 2010.<sup>38</sup>

**Parent advocacy: Working for our children.** P&As are also doing their part to support the educational needs of children and adults with developmental disabilities. For example, as part of its work in the past two years, the Connecticut P&A, the Office of Protection and Advocacy for Persons with Disabilities, provided parent advocacy training for a woman named Milagros. During her family's second year in the United States, her son was diagnosed with attention deficit hyperactivity disorder. The school her son attended did not provide the supports he needed to be successful. Milagros had not received the information she needed to navigate the educational system, so she reached out to community agencies for help. Through the Danbury Hispanic Center, the Connecticut P&A hosted training sessions that helped empower Milagros and other parents in their community and taught them how to be effective advocates for their children. Milagros has shared her knowledge with other parents and now supports them by attending Planning and Placement Team (PPT) meetings. A PPT is a group of professionals assigned to a specific school who are responsible for determining whether a child is eligible for special education services and for planning an Individualized Education Program for that child.<sup>39</sup>

In the past two years, P&As nationwide have successfully provided more than 20,000 students with the education and supports they need to reach their educational goals.<sup>40</sup>

**Continuing education for education.** In the past two years, the Ohio Council has supported three continuing education initiatives: Infant and Toddler Mental Health, Educational Options for Children, and Professional and Teacher Development Task Force.

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<sup>35</sup> Migliore, Alberto, John Butterworth and Debra Hart. "Fast Facts: Postsecondary Education and Employment Outcomes for Youth with Intellectual Disabilities." 2009. ThinkCollege.net. Institute for Community Inclusion at University of Massachusetts Boston. Accessed October 11, 2011. [http://www.thinkcollege.net/component/docman/doc\\_download/8-fast-facts-issue-1-pdf](http://www.thinkcollege.net/component/docman/doc_download/8-fast-facts-issue-1-pdf)

<sup>36</sup> Ibid.

<sup>37</sup> Grigal, M., Hart, D., and Migliore, A. "Think College: An Overview of National Research" Plenary Session, State of the Art Conference, George Mason University, Fairfax, Va. (October 2010)

<sup>38</sup> Florida Center for Inclusive Communities University of South Florida (Florida UCEDD) Annual Report, 2010.

<sup>39</sup> Office of Protection and Advocacy for Persons with Disabilities (Connecticut P&A) Program Progress Report, 2010.

<sup>40</sup> See Appendix.

These programs approach the issue of independence in and through education. The Infant and Toddler Mental Health initiative is a training program on the use of assessment tools for children in early intervention. Through this project, 51 infants and young children showed measurable improvement as a result of screening and assessment services, with 154 professionals trained on early childhood screening and assessment.

The Educational Options for Children initiative creates an informed advocacy base developed during preschool that works for positive systems change in the elementary education system. The project has trained 118 families on the educational rights of their children and involved 123 people (including teachers, administrators and policy makers) in facilitating inclusive education. The model for successful transition from early intervention to the educational setting is now used as a best practice by early intervention and education systems statewide.

The Professional and Teacher Development Task Force provided training to 429 educators and families to ensure that the new Ohio Teacher Standards that were adopted by the Ohio Board of Education were widely understood and applied in the state's school districts.<sup>41</sup>

Because of the work of the Ohio Council and other Councils around the nation in the past two fiscal years, more than 65,000 students have the education and support they need to reach their educational goals.<sup>42</sup>

**Interdisciplinary professional training: Starting at the college level.** The work of the Arizona Council is another example of efforts by DD networks nationwide to support the DD Act and ADD's mission to better serve individuals with developmental disabilities and ensure their independence in American society.

Arizona Council funds were provided to the Sonoran UCEDD of the University of Arizona to host 240 medical, nursing, social work, public health and law students participating in the second Inter-Professional Training Day on Disability. The training was designed to enhance the capacity of the health care service system to provide competent, caring services to individuals with developmental disabilities. Participation in the training day was required as part of the curriculum for students of the university colleges.

Students listened to a keynote speaker and watched a video of an adult with autism in her home environment. The students then worked together on case problems involving children and adults that emphasized medical, legal, service system and other issues. They shared their experiences and proposed solutions, and heard from a writer with a disability who has written about her experiences within the health care system.<sup>43</sup>

For many students, this program offered a unique opportunity to work in an interdisciplinary setting and develop problem-solving skills that relate to the diverse needs of cases involving individuals with disabilities.

This educational opportunity promoted understanding and competency in future service providers that will enable greater success for the overall disabilities community.

### *Transportation*

A person's ability to find and maintain employment, attend school, consult their choice of health care professionals, choose a place to live and participate in community activities is dependent on

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<sup>41</sup> Ohio Council Program Progress Report, 2009.

<sup>42</sup> See Appendix.

<sup>43</sup> Arizona Council Program Progress Report, 2010.

transportation to and from these locations. ADD's grantees work to increase the availability of accessible transportation that will allow individuals with disabilities to get to work, medical appointments and other activities that provide a degree of independence that would not be possible otherwise.

Councils across the United States are working to make accessible transportation available to individuals with developmental disabilities so they may continue to move independently in the areas where they live. In 2009 and 2010, Councils ensured that 29,794 individuals around the country had access to transportation services.<sup>44</sup>

**Transportation options for everyone.** The Idaho Council is involved in two projects dedicated to improving accessible transportation options throughout the state. The AmeriCorps Accessible Transportation Network project completed its second year with help from funds provided by the Council. The project was developed in response to the lack of transportation options that often isolate individuals with disabilities. The project has recruited and trained 11 AmeriCorps members and 67 volunteers to work on local transportation projects. The Accessible Transportation project has been able to leverage funds to purchase three accessible vehicles, provide ride vouchers in one area of the state and introduce new bus benches in another area.<sup>45</sup>

The Council also serves on the Interagency Working Group on Public Transportation, with the Council executive director selected as chair of the working group for 2009 through 2010. The group supports development of local services and provides input into Idaho's new mobility management plan that integrates locally identified needs into a statewide plan that focuses on the transportation user when developing mobility solutions.<sup>46</sup>

**Achieving equal access to education.** The Nevada P&A, the Nevada Disability Advocacy & Law Center (NDALC), has been involved in cases regarding bus transportation for children with disabilities. NDALC filed a complaint with the Office of Civil Rights for violations of Section 504 of the Rehabilitation Act of 1973, which guarantees children the right to full participation and access to free and appropriate public education. The P&A's complaint ultimately led to district wide policy changes regarding early release and transportation of students with disabilities. While the settlement agreement was limited to one district, the effect on all school districts within the state is clear: bus transportation must ensure that students with disabilities receive the same amount of instructional time that peers without disabilities receive. As a result of this complaint, district wide training on equal access rights under Section 504 was provided — a real example of systems change beginning at the self-advocate level.<sup>47</sup>

**Transportation systems solutions in New Hampshire.** One of New Hampshire's UCEDDs is undertaking efforts to support transportation improvement in their state. The University of New Hampshire's Institute on Disability has formed a coalition called Transportation Solutions New Hampshire to analyze existing transportation issues, provide information resources, and initiate policy changes that support movement toward a more sustainable, accessible transportation system. The coalition brings together businesses, service providers, government and advocates addressing the challenges and needs of the New Hampshire transportation system.

The coalition will build on existing research and resources developed in and outside the state to educate leaders about transportation needs and opportunities and will work with ongoing and new efforts within the state to ensure success.<sup>48</sup>

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<sup>44</sup> See Appendix.

<sup>45</sup> Idaho Council Program Progress Report, 2009.

<sup>46</sup> Ibid.

<sup>47</sup> Nevada Disability Advocacy & Law Center (Nevada P&A) Program Progress Report, 2010.

<sup>48</sup> University of New Hampshire Institute on Disability (New Hampshire UCEDD) Annual Report, 2009.

## *Financial Independence*

Another key marker of independence is the ability to manage one's money and finances. Many DD networks have addressed financial independence by providing supports and trainings for individuals with developmental disabilities and their families to not only help them build their finances but also to protect them from financial manipulation or exploitation.

**Asset building for financial independence.** The North Carolina Council reported that the Individual Development Account and Asset Building Collaborative of North Carolina and MDC, Inc., along with a project officer from the National Disability Institute, updated the Asset Building Toolkit for Persons with Disabilities. The toolkit provides information that people with intellectual and developmental disabilities can use to make the most of each dollar by taking advantage of asset development opportunities in their own communities. The kit contains information and activities in six modules, addressing topics from basic finances to tax credits, including the Earned Income Tax Credit.<sup>49</sup>

Asset building is a way for households to acquire the financial resources to get ahead, not just get by. For individuals with developmental disabilities and their families, it can be difficult to save and build a nest egg because of how financial support systems are structured. The toolkit represents a successful effort to support individuals with developmental disabilities as they move toward financial security and independence.

**Ending exploitation.** The West Virginia P&A, West Virginia Advocacy (WVA), participated in the West Virginia Financial Exploitation Task Force, a multi-agency committee whose mission is to empower individuals and create a culture and environment where vulnerable adults, including those with disabilities, are safe from financial exploitation. WVA is a member of the education/outreach subcommittee of the task force. WVA has been working with the subcommittee to create a self-advocacy brochure to educate vulnerable West Virginians about the threat of financial exploitation and how to seek remediation when victimized. The task force provided training to financial professionals on recognizing the warning signs of financial exploitation and is working to create a closer, more collaborative network of state and nonprofit agencies to address the issue of financial exploitation in West Virginia.<sup>50</sup>

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<sup>49</sup> North Dakota Program Progress Report, 2010.

<sup>50</sup> West Virginia Advocacy (West Virginia P&A) Program Progress Report, 2009.

## Chapter 5: Productivity

The DD Act defines productivity as the engagement in income-producing work that is measured by increased income, improved employment status, or job advancement or engagement in work that contributes to a household or community.

To that end, ADD's grantees worked in FY 2009 and FY 2010 to increase productivity through programs that encourage gainful, competitive, meaningful employment and the development of job skills. Productivity was also supported through strides made in securing access to technology that enables individuals to participate equally in activities.

### *Employment*

Employment is a critical component of community living for most adults, including people with intellectual and developmental disabilities. Work is not only the means to economic self-sufficiency, it is also an important way for individuals to contribute to their communities, build a network of social relationships and create opportunities for lifelong learning.

Obtaining competitive employment in an integrated setting can be difficult. DD networks across the United States have been working to ensure that all individuals with developmental disabilities have access to the employment opportunities that they desire and that allow them to be contributing members of their communities.

According to the research presented in the National Report on Employment Services and Outcomes by the Institute for Community Inclusion at the University of Massachusetts Boston, the percentage of individuals receiving integrated employment services declined to 20.3 percent in FY 2009.<sup>51</sup>

Education is one of the key determinants in employment success for students with intellectual and developmental disabilities. Even with a diploma, however, youth with intellectual disabilities demonstrate the lowest rate of paid employment among students with disabilities (29.8 percent), one to four years after exiting high school. Despite these statistics, individuals with intellectual disabilities can, and do, succeed in employment.

The majority of state DD networks work to improve integrated, community-based employment opportunities at competitive wages for people with intellectual and developmental disabilities. In 2010, 44 P&As and 39 Councils reported actively supporting employment.<sup>52</sup>

**Supporting self-employment.** The Alaska DD Council implemented START-Up/Alaska, part of the Alaska Works Initiative, to increase the self-employment of Alaskans with disabilities.<sup>53</sup> As a result, in FY 2009, 20 individuals completed business plans (a 150 percent increase from the previous year), 15 individuals completed a business feasibility study (50 percent increase), 19 individuals received startup financing (138 percent increase), 13 new businesses were created (63 percent increase), and 16 new businesses made their first sale or contract (23 percent increase).<sup>54</sup>

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<sup>51</sup> Ibid. p. 20

<sup>52</sup> See Appendix.

<sup>53</sup> Alaska Governor's Council on Disabilities and Special Education. "Alaska Works Initiative." Accessed November 28, 2011. <http://hss.state.ak.us/gcdse/projects/alaskaworks.htm>

<sup>54</sup> State of Alaska. "Health Planning and Systems Development." Accessed November 28, 2011. <http://hss.state.ak.us/dph/healthplanning/movingforward/initiatives/vulnerable.htm>

Similar to the Alaska Council, the Washington Council has also been working toward the goal of integrated, competitive employment for people with developmental disabilities by focusing on self-employment. The Council contracted with the Provident Horizon Group to develop a training curriculum for individuals with developmental disabilities who are interested in self-employment. The project assists these individuals through each stage of business planning, including marketing strategies and day-to-day business management. The project will work to identify systems barriers and policy issues that could be addressed to increase the likelihood of replicating the project in other areas.

The project has resulted in some unique partnerships, such as university students with potential business owners. The project's board has local, successful business owners who provide mentoring and business assistance to potential new business owners. Currently, 10 individuals are in the process of opening their own business through the assistance received through this project.<sup>55</sup>

**Project SEARCH: Work-based training, job skills development.** Through Project SEARCH, DD Councils work toward the goal of providing competitive, integrated employment opportunities and developing a range of customized employment services for individuals with disabilities.

Project SEARCH is an innovative work-based program that provides training in independent living, employability skills and specific job skills. The career program is offered to high school students as a school-to-work program, as well as to adults following graduation. The program originated in 1994 at University of Cincinnati Children's Hospital,<sup>56</sup> but now has grown to include more than 150 programs across 42 states and in four countries.

There are seven DD Councils (Arizona, Colorado, Florida, Georgia, New York, Ohio and Oklahoma) and three UCEDDs (Arizona, Indiana and New York) that support Project SEARCH interns in their offices.<sup>57</sup>

The Florida Council in particular made significant progress toward its goal of providing employment opportunities and services for individuals with disabilities. The directors of the original Project SEARCH at Cincinnati Children's Hospital and a Florida statewide coordinator provided training and assisted pilot sites in Florida in beginning activities, with an emphasis on identifying and establishing business partnerships, providing technical assistance and support, and monitoring and evaluating pilot sites. In 2009 and 2010, 16 individuals found gainful employment because of this effort, and another 245 individuals participated in direct training relating to employment.<sup>58</sup>

In the past two fiscal years, Councils whose work included an emphasis on employment reported they have assisted more than 7,000 Americans with disabilities to either maintain or obtain jobs of their choice.<sup>59</sup>

**Supporting mutually beneficial professional relationships.** Efforts by the Washington UCEDD and the Center on Human Development & Disability at the University of Washington also exemplify DD network support of productivity through employment. The University of Washington Employment Program (UWEP) works to create and support mutually beneficial relationships between people with disabilities and the businesses that hire them.

UWEP staff members serve and advocate for adolescents and adults with developmental disabilities and other types of physical and cognitive disabilities. The staff provides direct services to clients and works to ensure successful and equitable employment by working with employers, parents, agencies and other support personnel. Direct services include job development, job placement, job training and continued

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<sup>55</sup> Washington Council Program Progress Report, 2009.

<sup>56</sup> Cincinnati Children's Hospital is a current ADD UCEDD grantee.

<sup>57</sup> ADD Commissioner U.S. Senate Testimony, Committee on Health, Education, Labor and Pensions. March 2, 2011.

<sup>58</sup> University of Cincinnati UCEDD Annual Report, 2010.

<sup>59</sup> See Appendix.

employment support. UWEP collaborates with numerous agencies to provide employment services to individuals with developmental disabilities, works with the Division of Vocational Rehabilitation, King County Division of Developmental Disabilities, and is a member of the Seattle Chamber of Commerce. UWEP also works with the Washington Education Association to develop and deliver training on employment issues for youth with disabilities to teachers statewide.

Other activities include assessment and career exploration services for adolescents with disabilities that inform both school district personnel and rehabilitation counselors about student interests and aptitudes, and workshops on disability and employment issues for employers, community members and professionals. Recent UWEP workshops included “Technology and the Employment of Individuals with Intellectual Disabilities” and “Supported Employment for Individuals with Intellectual Disabilities.”<sup>60</sup>

**Connecting employers to candidates.** The Iowa Council funded a website for the Employer’s Disability Resource Network (EDRN) that was developed as a centralized point of contact for businesses to find qualified candidates and receive information about hiring. EDRN is a collaborative group of state, federal and community partners who work together to identify, develop and mobilize resources, supports and services that add value to Iowa businesses that hire persons with disabilities. Through its website, EDRN connects with businesses to communicate the benefits of hiring individuals with disabilities and provides information and support to help businesses retain quality employees. During this reporting period, three employers contacted the site to learn more about strategies to retain employees with developmental disabilities whose functional status had changed, and 23 employers contacted the network and announced that they had job openings and were interested in hiring people with disabilities.

Additionally, the Iowa Council played a role planning and implementing the State Employment Leadership Network focus groups and research in Iowa. The Council identified participants, sent information and invitations, and reviewed and synthesized the data by developing written reports.<sup>61</sup>

### *Technology*

Assistive technology improves the functional capabilities of individuals with disabilities. These devices, pieces of equipment and other products enable individuals with disabilities to adapt to environments and circumstances, making them productive members of society.

According to data collected by the National Information System for Assistive Technology and reported in the State of the States in Developmental Disabilities 2011 report, in FY 2009, 54 of 56 state and territory assistive technology programs provided 37,833 assistive technology device loans, 38 percent of which were loaned directly to individuals with disabilities.<sup>62</sup>

**Bridges to productivity: Assistive technology.** University Legal Services, the P&A in Washington, D.C., advocated on behalf of two families in search of accessible apartments at a housing development financed by federal Department of Housing and Urban Development subsidies and investment tax credits. University Legal Services submitted a complaint letter to the D.C. Department of Health Care Finance and an assisted living facility provider regarding the inaccessibility of one of the two certified Medicaid Assisted Living Facilities. In response to the complaint, the provider installed a stair glide and other assistive technology devices for residents who use wheelchairs.<sup>63</sup>

In Idaho, the parents of a 17-year-old with an intellectual disability and language delays contacted the P&A when his school district refused to provide appropriate services to enable him to remain in school.

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<sup>60</sup> University of Washington UCEDD Annual Report, 2010.

<sup>61</sup> Iowa Council Program Progress Report, 2009.

<sup>62</sup> Braddock, D, et al. The State of the States in Developmental Disabilities 2011. Coleman Institute for Cognitive Disabilities at the University of Colorado Boulder. 2011. p. 29.

<sup>63</sup> University Legal Services (Washington, D.C. P&A) Program Progress Report, 2010.

The P&A attended a meeting to discuss the child's program and the need for assistive technology. As a result of the P&A's intervention, the district agreed to provide the services through the summer and provide a language device to enable the student to communicate more appropriately in the classroom and in the community.<sup>64</sup>

The use of assistive technology creates a necessary bridge for individuals with disabilities to participate in an activity that they would have been excluded from previously. Through the self-advocacy of those individuals and many others around the country, school systems, employers, landlords and other public bodies are being held accountable to provide reasonable accommodations for individuals with disabilities.

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<sup>64</sup> Idaho P&A Program Progress Report, 2009.

## Chapter 6: Integration and Inclusion

In the DD Act, Congress finds that “disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society ...”<sup>65</sup>

For individuals with developmental disabilities, integration into all aspects of society is often achieved through access to community supports, services and technology that are coordinated to benefit each person’s unique strengths, resources, priorities, concerns and capabilities.

Throughout the 2009 and 2010 fiscal years, ADD and its grantees have worked to ensure that individuals with developmental and intellectual disabilities are receiving the appropriate support and services.

### *Quality Assurance and Community Supports*

Community supports are among the essential elements that enable individuals with developmental disabilities to become fully integrated and included in their communities. These supports can be threatened by tightening budgets and economic downturn. DD networks around the country have engaged in programming that works to ensure that accessible and flexible quality supports and services are available to individuals with developmental disabilities and their families.

Through these efforts, people with disabilities are helped both in the short term and in the long term as ineffective systems are either changed or discarded, meaningfully altering the way individuals with disabilities are supported in the future.

**Securing access to services and supports.** The Massachusetts Council partnered with the Arc of Massachusetts, an advocacy organization for people with intellectual and developmental disabilities, to form the Massachusetts Alliance for 21<sup>st</sup> Century Disability Policy partnership, or “MA21.” MA21 is a coalition of statewide cross-disability organizations formed to advocate for establishing a comprehensive disability policy that will ensure access to quality community services and supports for people with developmental disabilities. The efforts of MA21 resulted in more than 13,000 people receiving needed community supports. More than 1,900 people were active in systems advocacy and 80 more were trained to participate in fellowship, offering a unique opportunity for a person with developmental disabilities, or a family member, to gain expertise in disability issues and work with the Massachusetts DD network on a project that they propose, design and implement.<sup>66</sup>

Through the work of the Massachusetts Council and the MA21 partnership, supports and services are being maintained that enable individuals with developmental disabilities to safeguard their places in their communities. In the past two fiscal years, more than 300,000 individuals have benefited from quality assurance efforts by Councils across the United States.<sup>67</sup>

**Ensuring continual educational access.** In Tennessee, the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC UCEDD) received a two-year grant from the Tennessee Council to develop and implement a postsecondary education program for students with intellectual disabilities at

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<sup>65</sup> Public Law 106–402, Section 101

<sup>66</sup> Massachusetts Council Program Progress Report, 2010.

<sup>67</sup> See Appendix.

Vanderbilt University. The program, called Next Steps, is the first and only program of its kind in the state.

Working with university, medical center and community disability organizations, VKC faculty, staff and trainees have developed a two-year nonresidential certification program in the areas of education, social skills and vocational training. The UCEDD also developed a peer mentor program, disability studies classes, evaluation tools, an artist-in-residence program, and has built relationships with Project Opportunity (another VKC UCEDD program) and the Country Music Hall of Fame's Words & Music program, which allows students interested in exploring songwriting to do so with professionals.

Launched January 1, 2009, the program underwent a year of development and selection of the first cohort of students. The first six students joined the Vanderbilt campus in January 2010 and anticipate graduation in 2012.<sup>68</sup>

The VKC UCEDD was also involved in a continuous access effort collaborating with the other Tennessee UCEDD (Boling Center on Developmental Disabilities), the Tennessee Disability Law & Advocacy Center of Tennessee, the Tennessee Council on Developmental Disabilities, a transition specialist with the Mountain Plains Regional Resource Center, The Arc Tennessee, and other advocacy organizations. Beginning in 2006, these organizations worked together to open up community options for youth transitioning from the public school system into community services.

The transition specialist developed the Transition Outcomes Project (TOPS), a statewide transition program that focused on the student's goals for life after secondary school. During the first year of the program, 10 school districts participated in trainings and analysis of the changes that were made to improve the transition process of students leaving public schools and moving to post-secondary education or work. As a result of this collaborative effort, in 2010, all 138 school districts in Tennessee had incorporated TOPS for facilitating the post-secondary transition process.<sup>69</sup>

**Opening doors to the community.** For the Maryland Council, milestones in quality assurance and community living included the closure of the Rosewood Center in Owings Mills. The center was Maryland's largest institution. Rosewood Center was established in 1888 and was closed by the State of Maryland Department of Health and Mental Hygiene on June 30, 2009. The closure was long sought, and the Maryland Council sat on the Closure Advisory Committee to support a successful closure process. The Council advocated successfully for the individuals being displaced by the center's closure, limiting the number of people who would go into a forensics facility, and they advocated for the development of community-based services for individuals with co-occurring disabilities and those involved in the courts. Because of the Council's efforts, two people were transferred to another institution, 11 were transferred to a new forensics facility, two went into a nursing facility, and 148 were transitioned into the community.<sup>70</sup>

The Council developed a publication that featured stories and photos of people who moved into the community and will be used for education and advocacy. They also funded and aided the production of a documentary about the center's closure, "Departing Rosewood," which aired on PBS. The documentary followed a former Rosewood Center resident named Steven in his transition out of the institution and into an apartment of his choosing and a life of independence.<sup>71</sup>

Councils across the United States are opening doors and educating individuals with disabilities on their options for community living. More than 4,600 individuals with developmental disabilities have been

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<sup>68</sup> Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Tennessee UCEDD) Annual Report, 2010.

<sup>69</sup> National Association of State Directors of Developmental Disabilities Services. "Realizing the Intent of the DD Act: How the DD Network Advances the Independence, Productivity, and Integration of People with Intellectual and Developmental Disabilities." July 2011. Accessed November 28, 2011. [http://www.nasddds.org/pdf/DDNetworkPaper\(July2011\).pdf](http://www.nasddds.org/pdf/DDNetworkPaper(July2011).pdf)

<sup>70</sup> Maryland Council Program Progress Report, 2009.

<sup>71</sup> Maryland Public Television. "Departing Rosewood." March 23, 2011. Accessed September 13, 2011. <http://video.mpt.tv/video/1861668308/#>

supported by more than 20 Councils each year in the past two years to maintain or secure homes of their choice. This number, compounded by the numbers of individuals served by P&As, UCEDDs and various PNS programs in the area of housing, represents thousands of individuals with developmental disabilities who are now transitioning or learning how to transition into American communities simply through their living situation.<sup>72</sup>

According to a 2009 RISP report, *Status and Trends Through 2009*:

“On June 30, 2009, states reported providing residential supports to 122,088 people living in an estimated 89,639 homes owned or leased by the person or a roommate. The estimated 122,088 people with ID/DD living in homes owned or leased by a person with ID/DD on June 30, 2009 were 27.8 percent of all people receiving residential services in the congregate care, host family/foster care, and own home service types.”<sup>73</sup>

Additionally, “states reported supporting 599,152 people with ID/DD who were living in the home of a family member compared to 439,515 people receiving residential supports in a congregate care, host family/foster care or own home setting. Nationally, an estimated 57.5 percent of all people with ID/DD receiving support lived in the home of a family member,” the report states.<sup>74</sup>

The report also provided the following promising news: “Between 2005 and 2009 the average daily population of large state facilities declined an average of 1,646 people per year (4.0 percent). This was a faster rate of depopulation than the average annual decrease of 3.1 percent between 2000 and 2004.” Although the rate of depopulation between 2005 and 2009 was lower than the rates seen in the 1990s (4.8 percent per year between 1990 and 1994; 5.2 percent per year for 1995–1999), it is still significant.<sup>75</sup>

Coupled with the numbers of individuals who are living in their own homes or homes owned by family members, this means that more individuals with developmental disabilities are joining society.

### *Family Support Initiatives*

Family Support Initiatives provide an opportunity for ADD to support projects that rely on collaborative efforts and community-based solutions to reach unserved and underserved families, and to encourage systemic change and improved community capacity to support families of individuals with developmental disabilities.

**Emergency Preparedness Special Initiatives.** In FY 2009, ADD awarded 12 PNS grants to plan multi-agency partnerships to design emergency preparedness planning projects to assist unserved and underserved families with a member who has a disability. The applicants were asked to pool resources, coordinate services and share expenses in order to effectively train individuals with developmental disabilities and family members to prepare for emergencies. ADD provided planning and implementation grant opportunities to create one-stop centers to assist the families of individuals with developmental disabilities.

Empowering individuals with developmental disabilities and their families to respond to emergencies and prepare for transitions during emergencies enhances their ability to maintain more independent lives.

The University of Hawaii at Manoa was the recipient of another Emergency Preparedness PNS grant. The UCEDD worked to identify and define the needs, resources and training necessary to assist individuals

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<sup>72</sup> See Appendix.

<sup>73</sup> Lakin, K. et al. “Residential Services for Persons with Developmental Disabilities: Status and Trends through 2009.” 2010. p. 70. Accessed July 13, 2011. <http://rtc.umn.edu/risp09>

<sup>74</sup> Ibid.

<sup>75</sup> Ibid. p. 6.

with developmental disabilities and families during emergency transitions by establishing a collaborative relationship among agencies, community resources and individuals with a disability. This project aids development and implementation of educational opportunities for individuals and their families to build independence, community relationships, local allies, integration, and awareness of resources with respect to emergency preparedness. It also coordinates an inclusive single-point-of-entry information system for the trainings and resources related to emergency preparedness.

In addition, this emergency preparedness project equitably increases the resilience of diverse cultural and geographic populations through training communities' most vulnerable members to be preparedness trainers. These individuals are further strengthened to assume leadership positions within their natural cultural and geographic community as preparedness resources.

The advisory council held a statewide summit on Oahu in May 2010. Because Hawaii had a tsunami emergency alert the weekend prior to the summit, people came prepared to discuss what worked, what needs existed, and what information was unknown throughout the community. Summit participants agreed that there was a lack of a single source of information; a consistent user-friendly method to access resources; and sustainable, flexible training to assist individuals with developmental disabilities and their families to prepare for upcoming emergency transitions.

Additionally, the attendees identified an educational curriculum developed in California as a possible training tool. The curriculum, *Feeling Safe Being Safe*, was pilot tested by the Hawaii UCEDD (with help and technical assistance from the California UCEDD) and stakeholders agreed that with the proper support and training, it would be acceptable for the diverse needs of individuals and families in Hawaii.

The project conducted formal meetings and maintained regular contact with the advisory council throughout the planning grant to begin developing a one-stop system for individuals with developmental disabilities and their families by reporting on progress, facilitating discussion and building consensus for an implementation plan that would meet the needs of stakeholders and be sustained within the community. They determined target populations for the services, appropriate outreach methods, referral systems, and the types of supports that should be provided.

Once the systems associated with this project are fully in place, they will be a vital set of supports for individuals with disabilities and their families facing transitions or challenges associated with emergency preparedness.<sup>76</sup>

**Family Support 360.** The New Jersey Institute for Developmental Disabilities is the recipient of a number of PNS grants. It administers the grant for the Alianza Family Support 360 Center in Perth Amboy, NJ. It is what is called a “wrap-around” program for teenagers and young adults with developmental disabilities and has partnered with other community agencies and faith-based groups to serve hundreds of families with referrals and to help them navigate available services. The center serves populations who not only have developmental disabilities, but also have mental health diagnoses, are involved with the juvenile justice system or are young mothers with children.<sup>77</sup>

AK 360, part of the Family Support 360 program in Alaska, helps not only individuals with disabilities, but their families as well. Services and supports are available for any family member as needed, not just the member with the disability. One woman named Amanda, whose daughter, Faith, was born with cerebral palsy, was aided by the AK 360 program.

“Having a vehicle with a working ramp is essential for families caring for a child with CP since many require the use of a CP wheelchair,” Amanda writes. When the ramp on Faith’s family vehicle needed

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<sup>76</sup> University of Hawaii at Manoa (Hawaii UCEDD) Year-End Grants Report, 2009.

<sup>77</sup> New Jersey Institute for Developmental Disabilities Year-End Grants Report, 2009.

repair, the family sought assistance from AK 360. Through funding available to them, the Military Family Support for Alaska was able to repair the ramp on the family's van. Now Amanda, Faith and Faith's sisters Ellie and Kim can attend various doctors' appointments, and go to museums and their favorite store, Build-A-Bear Workshop, with ease.<sup>78</sup>

**Military Family Support 360.** The Statewide Parent Advocacy Network of New Jersey's Military Family 360 Center provided assistance to at least 30 military families of children with developmental disabilities in 2009 and 2010. The SPAN program is geared toward what the military calls EFMs, exceptional family members, or people with disabilities, helping them secure the medical support and services they need and providing advocacy to help them access special health plans or educational services.

The program helps an estimated 1,000 exceptional family members of Army, Air Force and Naval personnel navigate new educational, health care and service delivery systems, as well as the pitfalls and challenges associated with individuals with developmental disabilities living in a military family environment.<sup>79</sup>

In FY 2010, 3,823 youth were served by the FS360 Projects of National Significance and 4,471 families were served.<sup>80</sup>

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<sup>78</sup> Alaska Family Support 360 Semi-Annual Report, 2010.

<sup>79</sup> Statewide Parent Advocacy Network of New Jersey Year-End Report, 2010.

<sup>80</sup> Compiled from year-end reports from all FS360 grantees.

## Chapter 7: Training and Technical Assistance

ADD employs training and technical assistance to help meet and advance ADD's mission as mandated by the DD Act. Training and technical assistance can be used when a grantee needs to address an issue it cannot handle independently. It may wish to tackle a problem that crosses state lines, or may need assistance to carry out its work in a manner that is both responsive to the needs of its clients and efficient in its use of taxpayer dollars.

Training and technical assistance can take many forms. Contractors can help build capacity for greater service, provide training to personnel, improve inter-grantee communication, facilitate cross-grantee collaboration, streamline administrative processes, collect information, implement technology advances and provide expert advice in a wide range of areas. Technical assistance provides a greater ability for ADD and its grantees to meet ongoing needs and sustain progress toward more successful, fulfilling lives for individuals with developmental disabilities.

In the past two fiscal years, ADD provided training and technical assistance to each of its grantee programs through contracts with a number of organizations:

- UCEDD Resource Center, implemented under contract by the Association of University Centers on Disabilities (AUCD), which provides technical assistance to UCEDDs.
- Training and Advocacy Support Center (TASC), implemented under contract by the National Disability Rights Network (NDRN), which provides technical assistance to state P&As.
- Information and Technical Assistance for Councils on Developmental Disabilities by the National Association of Councils on Developmental Disabilities (NACDD), which provides technical assistance to state Councils through the Information and Technical Assistance Center for Councils (iTACC) contract.
- BETAH Associates, which provides technical assistance to the PNS family support grantees.

### *Technical Assistance for UCEDDs — Association of University Centers on Disabilities (AUCD)*

For more than 20 years, AUCD has served as the ADD technical assistance contractor for the national network of UCEDDs. AUCD supports its members in research, education and service activities by disseminating information; providing training, research, expert advice and guidance; facilitating electronic information sharing; and serving as a resource for federal and state policymakers. AUCD also undertakes other activities that promote the viability and use of UCEDD resources and expertise nationally and internationally.

AUCD hosted ADD's annual technical assistance institutes for UCEDD grantees. In 2009, the institute was held June 1–2 in Washington, D.C. Attendees participated in sessions on leadership development, strategies for achieving broad-based diversity in the network, and accountability, and received updates from ADD and AUCD. In 2010, the institute was held April 22–23 in Washington, D.C., where attendees received updates from ADD and AUCD, and attended sessions on health care reform, implications of state budget cuts on disability services, and Medicaid trends and predictions.

Additionally, AUCD carried out the following activities during FY 2009 and FY 2010:

**Information dissemination.** AUCD led the dissemination of topical information from multiple UCEDDs and others whose work affects the lives of individuals with developmental disabilities. They disseminated the information through multiple channels: electronic newsletters, papers and/or reports, topical pages on the UCEDD Resource Center website, and state-of-the-art Internet technologies such as real-time online discussions, multipoint video conferencing, and web-based audio/video broadcasts on emerging topics

that affect individuals with developmental disabilities and their families. AUCD also monitored multiple sources of information on topical areas related to developmental disabilities and UCEDD operations, and disseminated relevant information to the network of 68 UCEDDs through four types of electronic newsletters: *Announcements* (produced 50 issues of the weekly newsletter), *Resources* (24 issues of the biweekly newsletter), *Funding Opportunities* (51 issues of the weekly newsletter), and the *AUCDigest* (11 issues of the monthly newsletter).

**Developing and maintaining UCEDD resource webpage.** AUCD developed, launched, maintained and updated the UCEDD Resource Center webpage ([www.aucd.org/urc](http://www.aucd.org/urc)) with:

- ADD information, the DD Act, related resources, archived UCEDD Resource Center events, meetings, and webinar resources.
- General information about UCEDD grants, guidance on continuation applications and grant modifications, grant management documents and historical documents.
- UCEDD annual report requirements, technical assistance materials and workgroup meeting notes and materials.
- ADD Monitoring and Technical Assistance Review System resources, tool, schedules, and related resources.
- Guidelines for onsite technical assistance visits.
- Promising practice briefs and Consumer Advocacy Council orientation curriculum.
- National Training Initiative materials.
- Additional ADD project information and resources.
- Two AUCD-developed promising practice briefs.

**Convening conferences, maintaining communication.** AUCD maintained communication with UCEDDs, workgroups, partners and funders through conference calls, online meetings, video chat, conferences and other means to inform the development of all technical assistance activities. AUCD also disseminated relevant results through compilation, analysis and dissemination of state-of-the-art training, research policies and annual publications of innovative practices.

During FY 2009 and FY 2010, AUCD undertook activities to convene UCEDD leadership and members:

- Convened and facilitated a one- and a half-day annual Directors Technical Assistance Meeting.
- Coordinated and convened network partner collaboration meeting for UCEDDs, Councils and P&As.
- Planned sessions to address issues related to UCEDD senior leadership development and culturally and linguistically diverse backgrounds.
- Convened two meetings of project advisory committee to solicit input regarding national emerging needs and feedback on implementation of technical assistance contract.
- Maintained web portal with links to each of the 68 UCEDD websites and updated a UCEDD directory with contact information for each center, its leadership and key staff.

**Designing and implementing technical assistance.** AUCD designed and implemented targeted technical assistance to support UCEDDs as they carry out the mandated core functions and address specific topical issues. Technical assistance was administered through training events, annual Directors Technical Assistance Meetings, onsite technical assistance visits and web-based outlets. Onsite visits to UCEDDs were conducted in Arkansas, California, Connecticut, Delaware, Georgia, Massachusetts, New Hampshire, Oregon and Virginia.

**Technical assistance for reporting requirements.** AUCD provided assistance for ADD reporting requirements and the evaluation of overall program performance through maintenance of the National Information Reporting System (NIRS); annual trainings and regular conference calls with UCEDD data coordinators; annual Directors' Technical Assistance Meetings; rapid response technical assistance;

systematic review, including measurement measures, to further develop and revise the ADD reporting system; and onsite technical assistance. AUCD participated in the following activities:

- Implemented new data coordinator orientation.
- Facilitated annual report workgroup with monthly conference calls and in-person meetings to develop logic models informing the UCEDD annual report.
- Solicited UCEDD input for design changes to NIRS.
- Developed design specifications and implemented changes for NIRS to support UCEDD annual report modifications and network recommendations.
- Provided technical assistance on annual report modification changes at annual Directors' Technical Assistance Meeting.
- Held webinar introducing NIRS changes to UCEDDs.
- Provided ongoing technical assistance by e-mail and phone to UCEDDs to solve problems, support data entry in NIRS, and develop annual report.
- Provided ADD with electronic copies of UCEDD annual reports.<sup>81</sup>

### *Technical Assistance for P&As — National Disability Rights Network (NDRN)*

The Training Advocacy and Support Center (TASC) contract is designed to improve program performance, statutory compliance and systems change across the P&As. NDRN provides training and technical assistance to the 57 P&As across the United States and its territories that protect the interests of individuals with disabilities. TASC provided training and technical assistance to help P&A staff members enhance their ability to effectively advocate on behalf of all people with disabilities.

NDRN involved the P&As in directing technical assistance toward the most critical needs and in identifying and providing technical assistance resources. NDRN recruited P&A staff, board and committee members to sit on TASC advisory committees that provide advice on technical assistance issues to the contractor and federal staff, and devote time to technical assistance resource development through their members.

In 2010, as a result of NDRN's technical assistance work for P&As:

- 51 percent of participating P&As indicated that they have improved their skills in protecting individuals from abuse and neglect.
- 57 percent have improved their skills for pursuing legal or administrative remedies.
- 61 percent have indicated that they have improved their skills in providing information and referrals.
- 74 percent indicated that they have improved their skills at engaging in advocacy or self-advocacy.
- 38 percent indicated that they have improved their skills at engaging in priority setting or governance activities, including changing questions to meet the client's level of understanding and stressing self-advocacy rather than just advocating.

NDRN carried out a wide range of activities under the TASC contract:

- Staff resources were made available to P&As by e-mail and phone, with experts providing consultation on disabilities law, organizational management and board management. Additionally, staff responded to more than 800 programmatic issues per year, especially with regard to abuse, neglect, seclusion, restraint, community integration and ADA compliance. Staff also responded to nearly 200 P&A management related issues per year.

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<sup>81</sup> AUCD Contract Year-End Reports, 2009 and 2010.

- Training meetings and problem-solving conferences were provided to nearly 1,000 trainees per year (e.g., annual CEO Meeting, new CEO training, annual Fiscal Manager Meeting, new fiscal manager training, annual Legal Directors Meeting and a general Annual TASC Conference).
- Teleconferences and web-based training addressed emerging issues, such as trainings on new provisions in the Individuals with Disabilities Education Act, which was carried out in six sessions with about 60 attendees per session.
- Onsite training addressed needs specific to individual P&As or to a regional group of P&As. Such training was carried out for P&As in the Pacific Rim that face high costs in attending most other trainings. Onsite trainings were conducted on board member roles, strategic planning and management issues.
- Two monthly newsletters (a general P&A issues newsletter and a legal issues newsletter) were produced.
- Maintained a website dedicated to TASC that features a calendar of technical assistance events and resources such as dockets (a compendium of legal advocacy being carried out by other P&As) and manuals in areas of P&A best practices.
- Manuals were developed to provide guidance to P&A managers on issues and best practices (e.g., outreach practices manual, access issues manual, communications handbook, guide to practice for P&A attorneys, information and referral manual).
- Listservs were managed for issues such as legal advocacy, abuse and neglect, and education.
- Three Legal Backup Centers are subcontracted to develop technical assistance resources and provide legal advice and support in highly specialized areas of disabilities law, such as foster care, Medicaid and health care, and conditions in communities and institutions. They have responded to more than 700 requests for technical assistance, supported nearly 90 legal actions, and developed nearly 50 written technical assistance pieces per year.
- NDRN continued its Passport to Advocacy learning program, which structures training for non-attorney advocates.<sup>82</sup>

### *Technical Assistance for Councils — National Association of Councils on Developmental Disabilities (NACDD)*

Similar to the technical assistance contract for P&As, the Council technical assistance contract works to improve program performance, statutory compliance and systems change across the network of Councils in the United States. The contractor, NACDD, is expected to identify program-specific and/or cross-cutting initiatives that will be undertaken to support the improvement of Council operations and performance.

In FY 2009 and FY 2010, NACDD used federal and non-federal experts to provide technical assistance through a wide array of methods, such as onsite consultations, annual training events and webinars.

**ADD technical assistance institutes.** The 2009 Technical Assistance Institute was held in Arlington, Va., July 27–28 and was attended by 142 people. The theme for the institute was Shared Commitment — Shared Results. Keynote sessions centered on collaboration strategies and system change. Additional 2.5-hour sessions offered discussion and interaction on topics such as employment initiatives, use of data in strategic planning, and collaboration.<sup>83</sup>

<sup>82</sup> NDRN Contract Year-End Reports, 2009 and 2010.

<sup>83</sup> iTACC. *iTACC 2009 Annual Report*. Accessed August 1, 2011.

[http://www.itacchelp.org/uploads/TA\\_Contract\\_FY\\_2009\\_Annual\\_Report\\_102109.doc](http://www.itacchelp.org/uploads/TA_Contract_FY_2009_Annual_Report_102109.doc)

**Information dissemination.** The Information and Technical Assistance Center for Councils (iTACC) hosted a website that is the primary information dissemination vehicle to Councils, and operated a listserv that saw a 61 percent increase in postings from FY 2008 to FY 2009.<sup>84</sup>

**Rapid response.** Through iTACC, NACDD assisted the Councils in carrying out congressionally mandated activities by providing Council members, staff and executive directors with access to information, technical assistance and training resources quickly. In FY 2009, 119 requests were received and completed by iTACC staff.<sup>85</sup>

**State Council Five-Year Plans.** NACDD assisted with revising the Council Five-Year Plan template to improve the planning process. The Five-Year Plan is a strategic tool that the Councils use to guide their work. It includes long-term goals and provides guidance to Councils for using resources. The new template emphasizes the use of national data sets, such as the State of the States in Developmental Disabilities and the American Community Survey; focuses on emerging issues in health care and long-term services and supports, particularly related to the Affordable Care Act; and calls for more relevant competitive, integrated employment opportunities for people with developmental disabilities.<sup>86</sup>

#### *Technical Assistance for Projects of National Significance: Family Support – BETAH Associates*

ADD funds a contract to BETAH Associates to provide technical assistance to ADD's family support grantees. Awarded in FY 2009, this contract promotes knowledge sharing, collaboration and understanding; builds skills; and facilitates collaborative problem solving among Family Support 360 grantees. Achievements included:

- Provided training and technical assistance to 17 grantees (FY 2010).
- Grantees completed 514 family service plans (FY 2010).
- Grantees reported conducting 5,022 information and referral activities.
- The technical assistance website received 7,289 visits.
- The Family Support 360 Technical Assistance Institute, held July 2010, with a theme of Family Support 360: Reach. Educate. Connect, received a 3.63 out of 4.00 rating from the grantees, reflecting its effectiveness.<sup>87</sup>

#### *Information Collection and Dissemination*

ICF International supported the Developmental Disabilities Program Information Resources Management (PIRM) contract. ICF ensured that program information resources generated by ADD and its grantees were collected, analyzed, synthesized and disseminated using techniques that provide maximum utility to ADD stakeholders. The PIRM contract provided technical assistance for online data collection, statistical and analytical reports, and development and maintenance of the ADD Internet and intranet sites, as well as publication, production and information dissemination.

**Online data collection.** Grantees in ADD's three primary grant programs (Councils, P&As, and UCEDDs) submit annual performance and annual state plan reports to ADD using the U.S. Department of Health and Human Services Online Data Collection (OLDC) tool and the newly implemented DD Suite tool. The OLDC system makes it possible for ADD to meet the reporting requirements of the DD Act and the Government Performance and Results Act of 1993. ICF provided technical assistance to ADD's grantees and staff.

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<sup>84</sup> Ibid.

<sup>85</sup> Ibid. (Data for FY 2010 is not yet available.)

<sup>86</sup> NACDD Contract Year-End Report, 2009 and 2010.

<sup>87</sup> BETAH Associates Contract Year-End Reports, 2009 and 2010.

**ADD websites.** ADD's Internet and intranet sites are crucial for providing information to ADD grantees, the disability community and the general public. The PIRM contract provided development and maintenance for these sites and ensured that all online content is accessible and section 508 compliant.

**Publications.** ICF used the material gathered through online data collection and other reporting systems to develop multiple publications and communications materials for ADD. Under this contract, ICF wrote and/or edited all ADD publications, including web content; ADD's newsletter, the *ADD Update*; various brochures providing an overview of ADD's programs and successes; and this Biennial Report to Congress, the President and the National Council on Disability.

## Chapter 8: Interagency Collaboration

Interagency collaboration is an essential part of the work conducted to ensure the successful implementation of the DD Act and positive, productive futures for individuals with developmental disabilities across the United States.

Given the complexity of federal, state and local programs and services that touch the lives of individuals with disabilities, cross-agency dialogue is essential to address the challenges and issues facing this group.

ADD has undertaken many partnerships and collaborative efforts over the past two fiscal years:

**Community Living Initiative.** ADD was part of the communications, housing and workforce subgroups in 2009 and 2010 for the initiative, which was created in June 2009 by the Department of Health and Human Services (HHS) to promote federal partnerships that advance the directive of the *Olmstead* decision. It develops and implements strategies that increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living. ADD participates in three of five working groups that carry out the overall goals of the Community Living Initiative.

Through the housing group, workforce and communications strategy groups, ADD identifies ways to create more affordable and accessible housing opportunities for people with disabilities and older people, and explores ways to better support both paid and unpaid caregivers, and consider solutions to recruitment and retention challenges related to community-based services. ADD also develops ways to promote communication between HHS and the community about the collaboration, identifies provisions that expand services and access to services, and obtains feedback from the community regarding the effectiveness of the initiative.

**2402(a) workgroup.** For the past 30 years, federal, state and local governments have incorporated Home and Community-Based Services (HCBS) into programs for people with disabilities across the lifespan. Significant variation in the definitions and applications of various aspects of HCBS persists across programs funded by HHS. Some public payers have developed specific regulations and guidance regarding key components of HCBS; other public payers have been less clear in their approach (or may have no organized approach) to HCBS.

In an attempt to provide guidance to stakeholders on key aspects of HCBS, the HHS Office on Disability has convened a workgroup of representatives from key HHS agencies to implement section 2402(a) of the Affordable Care Act, "Oversight and Assessment of the Administration of Home and Community Based Services." Section 2402(a) gives the Secretary authority to encourage states to create an HCBS system that is designed to provide individuals, their families, caregivers or other representatives the support and coordination needed to design an individualized, self-directed, community-supported life.

The workgroup is comprised of representatives from the following HHS agencies:

- Centers for Medicare & Medicaid Services (CMS)
- Substance Abuse and Mental Health Services Administration
- Office for Civil Rights
- Administration for Developmental Disabilities
- Health Resources and Services Administration
- Administration on Aging
- Assistant Secretary for Planning and Evaluation
- Indian Health Services

The 2402(a) workgroup developed consensus on several of the key areas of section 2402(a). These include the following topics:

- Overview of HCBS
- Participant direction
- Person-centered planning
- Quality and system improvements
- Participant rights and safeguards
- Provider qualifications and workforce development

ADD contributed to the group effort to reach consensus on these important policy areas. The workgroup is close to finalizing all these topic areas, pending the completion of the CMS rulemaking process.<sup>88</sup>

**Expanding Opportunities with the Office of Child Care.** ADD continued its participation in Expanding Opportunities with the Office of Child Care (formerly Child Care Bureau), Office of Head Start and the U.S. Department of Education Office of Special Education Programs supporting Kentucky, Michigan and Texas in 2009 and Hawaii, New York and Utah in 2010. Each year, cross-agency teams from three or four states participate to develop and implement plans with the goal of increasing inclusive opportunities for young children with disabilities to improve the quality of early care and educational programs and services in their communities, and to make their findings and resources available to other states.

ADD participated in conference calls to discuss the process for identifying participating states, assisted in review of applications to determine participating states, notified UCEDD and contract staff regarding procedures for participation and support, and implemented an evaluation of the initiative.

**Interagency Autism Coordinating Committee.** The ADD Commissioner is a federal member of the Interagency Autism Coordinating Committee (IACC), serving on the Services Subcommittee, the Subcommittee for Planning the Strategic Plan Updating Process, and serving as a co-chair of the Subcommittee on Safety. ADD also attended committee and subcommittee meetings, served as co-facilitator for Panel 1 of the 2009 Scientific Workshop, and edited Chapter 1 of the Strategic Plan in 2009 and 2010.

The IACC is a federal advisory committee that coordinates all efforts with HHS concerning autism spectrum disorder. Through its inclusion of both federal and public members, the committee helps ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

**Interagency Coordinating Committee on Emergency Preparedness.** ADD staff members attended and contributed to the committee and subcommittee meetings for the Interagency Coordinating Committee on Emergency Preparedness and People with Disabilities, which was established to ensure that the federal government appropriately supports safety and security for individuals with disabilities in disaster situations.

The committee considers and encourages the facilitation of the unique needs of agency employees with disabilities and individuals with disabilities whom the agency serves, and coordinates the implementation of emergency preparedness plans as they relate to individuals with disabilities among federal, state, local and tribal governments and private organizations and individuals.

**Early Learning Initiative work and the 2010 Early Childhood Summit.** ADD's contribution includes participation in large and working group meetings, actively providing ideas and feedback on a number of documents. ADD also supported planning and implementation for the Department of Education (ED) and HHS Joint Early Childhood Summit in August 2010, and disability content was included in the sessions.

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<sup>88</sup> 77Fed. Reg. 26232 (May 3, 2012)

Work conducted for the August meeting included recruiting speakers; arranging planning meetings; facilitating panels at the meeting; serving as the liaison between federal partners and AUCD, who were conducting the evaluation; and contributing to post-meeting de-briefing with federal partners and contractors.

The summit brought together HHS grantees, including those from ADD, and ED grantees, as well as representatives from state agencies and more than 50 national organizations to discuss new approaches to unlocking the potential in all American children. The summit was designed to improve collaboration at the federal, state and community levels in support of a more integrated early childhood system of services.

**Federal Partners in Transition workgroup.** The workgroup allows federal agency staff to discuss and share information about what their respective agencies are currently doing or planning to do in the area of transition. In collaboration with representatives from the National Council on Disability, the Departments of Education, Justice, Labor and Transportation, the Equal Employment Opportunity Commission and the U.S. Social Security Administration, ADD and other offices within HHS compiled a Transition Resource Directory that provides descriptions of federally-supported projects and centers that focus on youth transitions.

**National Conference on Child Abuse and Neglect.** ADD staff participated in the 17th National Conference on Child Abuse and Neglect in 2009, which led to an invitation for participation in the interagency committee as a federal partner by the Office on Child Abuse and Neglect.

**Institute of Medicine Study of Epilepsies.** Staff represented ADD and ACF at the Assistant Secretary for Health meeting on epilepsies, providing information about ADD's programs. ADD will contribute funding for a study of epilepsies. As part of this continued funding, ADD also participated in agency calls to discuss the request for proposal, actively providing input to better reflect the ADD values in the study.

The Institute of Medicine study of epilepsies will consider the public health dimensions of epilepsies in the United States, including health care and human services, health literacy and education. The Institute of Medicine will recommend priorities in these areas to better understand the public health impact of epilepsies and to meet the needs of people with epilepsy and their caregivers.

**Federal Partners workgroup meetings.** Staff participated in monthly conference calls of various federal agencies in HHS concerned with early childhood issues.

## **Conclusion: Envisioning the Future**

This report offers examples of the successful implementation of each of the core values defined by the DD Act: self-determination, independence, productivity, and inclusion and integration. ADD grantees have worked tirelessly to embody these values and achieve their goals of providing a better, more fulfilling life for individuals with developmental disabilities.

ADD's work to strengthen health care and supports, increase employment opportunities, expand educational opportunities, protect civil rights, promote access to community living, and support the development and use of accessible technologies has successfully supported the opportunity for brighter futures for Americans with developmental disabilities.

ADD's work supports approaches that shape attitudes, raise expectations, change outdated or broken systems and empower individuals with disabilities to pursue the lives they imagine for themselves. To that end, ADD provides financial and leadership support to organizations in every state and territory in the United States. These bodies assist individuals with developmental disabilities of all ages and their families with obtaining the support they need to achieve all the aspects of a life envisioned and defined by the DD Act.

With this focus in mind, in 2010 ADD held listening sessions around the country and hosted an online submission process for individuals to voice their needs, opinions and concerns. Nearly 800 people representing all 50 states, Puerto Rico, Guam and Washington, D.C. participated in person at the summits, which were held in Philadelphia, Orlando, Dallas, Detroit, Denver and Washington, D.C. About 4,000 online submissions were also collected. The foundational themes of the comments included self-advocacy and individual empowerment, improving access to home and community-based services and supports, and employment first initiatives. From this valuable feedback, a strategic framework will emerge that will shape the future policy and implementation activities of the ADD.

ADD and its network continue to support the changing needs of individuals with developmental disabilities and evaluate their quality of life so that more effective solutions can be devised.

Now, more than ever, these and other collaborations between service systems and the individuals they support, among state and federal government agencies, and across the DD network are essential to ensuring success and a brighter future for all.

## Appendix: Program Performance Reports

### Outcome Measures for Protection & Advocacy Agencies (P&As) — Selected Outcome Data

Areas of Emphasis: Core Outcomes		FY 2009		FY 2010	
		Individuals	Number of P&As	Individuals	Number of P&As
<i>Area of Emphasis</i>	<i>Description</i>				
Employment	Adults have jobs of their choice	410	41	309	44
Education	Students have education and support they need to reach their educational goals	11,629	56	9,097	57
Housing	Individuals have homes of their choice	546	50	518	53
Health	People have needed health services	2,068	53	1,797	52
Child Care	Children in inclusive child care settings	80	27	130	22
Transportation	People have transportation services	126	34	126	34
Recreation	People active in recreational activities	95	23	111	30
Quality Assurance	People benefiting from quality assurance efforts of P&As	5,726	56	5,613	56
Complaints of Abuse, Neglect, Discrimination or Rights were Remedied	Complaints were addressed and situations were resolved	9,000	56	9,156	56

## Outcome Measures for Developmental Disability Councils (Councils) — Selected Outcome Data

The DD Act directs Councils to spend funds on initiatives recommended by people with developmental disabilities, family members and advocates. The law does not require Councils to engage in activities in each area of emphasis, thus the data reflects what people in a state consider important.

The outcome measures shown below are a representative sample of outcome measures reported in the annual Program Performance Report.

Areas of Emphasis: Core Outcomes		FY 2009		FY 2010	
		Individuals	Number of Councils	Individuals	Number of Councils
<i>Area of Emphasis</i>	<i>Description</i>				
Employment	Adults have jobs of their choice	3,502	38	3,527	39
Education	Students have education and support they need to reach their educational goals	38,561	32	29,153	31
Housing	Individuals have homes of their choice	2,399	22	2,278	22
Health	People have needed health services	17,137	30	15,130	31
Child Care	Children in inclusive child care settings	537	6	601	9
Transportation	People have transportation services	15,520	19	14,274	21
Recreation	People active in recreational activities	5,655	19	6,189	20
Quality Assurance	People benefiting from quality assurance efforts of the Council	149,366	47	151,564	49
Formal/Informal Community Services	Individuals benefiting from formal/informal community services	57,209	39	61,277	44

**Outcome Measures for University Centers of Excellence in Developmental Disabilities Education, Research and Service (UCEDDs) — Selected Outcome Data**

<b>Areas of Emphasis: Core Outcomes</b>		<b>FY 2009</b>		<b>FY 2010</b>	
		Individuals	Number of UCEDDs	Individuals	Number of UCEDDs
<i>Area of Emphasis</i>	<i>Description</i>				
Research	Number of researcher activities undertaken	157,719	58	73,635	56
Technical Assistance	Interdisciplinary pre-service preparation and continuing education	1,574,751	61	1,167,329	61
Direct Services	Direct or model demonstration services	99,963	47	183,960	54
Information Dissemination	Number of individuals reached through information dissemination	2,678,548	60	4,551,748	58
Trained	Number of professionals trained	4,563	61	4,922	63

**Outcome Measures for Projects of National Significance — Selected Outcome Data**

		<b>FY 2009</b>	<b>FY 2010</b>
Number of Families Served by Projects of National Significance	Family Support	2,391	4,471
Number of Youth Served by Projects of National Significance	Youth	1,105	3,823

## **Contact ADD**

Administration on Intellectual and Developmental Disabilities  
Administration for Community Living  
U.S. Department of Health and Human Services  
370 L'Enfant Promenade, S.W.  
Second Floor, East  
Washington, D.C. 20447

<http://acf.hhs.gov/programs/aidd>

ADD Main Number: (202) 690-6590  
Fax Numbers: (202) 690-6904; (202) 205-8037

## **Contact ADD Grantees**

P&As: <http://www.acf.hhs.gov/programs/aidd/programs/pa>  
Councils: <http://www.acf.hhs.gov/programs/aidd/programs/councils>  
UCEDDs: <http://www.acf.hhs.gov/programs/aidd/programs/ucedd>  
PNS: <http://www.acf.hhs.gov/programs/aidd/programs/pns>

Search for DD program contacts by state: <http://www.acf.hhs.gov/programs/aidd/state-contacts>