

Rising Expectations: The Developmental Disabilities Act Revisited



National Council on Disability
February 15, 2011

National Council on Disability
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Rising Expectations: The Developmental Disabilities Act Revisited

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

February 15, 2011

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit the report entitled *Rising Expectations: The Developmental Disabilities Act Revisited*. The Developmental Disabilities Assistance and Bill of Rights Act (Developmental Disabilities Act), originally authorized in 1963 and last reauthorized in 2000, established a set of programs to improve the lives of people with developmental disabilities (DD), to protect their civil and human rights, and to promote their maximum potential through increased independence, productivity, and integration into the community.

NCD conducted a year-long study of how well these programs are meeting the needs of people with developmental disabilities and their families. This report presents the findings and offers recommendations for changes to help develop a more uniform national policy that will support the goals of the Developmental Disabilities Act and improve the program supports and services for people with developmental disabilities.

Since passage of the Developmental Disabilities Act, the United States has witnessed a major transformation of what it means to live with a developmental disability. Before the Act, professionals routinely advised parents and other relatives to institutionalize family members with developmental disabilities. As this report is prepared, more than 70 percent of people with developmental disabilities who receive residential services live in small group homes or on their own in the community. Access to a free appropriate public education is the right of and typical for children with DD rather than universal exclusion from public education. People with developmental disabilities were once expected to die young, and expectations for their lifetime accomplishments were small, but today their life expectancies approach that of the general population. They are among the ranks of Americans who graduate from high school, pursue post secondary education or training, enter the workforce, volunteer, and otherwise participate in the daily life of their communities.

Despite some identified gains in disability rights, people with developmental disabilities continue to face considerable barriers to full integration, maximum independence, and self-determination. Support services vary dramatically by state, and long waiting lists restrict access to services such as health care, housing, and employment. Major issues and needs remain in some areas, including unmet federal requirements for transition from school age to adulthood, access to and use of assistive technology, and support to children with disabilities in foster care.

Although the original intent of Congress was that the Administration on Developmental Disabilities would encourage collaboration among agencies that manage the key domains in the life of people with developmental disabilities, such collaboration is lacking. Today, federal developmental disability policy is established, primarily by default, through the reimbursement mechanisms of the Centers for Medicare and Medicaid Services.

Congress is expected to reauthorize the Developmental Disabilities Act (the Act) soon, making this an opportune time to consider recommendations to ensure that the Act is structured appropriately in relation to the new realities and expectations of people with developmental disabilities, their families, and the goals of our nation for all Americans. The recommendations in this report are intended to address key issues and offer a way forward when the Developmental Disabilities Act reauthorization process begins.

NCD is deeply appreciative of your efforts on behalf of people with disabilities. NCD stands ready to work with you, members of your Administration, and the leadership in Congress as you work to improve programs and outcomes for people with developmental disabilities.

Sincerely,

A handwritten signature in black ink, appearing to read "Jonathan Young", with a long horizontal flourish extending to the right.

Jonathan Young
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the House of Representatives.)

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Executive Summary

Originally authorized in 1963 and last reauthorized in 2000, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402) addresses the changing needs and expectations of the estimated more than 4.7 million individuals with developmental disabilities (DD). Congress set out to establish a set of programs to improve the lives of people with DD; to protect their civil and human rights; and to promote their maximum potential through increased independence, productivity, and integration into the community. Today, these initiatives have evolved into University Centers of Excellence in Developmental Disabilities (UCEDDs), State and Territorial Councils on Developmental Disabilities (DD Councils), Protection and Advocacy for People with Developmental Disabilities (PADD), and Projects of National Significance (PNS).

Over the past 40 years, the United States has witnessed a major transformation of what it means to have DD, moving from a medical model to a social model and involving a truly interdisciplinary approach to identifying needs and delivering supports and services in the community. Despite some identified gains in disability rights, people with DD continue to face considerable barriers to full integration, maximum independence, and self-determination. Furthermore, major programs funded by the Federal Government that affect the lives of people with DD have been established since the inception of the DD Act. Most significantly, the growth of the Medicaid program has shifted the system of supports for people with DD from one that is funded predominantly by state funds to one that is funded predominantly by Medicaid—with joint federal and state funding. Currently, there is no national policymaking or funding stream to create effective community-based alternatives to Medicaid-funded supports for people with developmental and related disabilities. Although the original intent of Congress was that the Administration on Developmental Disabilities (ADD) would span agencies that manage the key domains in the lives of people with developmental disabilities, today the power to affect DD programs is concentrated in the Centers for Medicare and Medicaid

Services (CMS), and DD policy is generally absent from other departments and agencies.

This report addresses three basic questions:

- What has the DD Act accomplished in the past 40 years?
- What are the strengths and weaknesses of the current structure?
- Is the current structure suited to address the current and future social and policy environment?

The report is divided into seven chapters. Chapter 1 introduces the programs and reviews the issues that cut across the different types of grantees. Chapters 2 through 7 describe and analyze each program type in more detail. The programs are presented in the order in which they were legislated, as follows: (2) UCEDDs, (3) DD Councils, (4) PADD programs, (5) PNS, (6) Family Support, and (7) Direct Support Workforce (DSW).

To provide a comprehensive review of the DD Act, stakeholders representing consumer groups, advocacy organizations, experts, ADD staff, and self-advocates were interviewed. Focus groups were held, and documents produced by advocacy groups, researchers, and ADD grantees, annual reports, monitoring and technical assistance reports, and five-year plans were reviewed. A panel of stakeholders was consulted monthly.

Major findings include:

- The DD Act has evolved in a nation whose expectations, attitudes, policies, and services for people with disabilities have changed and continue to change.
- Congress established a three-pronged approach, with each network partner (used in this report to mean UCEDDs, DD Councils, and PADD programs)

having a distinct role. The UCEDDs provide research to identify successful community-based alternatives and train practitioners and leaders. The DD Councils advocate for, and educate policymakers on, laws, regulations, and policies to enhance community living. The PADD program uses advocacy skills and legal avenues to enforce the laws.

- The DD Act, in conjunction with self-advocates, families, other advocacy groups, state and local governments, and other stakeholders, has changed the way people with DD live. In many ways, it has been a remarkable change.
- The majority of professionals, families, and self-advocates interviewed for this report concur that people with DD lack access to supports in the community to ensure adequate access to health care, housing, and employment. Significant issues remain in some areas, including transitions from school age to adulthood, use of assistive technology, and support for children with disabilities in foster care.
- Most of the current challenges can be reduced to four underlying issues: the system is complex and fragmented; services vary dramatically by state; long waiting lists restrict access to services; and attitudes of the public are outdated.
- The ADD is dislocated structurally *within* the Department of Health and Human Services (HHS) and from other federal agencies that develop and fund programs for people with DD. Most notably, within HHS CMS has the primary responsibility for services and supports to this population. In the Department of Education, the Office of Special Education and Rehabilitative Services funds and supports disability-related programs. ADD appears to lack influence beyond the DD Act programs themselves.
- ADD is a small office within the HHS Administration on Children and Families (ACF). In addition to being overshadowed by larger programs within ACF and other disability funding programs within HHS (such as Medicaid), ADD is misplaced structurally in terms of focus and philosophy, resulting in low visibility and limited influence. Thus no entity is directing federal policy for

people with DD. Decisions are often deferred to the largest payer: the Medicaid system.

- The perceived “quality” and “effectiveness” of PADD grantees, UCEDDS, and DD Councils varies dramatically among states. It is difficult to identify consistent performance standards for each program that would be relevant across all states. Compounding the challenge, the goals of the DD Act—advocacy, capacity building, and systemic change—are inherently difficult to quantify. Furthermore, ADD does not have an effective system to identify underperforming grantees.
- The DD Act programs have a relatively low level of funding to address a relatively broad mandate for a vulnerable population. In 2009, Congress appropriated \$160 million to the DD Act. Adjusted for inflation, this appropriation has remained at the same level for the past 20 years.
- Congress has recognized the value of the growing self-advocacy movement and has written it into the legislation in two places: First, the Act mandates that self-advocates be included as members of the DD Councils, on the Boards of the PADD agencies, and on the Consumer Advisory Councils for the UCEDDs. Second, the DD Act of 2000 requires DD Councils to support the establishment and strengthening of at least one statewide self-advocacy organization for individuals with DD in each State and Territory. The network partners and most self-advocacy organizations interviewed for this report would prefer that a separate source of additional funding be established for self-advocacy, instead of relying on DD Councils’ funding.

Recommendations

- 1.1 ADD should be reconfigured to assume important public policy development responsibilities and receive increased resources to equip it to accomplish this new role. In addition, the experience and skill sets of staff assigned to this

newly positioned agency should reflect its enhanced role in public policy development.

- 1.2 Congress should require that the Councils review and comment on any proposed changes to the state Medicaid plan or waivers that affect individuals with DD. Any application from the state to CMS should be accompanied by a letter of support or a list of concerns for CMS's consideration when deciding whether to approve the change to the plan.
- 1.3 Congress should ask the Government Accountability Office to assess the effectiveness of ADD's collaboration with appropriate federal agencies. The purpose is to determine the accessibility and benefits that generic and specialized federal programs, services, and supports are providing to individuals with DD.
- 1.4 ADD, in partnership with the UECDD network, should develop a manageable and useful monitoring plan that yields data that accurately reflects the range of grantee activities and is useful for program administration and improvement. The data should enable ADD to identify underperforming grantees and develop an applicable series of interventions and actions. The National Core Indicators project could serve as a conceptual framework and model to be considered for adoption or adaptation for this activity.
- 1.5 Congress should require ADD to identify, analyze, and synthesize trends in the needs, goals, activities, outcomes, and major initiatives of state DD Council plans, PADD state plans, and UCEDDs statements of work, and report the results of this analysis to Congress annually.
- 1.6 The Secretary of HHS should require ADD to identify the barriers and challenges currently encountered by state DD Councils, PADD programs, and UCEDDs when implementing their state plan activities; and document the type, amount and cost, and effectiveness of technical assistance or support ADD has provided to enable the programs to overcome these challenges.

- 1.7 Congress should establish and maintain a dedicated funding source for technical assistance from organizations that have demonstrated successful experience with the workings and the context of each of the three network programs.
- 1.8 ADD should revise the Developmental Disabilities Program Independent Evaluation to realign it with recommendations 1.4, 1.6, and 1.7.
- 1.9 ADD should be staffed and resourced adequately so that it can be an active participant in mediating disputes between grantees and state agencies.
- 1.10 ADD should coordinate the reapplication process so that a state's DD Councils and UCEDDs are on the same five-year planning cycle.
- 1.11 ADD should streamline reporting requirements related to collaboration and coordination among the network partners and other entities and emphasize the results of meaningful collaboration.

UCEDDs

- 2.1 Congress should review the funding level of university-affiliated programs that are similar to UCEDDs and increase the UCEDD appropriations to be consistent with these programs and at a level sufficient to meet DD Act goals.
- 2.2 ADD should make other federal partners aware of UCEDD network resources for multistate research, evaluation, and information dissemination activities.
- 2.3 The Secretary of HHS should establish a mechanism to coordinate federally funded research on DD and develop a research agenda.
- 2.4 Congress should direct the Government Accountability Office to identify areas in which shortages of personnel restrict access to needed supports, measure the scope of current and future training needs in those areas, assess the existing training capacity, and identify options to expand the capacity.

State and Territorial Councils

- 3.1 Congress should reaffirm the critical role played by the DD Councils in promoting the independence, productivity, and community integration of individuals with DD by raising the annual appropriations for DD Councils in order to improve their capacity for systems advocacy and demonstration activities.
- 3.2 Congress should direct HHS, through ADD and the DD Councils, to launch a major new initiative to identify, analyze, and describe eligibility and funding inequities in the current Medicaid and state DD system, and to work collaboratively with major federal partners, state DD agencies, and state Medicaid agencies to eliminate these inequities.
- 3.3 ADD should redesign the required state plan development and reporting format for DD Councils, which focuses on activities in nine areas of emphasis, into a more relevant format that better reflects the systemic change, capacity-building, and advocacy roles of DD Councils and the long-term nature of their work.

Protection and Advocacy

- 4.1 Congress should increase funding for the PADD program to meet the growing need for advocacy and legal services for people with DD.
- 4.2 Congress should establish and authorize funding for a Protection and Advocacy program specific to the Individuals with Disabilities Education Act to be administered through the Department of Education. The new program will meet the critical need for legal advocacy related to education for children with DD.
- 4.3 Congress should require that ADD and the other five agencies that fund the PADD systems streamline their reporting requirements and progress indicators so that scarce resources can be used for client services.

- 4.4 Congress, in the next DD Act reauthorization, should preserve legal and investigative authorities embodied therein. Specifically, the Act should (1) ensure that the authorities are not superseded by state or other federal laws, (2) clarify that all PADD grantees, regardless of whether they are state or nonprofit entities, have the authority to enforce their access authority in court against both public and private providers, and (3) oppose legislation that restricts the legal authority of the PADD program to represent residents of institutions.
- 4.5 If a state does not comply with the DD Act section 143 to provide access to records, the HHS Secretary should hold ADD accountable for using its authority to support PADD grantees. Furthermore, the Secretary should request sufficient resources during the budget process to ensure that ADD can achieve its mandate.

Projects of National Significance

- 5.1 ADD should develop a transparent system for identifying PNS priorities that includes consumers, policymakers, and network partners.
- 5.2 ADD should develop an evaluation approach to track the follow up and outcomes of PNS programs in order to identify their effectiveness and the value of PNS grants.
- 5.3 ADD should fund additional data collection initiatives in areas such as health care access, direct care workforce issues, and educational outcomes.

Family Support

- 6.1 ADD should convene a meeting of experts, stakeholders, and government representatives to identify changes in family support services, policy, and philosophy that have occurred since the family support provision was written and recommend changes to Title II before the DD Act is reauthorized.

- 6.2 Congress should provide direct funding of Title II to ensure that funds are used consistent with the intent of the Act, rather than funding family support through PNS. The funding should be at a level of at least \$15 million.
- 6.3 ADD should coordinate intra- and interagency groups with other federal partners that work on family support issues.

Direct Support Workforce

- 7.1 Congress should rewrite Title III to provide grants to states to develop, implement, and evaluate comprehensive workforce development programs to attract, retain, and train direct support professionals who provide support to individuals with DD.
- 7.2 Congress should add recruitment, retention, and training of the direct care workforce to the areas of emphasis in the DD Act.
- 7.3 ADD should develop and help fund partnerships with other federal agencies to create a unified approach to ensure that an adequate direct care workforce is available to serve the needs of people who are aging or have disabilities.

Self-Advocacy

- 8.1 The Secretary of HHS should convene a process to develop a thoughtful approach to supporting the fledgling self-advocacy movement that does not rely on the scarce resources of the DD network partners. The approach should include the input of self-advocates, DD network partners, the Centers for Independent Living, and other relevant stakeholders and potential partners.

CHAPTER 1. Overview and Cross-Cutting Issues

1. Introduction

Originally authorized in 1963 and last reauthorized in 2000, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402) addresses the changing needs and expectations of the estimated more than 4.7 million individuals with developmental disabilities (DD) (Braddock, Hemp, & Rizzolo, 2008). Congress set out to establish a set of programs to improve the lives of people with DD; to protect their civil and human rights; and to promote their maximum potential through increased independence, productivity, and integration into the community. Today, these initiatives have evolved into University Centers of Excellence in Developmental Disabilities (UCEDDs), State and Territorial Councils on Developmental Disabilities (DD Councils), Protection and Advocacy for People with Developmental Disabilities (PADD) groups, and Projects of National Significance (PNS). In the DD Act, Congress authorized two additional titles: Family Support and Direct Support Workers, designed to address specific issues facing the DD community. These two titles have yet to receive appropriations.

Over the past 40 years, the United States has witnessed a major transformation of what it means to have DD, moving from a medical model to a social model and involving a truly interdisciplinary approach to identifying needs and delivering supports and services. Before the DD Act, professionals routinely advised parents and other relatives to institutionalize family members with DD. Today, more than 70 percent of people with DD who receive residential services live in small group homes or on their own in the community. Today, access to free appropriate public education is the right of children with DD rather than universal exclusion from public education. People with DD were once expected to die young, and expectations for their lifetime accomplishments were small. However, today their life expectancies approach that of the general population who graduate from high school, take advantage of continuing education or training opportunities, obtain jobs, engage as volunteers, and participate in the daily life of their

communities. Some of the same trends that improved the lifespan of people with DD also helped people with severe disabilities, who have functional similarities (e.g., traumatic brain injury, spinal cord injury), to attain new expectations for survival and life, including freedom, participation, and contribution. The rising levels of expectations for people with DD raise all boats; people with severe disabilities who are excluded from the DD definition (and Medicaid-funded community-based supports) have the same desire for freedom and full participation. Given current policy and program structures, however, it is easier to raise expectations and awareness than it is to serve needs.

A variety of forces contributed to these changes. Though it is impossible to identify the full extent of the DD Act's contributions, qualitative evidence suggests that in most states and for most types of services and supports, DD Act programs appear to have been influential. As new goals are attained, expectations continue to rise; the fact of life for DD Act programs is that their reach always exceeds their grasp.

Despite significant gains, people with DD continue to face considerable barriers to full integration, maximum independence, and self-determination. Some of these barriers result from state programs and policies and the wide variation in financial commitment and supports from state to state. Other barriers result from national policies that are inconsistent with each other and with the current DD paradigm.

Furthermore, major programs that affect the lives of people with DD have been established since the inception of the DD Act. Most significantly, the growth of the Medicaid program has shifted the system of supports for people with DD from one funded predominantly by the states to one funded predominantly by Medicaid, a federal/state partnership in which states decide what services to provide based on federal Medicaid reimbursement policies. This dramatic shift has given the Federal Government, through the Centers for Medicare and Medicaid Services (CMS), increased authority to shape DD policy. However, CMS is essentially a payment organization within the Department of Health and Human Services (HHS); although it has taken important steps to innovate the Medicaid program, it is not statutorily tasked with using the principles of the DD Act to develop policy or identify services. Many

innovations in CMS-funded support programs were identified or incubated by DD Act programs, but few funding streams exist except for Medicaid. There is no national policymaking or funding stream to create effective community-based alternatives to Medicaid-funded supports for people with DD and related disabilities. For comparison, within HHS, both the Administration on Aging (AoA) and the Substance Abuse and Mental Health Services Administration (SAMHSA) fund large state networks of community-based and volunteer-rich programs that help reduce reliance on Medicaid-funded individual supports in American communities.

The original intent of Congress was that ADD would span agencies that managed what were seen as the key domains in the lives of people with DD. In the early years of the DD Act, these needs were expressed primarily under a “medical model,” mostly at National Institutes of Health (NIH, in the then Department of Health, Education and Welfare). As the expectations for people with DD grew under an emerging “social model,” bureaucratic changes worked against their thoughtful inclusion in national systems. When the U.S. Department of Education (DOE) was created in 1979 and split from HHS, only minor provisions were made for ADD to have a role through interagency coordinating functions. When the Social Security Administration (SSA) was created in 1995, even fewer provisions were made. Outreach to these and other Departments, such as Labor, Housing, and Treasury, is tenuous at best, with the burden being assumed by the comparatively minuscule resources of ADD and dependent upon the leadership of the agencies.

What is guiding the policy for this vulnerable population today? The United States spends \$43.8 billion (Braddock et al., 2008) on Medicaid-funded supports for people with DD, and up to \$100 billion per year on all programs affecting people with DD. Is that spending leading to the outcomes articulated in the DD Act? With a fiscal year (FY) 2010 budget of \$170 million (less than 0.5 percent of total DD spending), DD Act programs typically work across all domains at a state level, and are authorized to provide systems change, research and training, and legal advocacy. Yet the DD Act outcomes have no direct connection to the federal funding of services or program

design, and no direct policy influence or authority over them. With Congress expected to reauthorize the DD Act within the next few years, this is an opportune time to assess whether the DD Act is structured appropriately in relation to the new realities and expectations of people with developmental disabilities and their families, and the goals of the nation on their behalf.

This report addresses three basic questions:

- What has the DD Act accomplished in the past 40 years?
- What are the strengths and weaknesses of the current structure?
- Is the current structure suited to address the current and future social and policy environment?

Our research revealed that the DD Act and its administration at the federal level have significant structural challenges, some of which reflect issues facing the disability services and support system as a whole. Our recommendations focus on politically feasible changes that can enhance the operation of the DD Act and outcomes for people with developmental disabilities.

The report is divided into seven chapters. Chapter 1 introduces the programs and reviews the issues that cut across the different types of grantees. Chapters 2 through 7 describe and analyze each program type in more detail. They are presented in the order in which the programs were created: (2) UCEDDs, (3) DD Councils, (4) PADD groups, (5) PNS, (6) Family Support, and (7) Direct Support Workforce.

2. Methodology

In an effort to provide a comprehensive review of the DD Act, NCD interviewed 14 stakeholders representing consumer groups, advocacy organizations, and self-advocates. We conducted three focus groups with directors of DD Councils, PADDs, and UCEDDs, and solicited comments at each of their annual conferences. We

contacted 25 experts; interviewed eight ADD staff; reviewed documents produced by advocacy groups, researchers, and ADD grantees; reviewed ADD's biannual reports to Congress from 2000 to 2008, grantee annual reports from 2008, monitoring and technical assistance reports from 2005 to 2008, and five -year plans from 2006 to 2008; analyzed existing data; and consulted monthly with an advisory group of stakeholders and experts. Appendix A lists interviewees and focus group participants.

When NCD uses the term “developmental disability” throughout this report, it refers to the definition in the DD Act: a severe, lifelong disability attributable to mental and/or physical impairments which manifest themselves before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more of the following areas: self-care, comprehension and language skills (receptive and expressive language), learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, and ability to function independently without coordinated services.

3. History and Context of the Act

The content of the DD Act has evolved in a nation whose expectations, attitudes, policies, and services for people with disabilities have changed and continue to change.

a. 1963–1975

In 1963, people with DD faced almost complete exclusion from schools, communities, and sometimes even homes. Families were regularly counseled to place children with DD in state-run facilities (Intermediate Care Facilities for People with Mental Retardation, or ICF/MR), and were assured that their children would be cared for and protected.

Unfortunately, the reality of the institutions often fell far short of the guarantee. Children and adults were housed in large state institutions where the per diem rate was \$5 (\$35 in inflation-adjusted 2009 dollars). These facilities were often riddled with systemic

neglect and abuse. It was within this context that President John F. Kennedy promoted the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, establishing “University Affiliated Facilities” (later to become the UCEDDs) designed to ensure access to safe institutional facilities, advance scientific understanding, and promote professional education. While the Federal Government was providing funds to enhance institutions, parent groups such as the National Association for Retarded Children (NARC—later to become The Arc) and other groups had been providing private special-education classes and sheltered workshops for children and adults who were living with their families and began to insist that the state provide the appropriate services in the community.

Dr. Elizabeth Boggs and Dr. Elsie Helsel were both mothers of sons with disabilities and members of NARC and United Cerebral Palsy, respectively. Together, they coined the term “developmental disability” to be inclusive of people with severe intellectual disabilities (then called “mental retardation”) and people who experienced severe functional limitations due to disabilities that were primarily physical or sensory in nature, such as cerebral palsy. Seeing that the majority of government funding had gone to institutional construction and improvement, they argued that government funding should be applied to a broad range of services and that parents and advocates should have a more substantial role in determining how DD funds were allocated. Rather than advocating for a significant amount of new funding, they advocated for the creation of an entity to coordinate the major streams of funding provided for people with DD. This movement led to creation of DD Councils and special projects (later to become projects of national significance), codified in the Developmental Disabilities Services and Facilities Construction Amendments of 1970. Strictly speaking, the 1970 Act was an amendment to the Facility Construction Act of 1963, but the scope had been broadened to the point that the 1970 legislation is sometimes considered the beginning of the current DD Act.

Recognizing the need to protect people with DD from neglect and abuse in institutions and to guarantee their rights, Congress, in the 1975 reauthorization of the Act,

established the PADD program and introduced a basic bill of rights. Thus, by 1975 Congress had created three programs that together were designed to, as Boggs said, “grant developmental potential, habilitation, and the right to optimal remediation to a group that had, in the past been relegated to custodial care” (Shorter, 2000). The vision of the three-pronged approach can be seen in the role of each network partner in the deinstitutionalization issue. UCEDDs provided research to identify successful community-based alternatives. The DD Councils promoted laws, regulations, and policies to implement UCEDD findings. The PADD program used advocacy skills and legal avenues to enforce the laws.

b. 1975–present

The DD Act, in conjunction with activities of self-advocates, families, other advocacy groups, state and local governments, and other stakeholders, has changed the way people with DD live. The social landscape in the United States has shifted from a place where people with DD were unheard and neglected to a country where far fewer people are relegated to institutional care, children with DD are in public schools, adults are living and in some cases working in the community, and a burgeoning self-advocacy movement is demanding that people with intellectual and developmental disabilities have power over their own lives. In many ways, it has been a remarkable change. Similar processes of liberation for this population are occurring throughout the developed and developing world.

Though most professionals, families, and self-advocates agree that the quality of life for people with DD should be based on inclusion and participation in the daily life of their communities, a small and politically active segment believes that institutional care is the only safe alternative for their family members and that their right to choose this option is fundamental. They assess the community resources provided under their state’s Medicaid plan as inadequate to meet the needs of individuals with severe and profound intellectual disabilities often complicated by physical and sensory impairments. They see long waiting lists for community services and strongly support the entitlement to services that are guaranteed in the institutional programs. They legitimately point out

that community services are not held to the federal standards for Intermediate Care Facilities for People with Developmental Disabilities, are unavailable in all communities, and often take years to access.

The majority of professionals, families, and self-advocates concur that people with DD lack supports in the community to ensure adequate access to health care, housing, and employment. Most of the current challenges can be reduced to four underlying issues:

- **The system is complex and fragmented:** With myriad programs administered by different federal, state, and local agencies, people with DD and their families face a maze of fragmented, sometimes conflicting, and complex system of benefits and supports.
- **Services vary dramatically by state:** State DD systems vary widely in terms of their financial commitment, their reliance on state institutions, and the character and quality of their community-based services. Although many best practices have been developed since the inception of the DD Act, they are rarely applied consistently across states and localities. In addition, eligibility for services is not portable across state lines.
- **Long waiting lists restrict access to services:** An estimated 88,349 people with DD were on waiting lists for residential services in 2007 (Prouty, Alba, & Lakin, 2008).
- **Public attitudes are often outdated:** Public attitudes, stereotypes, low expectations, and lack of understanding limit the ability of people with DD to integrate fully into the community.

Changes in laws, regulations, and programs that make up the organizational landscape have both advanced and complicated the emerging social trends. The major legislative and policy initiatives, shown as a timeline in Exhibit 1.1, have expanded the funding and services for people with DD. However, these initiatives have led to incoherent federal policy toward people with DD.

Exhibit 1.1
Timeline of Major Legislative and Policy Initiatives
Affecting People with Developmental Disabilities, 1960–2010

| | |
|-----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1960–1965 | <ul style="list-style-type: none"> • President Kennedy releases the <i>National Plan to Combat Mental Retardation</i>. • The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 creates a national network of research centers and university-affiliated facilities. • The Social Security Act of 1965 establishes the Medicare and Medicaid programs. |
| 1966–1970 | <ul style="list-style-type: none"> • The number of residents in large state institutions for people with mental retardation reaches its peak at 194,650* in 1967. |
| 1971–1975 | <ul style="list-style-type: none"> • In 1971, amendments to Title XIX of the Social Security Act authorize Medicaid reimbursements for intermediate care facility (ICF) services. • The Social Security Amendments of 1972 establishes the Supplemental Security Income (SSI) program for the elderly and people with disabilities. • The Rehabilitation Act of 1973 revises earlier vocational rehabilitation legislation to emphasize serving people with severe disabilities and includes a nondiscrimination clause (see 1976–1980). • The Education for All Handicapped Children Act of 1975 mandates that children with disabilities ages 3–21 receive a free and appropriate education in the least restrictive environment based on an individualized education program and with due process guarantees. |
| 1976–1980 | <ul style="list-style-type: none"> • Regulations implementing Section 504 of the Rehabilitation Act of 1973 are signed in 1977, implementing the nondiscrimination clause that prohibits the exclusion of people with disabilities from any program or activity receiving federal financial assistance. |
| 1980–1985 | <ul style="list-style-type: none"> • The Medicaid Home and Community-Based Services (HCBS) waiver program is established. • The Civil Rights of Institutionalized Persons Act of 1980 (CRIPA) provides the Department of Justice (DOJ) with the statutory authority to bring cases to protect people living in institutions. |

| Exhibit 1.1 (cont'd) | |
|-----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1985–1990 | <ul style="list-style-type: none"> • 1986 Amendments to Education for All Handicapped Children Act provide funding to states to offer early intervention programs for infants and toddlers. • The Technology Related Assistance for Individuals with Disabilities Act of 1988 establishes grant programs to encourage the development and distribution of assistive technology for people with disabilities. |
| 1990–1995 | <ul style="list-style-type: none"> • The 1990 Americans with Disabilities Act prohibits discrimination based on disability. • The 1992 Education for All Handicapped Children Act is changed to Individuals with Disabilities Education Act (IDEA) and language is added to support the transition from school to adulthood. |
| 1996–2000 | <ul style="list-style-type: none"> • The Ticket to Work and Work Incentives Improvement Act of 1999 establishes new programs and work incentives for SSI and Social Security Disability Income (SSDI) beneficiaries. • In 1999, the U.S. Supreme Court holds in the case of <i>Olmstead v. L.C.</i> that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. |
| 2001–2005 | <ul style="list-style-type: none"> • In 2001, the New Freedom Initiative includes a set of proposals designed to ensure that Americans with disabilities have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in their communities. • The No Child Left Behind Act of 2001 is designed to ensure that all children have a fair, equal and significant opportunity to obtain a high-quality education and requires that states develop accountability systems. |
| 2005–2010 | <ul style="list-style-type: none"> • The Social Security Administration modifies the regulations for the Ticket to Work and Work Incentives Improvement Act to enhance the ability of SSI recipients to benefit from the program. |

The DD Act emphasizes self-determination, productivity, and independence. However, certain other federal policies and laws, such as the following, do not adhere to these principles:

CMS – Medicaid

Prior to the enactment of the Medicaid legislation, most services were funded and controlled by state governments. Medicaid now provides 78 percent of the total individuals with DD spending (Braddock et al., 2008). Although states have some flexibility to define services and quality within federally defined parameters, there continues to be an “institutional bias” in the Medicaid program despite significant revisions in federal Medicaid rules. Any Medicaid-eligible individual who meets the criteria for an “institutional level of care” is *entitled* to institutional services, but states can limit the number of recipients in home and community-based services.

Department of Justice – Civil Rights of Institutionalized Persons Act (CRIPA)

After identifying significant and systemic abuse and neglect in institutions in Texas and several other states, DOJ ordered the states to add resources to the existing institutions rather than shifting significant resources to non-institutional settings that are more in line with the principles of the DD Act (National Disability Rights Network, 2009).

Social Security Administration – Social Security Disability Income (SSDI) and Supplemental Security Income (SSI)

SSDI and SSI, the major cash assistance programs for people with DD and all other disabilities, contain significant work disincentives. Although the Ticket to Work and Work Incentives Improvement Act has reduced these disincentives, the fundamental structure of SSDI and SSI limit the ability of recipients to reach their maximum level of productivity and financial independence. The disincentives are especially prohibitive for people with strenuous long-term support needs (Stapleton, O’Day, Livermore, & Imparato, 2006).

Developing a coherent federal policy requires the leadership of a federal entity with the authority and influence to bring federal partners to the table. Such an entity currently does not exist. The DD Act legislation codifies an important set of goals and rights for people with DD that could form the theoretical basis of a strong federal policy, but ADD

lacks the authority and influence to broaden the reach of these goals beyond the DD Act programs themselves.

At the state level, DD Councils and other network partners have a limited ability to influence Medicaid policy to the extent necessary to redirect funds in a manner that meets the needs of the community. The DD network is expected to unify and direct disjointed organizations based on a philosophy of self-determination, independence, productivity, and inclusion in all aspects of community living. However, Medicaid, with its funding dominance, has essentially usurped this role.

4. The DD Act

The goal of the DD Act 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...” [Sect 101, DD Act of 2000]. To achieve this broad goal, the DD Act reauthorized three programs that operate in each state and territory (UCEDD, DD Councils, and PADD) and one program that promotes nationwide initiatives (PNS). In addition, the DD Act authorized two new programs (Family Support and Direct Support Workforce). This section provides a brief overview of these programs; Chapters 2 through 7 contain full descriptions and analyses.

a. State and Territorial Councils

Each state, including the District of Columbia and the four U.S. territories, has a DD Council that addresses legislative, policy, programmatic, and fiscal issues through advocacy, capacity-building, and system change activities. Council members are appointed by governors, and the DD Act requires that more than 60 percent of Council members be people with DD or family members of a person with DD. In this way, the “customer” of the service system plays an important role in directing Council activities. Most DD Councils are

state or quasi-governmental agencies and thus could provide a credible voice in the policymaking process. Over the years, they have developed and tested some innovative service delivery models that have eventually been integrated into state systems.

Despite their relevant strategic position and their charge to execute a vital planning function, they are given little direct authority and have little or no statutory relationship to the state agencies that operate DD programs or to their funding sources. In 1980, the General Accounting Office (GAO) noted that councils “rely on cajoling, encouraging, and persuading others” to provide for people with DD (U.S. General Accounting Office, 1980). This situation has resisted change for close to three decades. Stakeholders report that, as a result, in some states DD Councils have substantial influence on policy, whereas in other states, they have been sidelined.

b. Protection and Advocacy for People with Developmental Disabilities

PADD programs in each state and territory, as well as one Native American program, are charged with protecting the legal and human rights of individuals with DD through legal advocacy and legal action. PADD grantees provide legal representation in individual and class action lawsuits, investigate cases of abuse and neglect, educate policy makers, and disseminate information. They work with individuals on specific issues (individual advocacy) and use their legal skills to address system wide issues (systemic advocacy).

PADD programs have been an integral part of the deinstitutionalization process, as well as aiding parents advocating for appropriate education of their children under the IDEA. As a result of their investigative rights and legal standing, PADD grantees can effectively compel agencies to provide services when benefits have been denied or rights of people with DD have been violated. Although actual court cases are filed only after other approaches have failed, PADD grantees report that the potential for legal action and the ability to collect restricted information is often enough to force delinquent agencies to change (U.S. Government Accountability Office, 2003).

The resources allocated to the PADD program and PADD grantees are too scarce to meet the demand of all potential clients. As a result, each grantee and its governing board must choose how to divide resources between individual and systemic advocacy and develop a set of priorities that define who they will serve and how. Unfortunately, this often leaves families and individuals with no one to advocate on their behalf.

c. University Centers for Excellence in Developmental Disabilities

The DD Act funds 67 UCEDDs to perform interdisciplinary academic research, prepare students and fellows for work in fields related to DD, disseminate information, and provide model direct service programs. The university affiliations put UCEDDs in a unique position to conduct research, train future leaders, and disseminate information that is seen as legitimate and unbiased. Since the inception of the DD Act, the UCEDDs have been instrumental in developing interdisciplinary approaches to diagnosis, service delivery, and DD research.

Each UCEDD receives a core grant from ADD that is used as a platform to garner grants from other federal, state, and private sources. As a result, the size and activity of UCEDDs vary dramatically. The practice of leveraging the DD grant into other funding allows the UCEDD to address the needs of people with DD in a far more comprehensive manner than they could with the DD grant alone. However, the process may restrict the ability of UCEDDs to respond directly to the needs of the community, and leveraged funding is naturally not accountable to the principles of the DD Act.

d. Projects of National Significance

PNS is a discretionary grant program designed to focus on and quickly respond to emerging areas of concern. This program is intended to support innovative and practical solutions as well as collect data to measure the status and progress of people with DD. PNS funds also support training and technical assistance activities for the other grant programs.

Stakeholders consistently pointed to several outstanding projects over the decades, including three data collection and dissemination projects that have provided vital information used by advocates, policymakers, and researchers to understand trends in community living, employment, federal and state government expenditures, and other activities.

Two factors limit the ability of the PNS program to meet its full potential. First, Congress often includes new appropriations language each year, directing PNS resources on a year-to-year basis—often to Family Support, significantly limiting the funds available for other projects or approaches. Second, even for projects that show promise with short-term PNS funding, there is often no other funding available for continued exploration or implementation.

e. Family Support Programs

Title II of the DD Act authorizes the Family Support Program to promote and strengthen the implementation of comprehensive state systems of support services for family members of people with DD. Although line item funds were not allocated to this program until 2008, when the appropriation was only \$1.7 million out of a \$15 million authorization, Congress increased the appropriation for PNS as early as 1998 and directed ADD to use the additional funds for Family Support initiatives consistent with Title II. PNS expenditures on these activities are frequently encouraged by congressional appropriations language.

In 1999, this directive led ADD to provide small demonstration grants to states, giving the states wide latitude in designing and developing initiatives. In 2003, ADD replaced these grants with a multiyear initiative to establish a limited number of Family Support 360 Programs, each of which was required to establish a one-stop center and serve at least 50 families per year. Most experts and stakeholders noted that Family Support 360 programs were inconsistent with the statewide systems change intent of Title II and described the program as anywhere from “wonderful for the people it served” to “an unconscionable waste of money.”

f. Direct Support Workforce

Title III of the DD Act authorized funds for two Direct Support Workforce initiatives to address the shortage of workers in the field. The title authorized \$800,000 per year to develop a Web-based training course for direct support workers and \$800,000 per year to fund scholarships for direct support workers. To date, Congress has never appropriated the funds for the program. However, ADD has used PNS funds to establish an online training course for direct support workers, the College of Direct Supports, which has shown significant promise and is now used in agencies and states across the country.

5. Position of the Federal Office

ADD, the federal office tasked with managing the DD Act programs, is structurally dislocated from the federal agencies that develop and fund programs for people with DD, most notably CMS in HHS and the Office of Special Education and Rehabilitative Services (OSERS) in DOE. In addition, ADD has few resources and little influence compared to an agency such as SAMHSA in HHS, which focuses on people with mental health needs and has a charge similar to that of ADD's focus on people with DD, but an entirely different structure.

ADD is a small administration (\$187 million, of which \$170 million is used to fund DD Act programs) within the \$52 billion Administration on Children and Families (ACF), part of the \$880 billion HHS FY 2010 budget. In addition to being overshadowed by larger programs within ACF and other disability funding programs within HHS (such as Medicaid), ADD is structurally misplaced in terms of focus and philosophy. The mission of ACF is to provide "national leadership and direction to plan, manage, and coordinate the nationwide administration of comprehensive and supportive programs for vulnerable children and families" (ACF, 2007), but the largest population of people with DD is now adults, not children. The placement of ADD has resulted in low visibility and limited influence for the Administration that should provide federal leadership on DD-related

issues. In fact, when members of other agencies and offices working on DD issues such as the Department of Labor (DOL), CMS, and the HHS Office of Disability, were interviewed for this report, none were concerned with ADD, nor did they see it as vital to the policymaking process.

Because ADD is not integral to important programmatic and policy decisions at either the state or federal levels, no agency is directing federal policy for people with DD. Decisions are often deferred to the largest payer: the Medicaid system. Although CMS has made significant modifications to federal Medicaid policy in the past several decades in an attempt to keep pace with the evolving DD paradigm, DD policy is not its core competency. CMS does not undertake policy initiatives for people with DD in the same way that the AoA or SAMHSA can undertake for people who use mental health or substance abuse supports. CMS does not fund a network of state administrators as these programs do.

Compounding its inadequate stature within the Federal Government, ADD has only 17 people administering more than 350 grants and contracts. As a result, the staff has few resources available for activities beyond basic grants management. For example, the agency has not had a strategic plan for more than 10 years. Nor has it developed final administrative rules for implementing the DD Act. The notice of proposed rulemaking was not released until 2008 (*Federal Register*, Notice of Proposed Rulemaking, 2008). The disassociation from other federal agencies, coupled with the lack of authority and resources, has damaging consequences for both the DD community and DD Act grantees. Several recent initiatives illustrate the low visibility and influence of ADD:

- SAMHSA and CMS have entered into an interagency agreement to undertake two joint initiatives per year. ADD and CMS have no such agreement.
- AoA and CMS have been collaborating since 2003 to develop a system of single points of entry into the long-term care system for older adults and people with disabilities through the Aging and Disability Resource Centers. ADD has not been involved in this initiative.

DD Act grantees report that the absence of interagency coordination at the federal level makes it more difficult to establish relationships at the state level.

ADD needs substantive responsibility and strong partnerships with CMS, state agencies, DOJ, Medicaid, and others in order to provide the DD community with a clear and unified strategic plan and philosophy, and it needs new authority to engage the network of state directors of DD services in technical assistance networks and policy initiatives.

6. Monitoring and Evaluation

a. Accountability and Oversight

Interviews with stakeholders and experts clearly suggest that the perceived quality and effectiveness of PADD grantees, UCEDDS, and DD Councils varies dramatically among states. Recognizing that the terms “quality” and “effectiveness” take on different meanings for each interviewee, it is apparent that some grantees achieve the vision of the DD Act while others flounder.

Because the discretionary grants (UCEDDs) are not openly competed, there is no weeding-out process whereby a grant may be awarded to a competitor that can prove in an application that it can be more effective than the current grantee. As a result, federal oversight is critical to maintaining a strong network. The orientation of formula grants (DD Councils, PADDs) is dependent on the will of each state’s governor.

Because each program operates in a different social and policy environment and the needs of the state and the receptiveness of government officials and the public to change may differ, it is difficult to identify consistent performance standards for each program that are relevant across all states. Compounding the challenge, the goals of the DD Act—advocacy, capacity building, and systemic change—are inherently difficult

to quantify compared with programs that provide direct service where the number of people served can be used as a rough gauge of whether the program is touching lives.

ADD also struggles with some of the same issues that face other government agencies that run programs whose outputs and outcomes are difficult to quantify. It does not have an effective system to identify underperforming grantees. In addition, to the extent that ADD is aware of underperforming grantees, the office has few mechanisms to help strengthen them, to condition future funding on specific improvements, or to eliminate funding. ADD does offer technical assistance on grant requirements, but interviewees report that ADD is not currently equipped to provide programmatic evaluation and oversight. Rather, it functions as a regulatory body that ensures grantees are following the grant regulations (e.g., reporting and budgeting). As a result, there is a lack of accountability and coherent strategy within the DD network.

The major programs are evaluated using two tools: annual performance reports and the Monitoring and Technical Assistance Review System (MTARS). On the whole, the monitoring process can be administratively burdensome to the grantee. Though the monitoring process can provide ADD with a substantial amount of documentation that can indicate whether the grantee is in compliance with laws and regulations, it provides little information that ADD can use to assess the grantee effectiveness or compare the grantee against any type of performance standard.

In the annual performance reports, grantees are required to report a substantial amount of qualitative information about their programs as well a small number of quantitative measures. Unfortunately, for the most part ADD does not analyze the qualitative data to identify grantee strengths and weaknesses, and the quantitative data (which ADD displays on its Web site) lacks the validity and reliability to be used as a monitoring tool.

Grantees had particularly harsh criticisms of the MTARS. The MTARS brings together peers, consumers, and ADD staff to comprehensively review all network grantees (UCEDDs, DD Councils, and PADDs) in two to five states per year. The review includes a site visit, a public forum to elicit local stakeholder comments, and a document review.

ADD established the MTARS to monitor individual grant programs and the collaboration between programs, address areas where grantees may benefit from technical assistance, and identify innovative practices that may benefit other grantees. This process is designed to evaluate the program in the context of its environment and network partners and provide feedback that will enhance its functioning and impact. However, grantees argued strongly that the MTARS is administratively burdensome, leans heavily toward compliance monitoring that can be accomplished using less time-consuming methods, does not lead to quality improvement, and does not link any useful information to the success or management of the programs in any significant way.

b. Outcomes

The ultimate goal of the DD Act programs is to enhance the quality of life for people with DD through increasing participation in the community; control over resources; informed choice; access to employment, housing, health care, and transportation; and freedom from abuse and neglect. Qualitative and quantitative measures clearly indicate that, on average, people with DD have made progress in these areas since the inception of the DD Act. However, it is difficult to assess the direct impact of the Act for several reasons:

- Multiple forces contributed to these changes, and it is not possible to tease out the impact of any one force.
- DD Act programs impact the entire DD system and community, in contrast to direct services that affect a defined set of individuals. Thus, outcomes are inherently difficult to measure.
- Specific outputs of some DD Act programs (such as research, innovative ideas, and legal arguments) were adopted by policymakers and others to empower consumers or change the system. However, no system is in place to track the long-term impact of specific outputs.

The dearth of quantitative outcome data has hampered our ability to present evidence on the success of DD Act programs. In the absence of outcome data, we relied on the

opinions and insights of stakeholders and experts who have been involved with the system for many of the past 40 years to identify program contributions that enhance the lives of people with DD. (Chapters 2 through 7 present available outcome data and stakeholder perceptions.)

Two sets of tools, the annual performance measures and the proposed Developmental Disabilities Program Independent Evaluation (DDPIE), are designed to evaluate the impact of the DD Act programs as a whole.

c. Performance Measures

The Government Performance Results Act of 1993 (GPRA) is intended to quantify goals for each federal program and require programs to report annually on progress toward those goals. The GPRA goals for DD Act programs under GPRA are to—

- Increase the percentage of individuals with DD reached by the Councils who are independent, self-sufficient, and integrated into the community. (DD Councils)
- Increase the number of individuals with DD reached by the Councils who are independent, self-sufficient, and integrated into the community, per \$1,000 of federal funding to the Councils. (DD Councils)
- Increase the percentage of trained individuals actively working to improve access of individuals with DD to services and supports. (DD Councils)
- Increase the percentage of individuals who have their complaint of abuse, neglect, discrimination, or other violation of human or civil rights corrected, compared with the total number of individuals assisted. (PADD groups)
- Increase the percentage of individuals with DD receiving the benefit of services through activities in which professionals were involved who completed UCEDDs state-of-the-art training within the past 10 years. (UCEDDs)

In theory, these performance measures quantify important program outcomes. However, with the exception of the measure for the PADD program, the data needed to estimate the value for each measure carries so much statistical uncertainty that it is not useful. Because of the uncertainty, without information from direct services and supports authorizations it would be impossible to see any meaningful year-to-year (or even decade-to-decade) changes that could be attributed to real changes in program performance, rather than to random variations in the measure or changes in reporting methodology.

d. Developmental Disabilities Program Independent Evaluation (DDPIE)

In response to the Office of Management and Budget (OMB) Performance Assessment Rating Tool (PART) assessment of the DD Act programs in 2005, which criticized ADD for failing to contract for independent evaluations to measure the effectiveness of its program and policies and promote accountability to the public, even though the program performance was scored as “adequate,” ADD contracted with Westat, a large private research corporation, “to determine the impact that DD programs (and the collaboration among programs) are having on people with DD, family members, state systems, and service providers” (Elinson et al., 2008).

Westat undertook a three-year initiative to identify indicators, develop evaluation tools, and pilot-test the tools in three states. To identify appropriate indicators, the evaluators consulted with a variety of experts and stakeholders including an advisory panel, working groups from each of the DD network program types, state programs, validation panels, and the public. Through this comprehensive process, the research team identified the processes, short- term and long-term outputs, and outcomes for the three network partners.

Westat created between 47 and 52 indicators for each program. The indicators generally reflect the type of work that each grantee should perform and thus the type of outputs and outcomes that should be addressed in this type of evaluation. Westat developed a research protocol that includes qualitative and quantitative data collection. It includes interviews with grantee staff, council and board members, consumer advisory

committee members, and others who have received services or participated in activities supported by DD Network programs. Given the resources required to collect data and perform interviews, the final evaluation will be based on a random sample of grantees rather than every grantee. As a result, the evaluation will not be able to, nor was it intended to, identify underperforming entities.

The evaluation has several limitations:

- Many of the Westat indicators are not conducive to quantitative measurement. Thus, in the planned second stage of the process, Westat intends to ask the grantees to provide examples for each indicator. The process will yield systematic anecdotal evidence of the strengths of DD Act programs but will not yield the quantifiable outcomes that national policy makers seek.
- The process does not evaluate two very important aspects of the DD Act programs: the role of ADD and the PNS programs.
- The evaluation protocol details a data collection strategy that is labor intensive and expensive for both the evaluator and the network partners. The cost of the data collection is disproportional compared to the total authorization of the DD Act.
- The network partners have not “bought into” the process. They expressed concern that much or all of the information that Westat will be collecting (1) is already available under current reporting requirements, (2) will be unnecessarily time-consuming for the grantee, and (3) will not yield useful results.

Despite these limitations, the DDPIE may be an important initiative. While researching this report, NCD found substantial anecdotal evidence about both the importance of the DD Act programs in enhancing the lives of people with DD and the issues facing the program. However, there is a dearth of data to substantiate these anecdotes quantitatively or systematically. As a result, it seems clear that a full-scale evaluation is warranted. For example, anecdotal evidence suggests that some DD Act grantees are not performing at

an acceptable level. However, currently no data or methods exist to identify whether these entities really are underperforming or whether they face unrealistic or inaccurate expectations of some citizens, or whether underperforming entities make up a very small portion or a significant portion of current grantees. In any case, the question may be moot if ADD is without authority and resources to remediate underperformance.

The strengths of the DDPIE include the following:

- Data will be robust enough to identify substantial issues facing the program.
- The DDPIE, with three years of planning completed, is the only approach that has been developed and is ready for implementation.

Because it is so resource intensive, this type of evaluation is unlikely to be done regularly. However, ADD will likely learn things from the evaluation that will help strengthen the current monitoring and evaluation approach. The process can identify key data elements to translate into performance standards that can be used in ADD's periodic monitoring processes. NCD initially recommended revisions to the current DDPIE (see Recommendation 1.8), but the revisions will have to be considered for future evaluations; according to ADD, the current DDPIE was funded with prior-year funds and cannot be revised for the current evaluation.

Another potential good source for assessing outcomes is the National Core Indicators (NCI), a systematic approach to performance and outcome measurement for state DD programs. The current performance indicators include approximately 100 consumer, family, systemic, cost, and health and safety outcomes that are important to the overall effectiveness of state developmental disabilities agencies. Each indicator is associated with a source from which the data is collected. These include consumer surveys (e.g., empowerment and choice issues), family surveys (e.g., satisfaction with supports), provider surveys (e.g., staff turnover), and state systems data (e.g., expenditures, mortality). The NCI also provide information for many of the desired outcomes stated in the Home and Community-Based Services Quality Framework. The NCI could serve as a model for the

development of a truly outcome-based systematic look at the effectiveness of the programs that are of concern to DD Act partners (<http://www.hsri.org/nci/>).

e. Previous Evaluations

In 1980, the General Accounting Office examined the operation and administration of the four programs funded under the DD Act. It found the following (U.S. General Accounting Office, 1980):

All of these programs have funded projects and activities to help people with developmental disabilities. However, the Department of Health, Education, and Welfare (HEW) had not developed criteria or standards to measure program performance or made any in depth reviews of the programs for overall impact on the conditions of the people they were meant to serve.

The State Formula Grant Program (now State and Territorial Councils) is particularly burdened. Many of its problems are so fundamental and pervasive that major improvements are needed, beginning with a clear congressional definition of what this program should accomplish.

Although the State Protection and Advocacy Program is too new to gauge its impact, early indications are that this program offers new hope for people with developmental disabilities. This program contains influence—a key ingredient that is lacking in the Formula Grant Program. However, the program also has some problems, not the least of which is lack of funds.

For the most part, the Special Projects Program (now projects of national significance) is not unique or special. Contrary to program goals, many projects were strikingly similar to projects funded under the Formula Grant Program (DD Councils). This was particularly true of regional projects—many of which were narrowly scoped, not designed for widespread application or replication, and were providing conventional services instead of developing unique or innovative techniques for service delivery.

The main problems with the University-Affiliated Facilities Program (now UCEDDs) are that it is funded from numerous sources with no fixed pattern, has vague mission statements, and has varying and incompatible guidelines.

All four programs need closer monitoring and more specific direction from HEW (now HHS) if they are to be effective and viable forces in improving the conditions of people with developmental disabilities.

Some of these findings are remarkably similar to the findings of this report.

7. Other Issues That Affect All Programs

a. Collaboration

Each of the network partners has its own role and is staffed with different types of expertise. In theory, effective collaboration between the partners would allow them to maximize their impact by coordinating their activities and harnessing the power of their different roles, perspectives, expertise, and strategies.

The DD Act's broad mandate identifies many issues in need of attention, so each network partner within a State may be focusing on different issues. The Act was intended to encourage and facilitate intentional cooperation between network partners by mandating that PADDs and UCEDDs be represented on DD Councils; that PADDs and DDCs sit on the UCEDD advisory committees; and that PADD boards may include UCEDDs, DDCs, and self-advocacy organization representation. The Act even specifies that the UCEDD five-year plan be "consistent with, and to the extent feasible, complement and further" the goals of the DD Councils and PADDs. The current mandates, however, do not ensure meaningful and productive collaboration. One barrier to collaboration is the staggered planning cycles. Both DD Councils and UCEDDs are on five-year planning cycles, but the cycles do not necessarily coincide. A DD Council planning document could be as much as four years old before it is considered by a UCEDD for its plan.

ADD has increased its emphasis on promoting collaboration. Currently, ADD does not have a specific definition of collaboration; however, network partners report that the ad hoc definition is the number of times the network partners meet in person or on the phone. Executive directors of all three network partners expressed that this is a narrow view of collaboration that yields neither true collaboration nor enhanced outputs and fails to capture many types of strategic collaborations that do occur. Consider, for example, the issues of DD student discipline in schools: PADDs may be developing lawsuits to create important legal precedents while the DD Council is meeting with special education directors to bring attention and publicity to the issue and UCEDDs are

training future teachers in positive behavioral support. If the groups do not actually meet, the network partners believe that ADD does not recognize the value of this type of strategic coordination. Equally if not more important than collaboration among network partners is the collaboration among the network and the state DD office; state and federal education, Medicaid, housing, and transportation agencies; and professional and advocacy groups. These relationships and alliances are essential to promote system change.

b. Funding Level

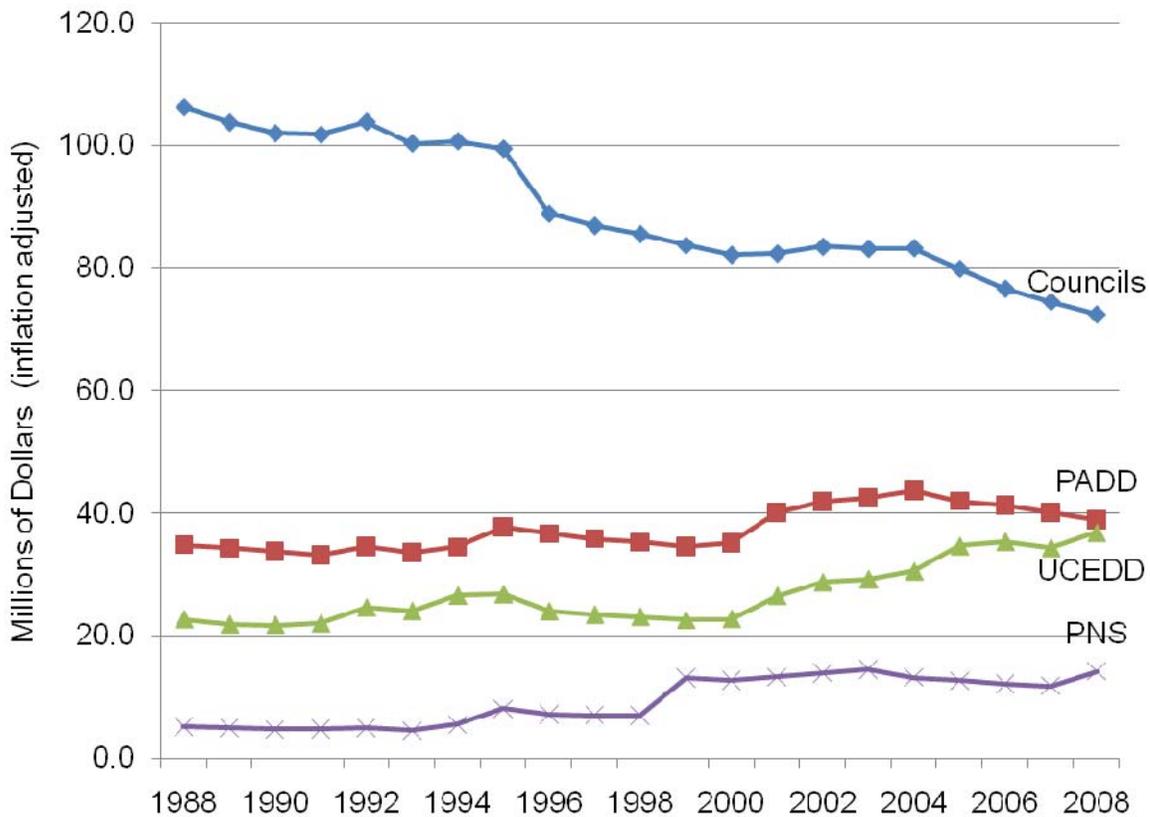
DD Act programs have a relatively low level of funding to address a broad mandate for a vulnerable population. In 2010, Congress appropriated \$170 million to the DD Act. Adjusted for inflation, this appropriation has remained at about the same level for the past 20 years. However, the distribution between programs changed; funding for the UCEDD and PADD program increased slightly, while funding for the state DD Councils declined (Exhibit 1.2). Many stakeholders argued that the level of funding for the network partners is far below what is required for them to fulfill their mandates as defined in the DD Act.

c. Areas of Emphasis

In each reauthorization of the DD Act, Congress modifies the focus of the programs by identifying specific areas in which the network partner should work. The DD Act of 2000 identifies nine “areas of emphasis”: child care, education, employment, health, housing, quality assurance, recreation, transportation, and other formal/informal community supports. The areas of emphasis are meant to direct the efforts of the programs and to provide a convenient way to categorize initiatives and measure progress.

These areas are broad enough to offer the network partners the ability to respond to almost any need identified in their planning processes. Nevertheless, stakeholders interviewed for this report identified important issues facing people with DD that are not reflected in the current areas of emphasis, including transition from school to adulthood and postsecondary education, aging caregivers, integration into the generic service

Exhibit 1.2
Funding Level for DD Act Programs, 1988–2008
(in inflation-adjusted 2008 dollars)



Source: Author’s calculations based on UCEDD appropriations reported in Graney, 2001; Sommers, 2008; and the Consumer Price Index for All Urban Consumers reported in Bureau of Labor Statistics (BLS), 2009

Note: The steady increase in funding for UCEDDs compared with that for other partners does not represent the funding trajectory for individual UCEDD grantees. While the number of State Council and PADD grantees remained constant over time, the number of UCEDDs increased from 41 in 1988 to 67 in 2009. Thus, the individual UCEDD grantees saw their inflation-adjusted funding decline steadily between 1988 and 2000 and then recover to the 1988 level by 2008 (see Chapter 2).

system, direct care workforce, access to technology, abuse and neglect, public attitudes, and empowerment/self-advocacy. As the areas of emphasis became more expansive and inclusive of all issues that affect people with DD, they became less effective as a means to focus the efforts of the resource-limited network partners and more of a categorization and reporting device. This tension between flexibility and focus runs throughout the DD Act and its implementation.

8. Self-Advocacy

Self-advocacy is based on the concept that all people with intellectual or developmental disabilities can and should have as much control as possible over their lives, and should be supported to speak on their own behalf. In the past 30 years, this concept has grown into a worldwide grassroots civil rights movement in which groups of people with disabilities “work together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other to gain confidence to speak out for what we believe in” (Self Advocates Becoming Empowered, 1991, from Hall, undated).

Some self-advocacy groups are national or statewide in scope and have local chapters. Others are more local or informal in nature. Most groups meet regularly to share their experiences, offer support, learn about their rights, and learn to speak up and advocate for themselves, and advocate on behalf of the group in legislative and policy arenas.

Congress has recognized the value of the growing self-advocacy movement and has written it into the legislation in two places. The DD Act mandates that self-advocates serve as members of the State and Territorial Councils and on the Boards of the PADD agencies, as well as on the Consumer Advisory Councils for the UCEDDs. The Act also requires State and Territorial Councils to support the establishment and strengthening of at least one statewide self-advocacy organization for individuals with DD in each state.

Self-advocates report that the three DD network programs have provided training, logistical, administrative, or financial support for the self-advocacy movement. The network partners would prefer that an additional source of funding be established for self-advocacy so that supporting the movement does not put additional strain on their already limited budgets and so that self-advocacy groups can attain and maintain their

independence. Many stakeholders interviewed for this project support the addition of a title that funds self-advocacy. However, they identified several important questions that should be addressed prior to the inclusion of a new title in the DD Act:

- Does the self-advocacy movement include those with the most significant disabilities (whom the DD Act is intended to serve) or is it structured for people with fewer support needs? Clearly, the concept of self-advocacy—that people with DD should be given maximum choice and control over their own lives and supported in communicating these choices—is applicable to all people. The question is whether the movement is, or can be, structured inclusively. Several interviewees were concerned that including a self-advocacy title would weaken the severity aspect of the DD definition in the Act, create broad new responsibilities without commensurate funding, and blur the distinction between intellectual and developmental disabilities.
- Does the self-advocacy movement have the institutional capacity to apply for and accept federal grants with the report writing and financial management requirements that accompany those grants? If not, what kinds of supports are needed to ensure that these types of requirements are met?
- What kinds of activities should be funded and what funding approach can require federal accountability while permitting the flexibility that the movement needs?
- Is the DD Act the appropriate funding source for this movement, or would it be better placed within the independent living movement, funded by the Office of Special Education and Rehabilitative Services in the DOE, and based on a similar approach of peer-to-peer effort?

The rise of the self-advocacy movement has brought an emphasis on personal choice and self-determination that impacts not only what decisions regarding DD are being made, but also *how* those decisions are made, and it has become an important force for change. It should be funded in a way most apt to ensure its success.

9. Recommendations

ADD should have a leadership role in developing and promoting public policy and programs for people with DD at the federal level based on the tenets embodied in the DD Act. Currently, ADD lacks visibility, influence, and authority.

- 1.1 ADD should be reconfigured to assume important public policy development responsibilities and receive an increase in resources to equip it to accomplish this new role. In addition, the experience and skill sets of staff assigned to this newly positioned agency should reflect its enhanced role in public policy development.
- 1.2 Congress should require that the DD Councils review and comment on any proposed changes to the state Medicaid plan or waivers that affect individuals with DD. Any application from the state to CMS should be accompanied by a letter of support or a list of concerns for CMS's consideration when deciding whether to approve the change to the plan.
- 1.3 Congress should ask GAO to assess the effectiveness of ADD's collaboration with appropriate federal agencies to determine the extent to which individuals with DD are able to access and benefit from the generic and specialized federal programs currently providing services and supports for them.

The administrative oversight of the DD Act programs should be strengthened. Currently, ADD requires grantees to report on a plethora of quantitative and qualitative measures. However, ADD does not use the data to effectively monitor grantees, hold grantees accountable, or develop national policy.

- 1.4 ADD, in partnership with the DD network, should develop a manageable and useful monitoring plan that yields data that accurately reflects the range of activities of the grantees and is useful for program administration and improvement. The data should enable ADD to identify underperforming grantees and develop applicable interventions and actions. The NCI project

could serve as a conceptual framework and model to be considered for adoption or adaptation for this activity.

- 1.5 Congress should require ADD to identify, analyze, and synthesize trends in the needs, goals, activities, outcomes, and major initiatives of DD Council plans, PADD state plans, and UCEDDs statements of work, and report the results of this trend analysis to Congress annually.
- 1.6 The Secretary of HHS should require ADD to identify the barriers and challenges currently encountered by DD Councils, PADD programs, and UCEDDs when implementing their state plan activities, and document the type, amount and cost, and effectiveness of technical assistance or support ADD has provided to enable the programs to overcome these challenges.
- 1.7 Congress should establish and maintain a dedicated funding source for technical assistance from organizations that have demonstrated successful experience with the workings and the context of each of the three network programs.
- 1.8 ADD should revise the Developmental Disabilities Program Independent Evaluation to realign it with recommendations 1.4, 1.6, and 1.7 above.
- 1.9 ADD should be staffed and resourced adequately so that it can be an active participant in mediating disputes between grantees and state agencies.

ADD should encourage meaningful collaborations among network partners and other entities. Currently, the office requires that network partners meet with each other but does not focus on the value of the collaboration and does not put the same emphasis on collaboration with other entities.

- 1.10 ADD should coordinate the reapplication process so that a state's DD Council and UCEDDs are on the same five-year planning cycle.
- 1.11 ADD should streamline reporting requirements related to collaboration and coordination among the network partners and other entities and emphasize the results of meaningful collaboration.

10. UCEDDs

UCEDDs are a rich source of research and expertise in a variety of topic areas. Their ability to provide training, engage in research, provide community services, and disseminate information is limited by the level of available funding.

- 2.1 Congress should review the funding level of university-affiliated programs that are similar to UCEDDs and increase UCEDD appropriations to be consistent with these programs and at a level sufficient to meet the goals of the DD Act.
- 2.2 ADD should make other federal partners aware of the resources available in the UCEDD network for multistate research, evaluation, and information dissemination activities.

To compete for grant funding, UCEDDs must respond to the priorities of a number of federal agencies. However, there is no coordinated approach to ensure that agencies are funding research and training to address the wide array of issues facing people with DD.

- 2.3 The Secretary of HHS should establish a mechanism to coordinate federally funded research on DD and develop a research agenda.
- 2.4 Congress should direct the GAO to identify areas in which shortages of personnel restrict access to needed supports, measure the scope of current and future training needs in those areas, assess the existing training capacity, and identify options to expand the capacity.

11. State and Territorial Councils

Councils play an important role in achieving the vision of the DD Act, yet their role could be strengthened by working more closely with Medicaid and other state agencies.

- 3.1 Congress should reaffirm the critical role played by the Councils in promoting the independence, productivity, and community integration of individuals with DD by raising the annual appropriations for Councils in order to restore the Councils' capacity for systems advocacy and demonstration activities.
- 3.2 Congress should direct HHS, through ADD and the DD Councils, to launch a major new initiative to identify, analyze, and describe eligibility and funding inequities in the current Medicaid and state DD system, and to work collaboratively with major federal partners, state DD agencies, and state Medicaid agencies to eliminate these inequities.
- 3.3 ADD should redesign the required nine areas of emphasis in state plan development and reporting format for DD Councils, and adopt a more relevant format that better reflects the systemic change, capacity-building, and advocacy roles of DD Councils and the long-term nature of their work.

12. Protection and Advocacy

The funding level for the PADD program and PADD grantees leaves some people with DD and their families without access to legal advocacy and representation. Almost 60 percent of PADD clients served needed help with education issues.

- 4.1 Congress should increase funding for the PADD program to meet the growing need for advocacy services of people with DD.
- 4.2 Congress should establish and authorize funding for a Protection and Advocacy program specific to IDEA, to be administered through the DOE, to meet the critical need for legal advocacy related to education for children with DD.
- 4.3 Congress should require that ADD and the other five agencies that fund the PADD systems streamline their reporting requirements and progress indicators so that scarce resources can be used for client services.

The investigative and legal authorities that the DD Act grants to PADD grantees are vital to the success of the program but are often under attack from states, provider groups, and a small but vocal group of parents and guardians.

- 4.4 Congress, in the next reauthorization, should preserve legal and investigative authorities embodied in the DD Act. Specifically, the reauthorization should (1) ensure that the authorities are not superseded by state or other federal laws, (2) clarify that all PADD grantees, regardless of whether they are state or nonprofit entities, have the authority to enforce their access authority in court against both public and private providers, and (3) oppose legislation that restricts the legal authority of the PADD program to represent residents of institutions.
- 4.5 If a state does not comply with the DD Act section 143 to provide access to records, the HHS Secretary should hold ADD accountable for using its authority to support PADD grantees. Furthermore, the Secretary should request sufficient resources during the budget process to ensure that ADD can achieve its mandate.

13. Projects of National Significance

PNS fund vital data collection projects, but in recent years PNS has moved away from its mission to also fund cutting-edge demonstrations that could become national models.

- 5.1 ADD should develop a transparent system for identifying PNS priorities that includes consumers, policymakers, and network partners.
- 5.2 ADD should develop an approach to track the follow up and outcomes of PNS programs in order to identify the value of PNS grants.
- 5.3 ADD should fund additional data collection initiatives in areas such as health care access, direct care workforce issues, and educational outcomes.

14. Family Support

Families play an essential and often challenging and increasingly lifelong role in supporting people with DD. Support for families is critical to enabling them to assume a proper role that recognizes the potential of a child and the freedom and legal status of an adult son or daughter. The nation needs systemic, statewide solutions that recognize the strengths and limitations of the existing family support structures in each state.

- 6.1 ADD should convene a meeting of experts, stakeholders, and government representatives to identify changes in family support services, policy, and philosophy that have occurred since the family support provision was written and recommend changes to Title II before the DD Act is reauthorized.
- 6.2 Congress should provide direct funding of Title II to ensure that funds are used consistent with the intent of the Act, rather than funding family support through PNS. The funding should be at a level of at least \$15 million.
- 6.3 ADD should coordinate through intra- and interagency groups with other federal partners that work on family support issues.

15. Direct Support Workforce

The shortage of qualified direct support workers threatens the opportunities for people with DD to be supported in the community. Currently, the shortage is not being addressed in a comprehensive manner.

- 7.1 Congress should rewrite Title III to provide grants to states to develop, implement, and evaluate comprehensive workforce development programs to attract, retain, and train direct support professionals who provide support to individuals with DD.
- 7.2 Congress should add recruitment, retention, and training of the direct care workforce to the areas of emphasis in the DD Act.

- 7.3 ADD should develop and help fund partnerships with other federal agencies to create a unified approach that ensures an adequate direct care workforce is available to serve the needs of people who are aging or have disabilities.

16. Self-Advocacy

The self-advocacy movement has a major impact on what and how decisions are being made. The movement should be supported in a way that maximizes the chance of success and maintains the principles of the DD Act.

- 8.1 The Secretary of HHS should convene a process to develop a thoughtful approach to supporting the fledgling self-advocacy movement that does not rely on the scarce resources of the DD network partners. The approach should include the input of self-advocates, DD network partners, the Centers for Independent Living, and other relevant stakeholders and potential partners.

CHAPTER 2. **University Centers for Excellence in Developmental Disabilities**

1. Introduction

ADD supports a discretionary grant program that funds 68 University Centers for Excellence in Developmental Disabilities (UCEDDs) to promote the purpose of the DD Act: “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...” [Sect 101, DD Act of 2000]. To accomplish this mission, the Centers are mandated to provide interdisciplinary training, technical assistance, research, and information dissemination services. Many also provide model direct services to children, youth, and adults with disabilities and establish model service demonstrations.

Each UCEDD receives core funding from ADD (\$528,000 in 2009) and leverages funding from other federal, state, and local sources. In 2008, with ADD committing only \$37 million, the centers leveraged more than \$485 million to work on issues related to developmental and other disabilities from federal, state, and local grants and contracts. While the ability to leverage such a substantial sum is one of the program’s overall strengths, it also represents a major challenge. Because a considerable portion of each UCEDD’s funding comes from sources other than ADD, the UCEDDs must be responsive to the mission and aims of the other funders and other authorizing legislation, such as IDEA, and therefore cannot focus exclusively on their mission as defined in the DD Act.

The DD Act began funding interdisciplinary university programs to address the critical needs facing people with DD in the early 1970s, when states were moving away from large congregate institutional placement toward active treatment and community-based care. At the time, policymakers conceptualized disability using a then current medical

model, and people with significant DD lacked adequate access to medical and allied health professionals in the community. As a result, the original programs focused on the interdisciplinary training of medical and allied health professionals, providing diagnostic services, and conducting research. The concept of disability has evolved to a “social model” with the understanding that people with DD have a broad range of needs, and the UCEDDs have contributed to establishing an academic *interdisciplinary* approach supporting this social model.

The number of UCEDDs has expanded over the years to include at least one in every state. Although all are interdisciplinary units of universities or entities associated with universities, they vary significantly in size, structure, and emphasis. For example, some continue to focus on training health and allied health care providers; others focus on early childhood, primary, secondary education, and/or employment; and others focus on public policy and broad national, state, and local systems change issues. Most UCEDDs address multiple issues, and most issues relevant to people with DD are addressed in at least one of the 67 UCEDDs.

ADD and many in government agencies and nonprofit national disability organizations consider the UCEDDs as both state and national resources. As such, many have developed strong relationships with state government agencies and have a significant impact on training and policy. However, their ability to address the issues facing their state varies based on the needs of the state, the expertise of the UCEDD, and the availability of resources.

The DD Act requires that UCEDDs develop a strategic plan that is data driven and that is consistent with and, to the degree feasible, complements and furthers the DD Council’s five-year plan goals. However, the extent to which the UCEDD has projects and expertise that support and complement the work of the DD Council varies by state.

UCEDDs have worked on many issues over the past four decades, ranging from early intervention to aging with a disability, from education to employment and recreation, from inclusive day care to school-based supports and clinical practice. In 2008, they

trained 3,560 students and fellows, provided clinical services to 105,388 individuals, and operated 1,163 projects with a research component. Over the years, as Dowrick (1998) noted, UCEDDs have been characterized as programs that have been successful at developing cutting-edge services, training, and research. The programs also have been cited in support of best practices internationally (e.g., supported employment, full inclusion, self-determination, and applied behavior analysis).

Nevertheless, after more than 30 years of funding, many challenges continue to exist and a great deal of work still needs to be done. For example:

- People with DD continue to have difficulty finding providers with appropriate training (Krauss, Gulley, Sciegaj, & Wells, 2003).
- Evidence suggests that health care providers in the community lack a current understanding of the needs and expectations of people with DD (U.S. Surgeon General, 2002). As one stakeholder said, “We need an educated and updated medical system to understand not what disability was 30 years ago but to understand what disability is right now.”

Could or should the UCEDDs play a bigger role in addressing these and other challenges facing people with DD? Do current policy, structure, and administration of the UCEDD program fully utilize their capabilities? Is there a disconnect between the breadth of the mandate and the funding level?

This report provides the background needed to address these questions by exploring the program’s strengths and challenges, ADD’s monitoring and evaluation efforts, outcomes achieved, and promising practices.

2. Program Goals

The UCEDD program is designed to complement the advocacy, capacity-building, and systemic change activities of the State Councils and the protection of legal and human

right initiatives of the PADD systems 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...” [Sect 101, DD Act of 2000].

More specifically, according to the Act, “UCEDDs are funded to provide leadership in, advise federal, state, and community policymakers about, and to promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life” [Sect 153, DD Act of 2000].

To address this broad mandate, the UCEDDs are required to engage in four core functions addressing, directly or indirectly, one or more of the areas of emphasis:

- **Interdisciplinary preservice preparation and continuing education of students and fellows.** UCEDDs provide formal training to students in a variety of fields to enhance skills in leadership, direct service, and clinical and other areas. Teaching faculty represents a variety of disciplines, such as pediatrics, early intervention, education, psychology, social work, law, public health, social services, disability studies, and nursing, in order to develop a cadre of individuals with the necessary knowledge, skills, attitudes, and values to provide or influence services and supports for people with DD and their families.
- **Community services.** UCEDDs provide training, technical assistance, and information to individuals with DD, families, support service organizations, professionals, paraprofessionals, students, state systems, volunteers and others. In addition, they provide clinical services and direct services to people with developmental and other disabilities using demonstration and model activities.

- **Research.** To advance general knowledge in the field and provide policy-relevant information, UCEDDs engage in basic and applied research in a variety of fields, most notably early intervention, education (at all levels) and rehabilitation, medical, pharmacological and biological, and public policy analysis.
- **Dissemination of information.** UCEDDs educate and inform various audiences, such as people with DD and their families, researchers, policymakers, professional and consumer groups, employers, and other DD network programs. They work to bridge the gap between research and practice by developing products and resources in a variety of formats that are then disseminated to families, consumers, and professionals throughout the United States and internationally.

3. History and Context

The UCEDD programs evolved out of the University Affiliated Facilities (UAFs) first authorized in the Mental Retardation Facilities Act, signed by President Kennedy in 1963 (P.L. 88-164). The original grants included funding to build medical/training facilities and emphasized clinical services, diagnosis and treatment programs, and interdisciplinary training of personnel. They were designed to train and expand a national cadre of health and allied health professionals to address the needs of individuals with DD (Fifield & Fifield, 1995). The focus of the centers has evolved as the values identified in the DD Act have moved from institution-based services to community-based services to community integration and self-determination.

The first UAFs were constructed in the early 1970s, when access to care in the community was severely limited. Most specialty care and dentistry was provided within institutions, and few community physicians and dentists had the training, knowledge, and understanding to serve people with significant DD. By exposing nonspecialists to patients with DD, the UAFs were able to expand the number of community physicians as well as motor and language therapists and educators who could serve people with DD.

The grants soon eliminated the funding for facilities and changed the name from “facilities” to “programs,” and since the late 1980s the programs have expanded their focus from medical and allied health care to include education, consumer empowerment, productivity, independence, and inclusion. Recent reauthorizations have increased the importance of community-based programming, technical assistance, and dissemination.

The 2000 reauthorization added research as a core function and renamed the University Affiliated Programs UCEDDs. This name change reflected the evolution of the entities from individual programs to centers that have multiple partners and multiple functions and carry out a profile of activities.

The size of the UCEDD network has been expanding slowly since its inception. As of 1996, ADD has provided funding for at least one UCEDD in each state.

4. How the Program Operates

Each of the 67 UCEDDs receives the same amount of funding, with annual funding levels determined by the appropriations process (FY 2009 funding is \$528,000 per year). The centers are expected to leverage this core ADD funding into federal, state, and local grant support to fund disability-related activities. UCEDDs employ a range of leveraging mechanisms including federal, state, and local grants and/or contracts; cooperative agreements; private sector support; and some fundraising.

Each UCEDD has a different mix of activities and populations served. Some provide direct service on-site, while others provide very few services on-site but provide substantial technical assistance and community services in their local community and throughout their state.

Every five years, each UCEDD must develop a five-year plan, in conjunction with a Consumer Advisory Committee, and reapply for funds.

a. Core Grant

The \$528,000 annual grant from ADD provides core funding for the UCEDDs. For some of the larger centers, the core grant covers administrative expenses that are difficult to cover with other funding sources. For the smaller programs, the core grant represents a substantial portion of their operating budget.

b. Leveraging Other Funding Sources

Since their inception in 1972, UCEDDs have been expected to compete for federal or state contracts and grants. Typically, these grants are relatively short term (one to five years). Some UCEDDs have secured additional predictable funding. Most notably,

- Thirty-four UCEDDs are co-located in universities that have Leadership Education in Neurodevelopmental & Related Disabilities grants from the Maternal Child Health Bureau of the Health Resources and Services Administration (HRSA). These grants support specific training initiatives for children by providing stipends for graduate students and subsidizing faculty from 13 disciplines.
- Twelve UCEDDs are also Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers funded by the NIH. These grants provide core funding for biomedical and behavioral research.
- Another growing funding source has been the National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC). Eight of the UCEDDs run State Disability and Health Programs with their respective State Health Departments, while others participate in surveillance research for disorders such as autism, fragile X, early hearing loss, and spina bifida funding by NCBDDD.

As shown in Exhibit 2.1, the DOE represents the largest source of funding, followed by NIH and ACF. CMS provides \$7.2 million to UCEDDs for research and training—only

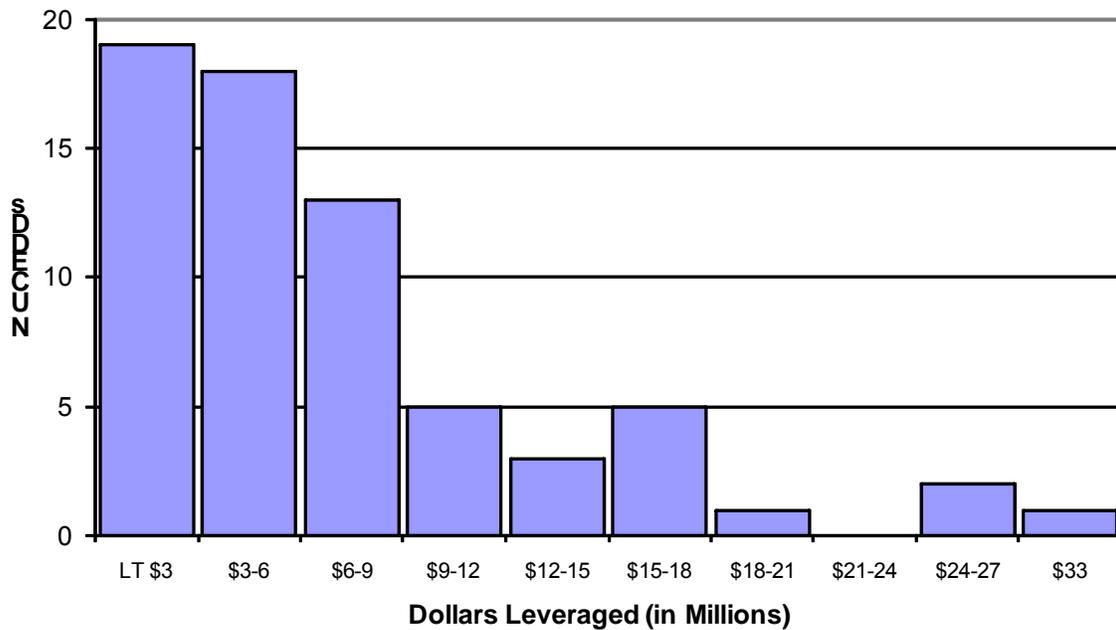
0.04 percent of the \$19.6 billion that CMS spends for direct services for people with intellectual and developmental disabilities in home- and community-based waivers, ICF/MR, and related Medicaid programs (based on data from Braddock et al., 2008).

| Exhibit 2.1 Federal Funds Leveraged for UCEDD Research, 2008 | | |
|-------------------------------------------------------------------------|------------------------------------------|---------------------------------------------------------------|
| Department or Administration | 2008 Funding (in \$ millions) | Percentage of Total Research Funding Leveraged |
| Department of Education | \$59.8 | 32% |
| National Institutes of Health | \$48.9 | 26% |
| Administration on Children and Families | \$35.2 | 19% |
| Health Resources and Services Administration | \$16.5 | 9% |
| Other Administrations in Health and Human Services | \$9.7 | 5% |
| Other federal | \$7.4 | 4% |
| Centers for Medicare and Medicaid Services | \$7.2 | 4% |
| Centers for Disease Control and Prevention | \$4.1 | 2% |
| All Sources | \$188.7 | 100% |
| Source: Association of University Centers on Disabilities (AUCD), 2009 | | |

On average, the ADD core grant represents only 6 to 15 percent of the total UCEDD budget (Association of University Centers on Disabilities, 2009), but it provides important infrastructure funds, ensures long-term viability and short-term bridge funding for the center when other grant funding is not available, and is intended to make the UCEDD program attractive to university administrations and academic departments.

The amount of funds leveraged varies significantly among centers. As shown in Exhibit 2.2, 16 programs leverage less than \$3 million, while one program leverages \$33 million.

**Exhibit 2.2
Distribution of Total Dollars Leveraged by UCEDDs, 2008**



Source: Retrieved from the National Information and Reporting System by AUCD staff upon request.

1. On average, 43 percent of the funds are from federal sources, 32 percent from state organizations, 10 percent from local governments, and 15 percent from other sources. The relative importance of each funding source varies significantly among centers. For example, state sources represent more than 50 percent of funding in 16 of the centers and less than 10 percent of the funding in 10 centers.

c. Five-Year Plans

Each UCEDD must develop a five-year strategic plan with input from staff, a consumer advisory committee, ADD sister programs (the Council and PADD), and other state agencies and organizations. This plan forms the basis of the application for continued funding that the UCEDD submits to ADD. The plan must include a projected goal related to one or more areas of emphasis for each of the core functions required by UCEDDs.

The ability of a UCEDD to adhere to the strategies outlined in its five-year plan depends, in large part, on available funding opportunities and its ability to secure these funds through grant applications. Because funding opportunities are unpredictable, UCEDDs must develop the strategic plan based on existing and projected funding. The center must formulate the plan without always knowing exactly what type of grants and contracts the funders will be awarding or whether the UCEDD will be successful in its applications.

d. Consumer Advisory Committee

In compliance with the DD Act, all UCEDDs have a Consumer Advisory Committee (CAC) that meets at least twice a year to assist with the development of the five-year plan, participate in an annual review of the plan, and make recommendations regarding any proposed revisions. The CACs are composed of self-advocates; parents who have children with DD; and representatives from the UCEDD, the PADD, and the DD Council. Typically, there is also representation from state and community partners. The majority of CAC members are individuals with DD and parents or family members of people with DD.

e. Areas of Emphasis

In the five-year application for reauthorization and the annual review, for each core function UCEDDs identify goals related to one or more of the nine areas of emphasis identified in the DD Act: quality assurance, education and early intervention, child care, health, employment, housing, transportation, recreation, and other. Taken together, the areas cover most but not all topics in which UCEDDs are or could be involved. Topics such as postsecondary education, aging, and assistive technology are not included, nor are barriers that cut across service systems. UCEDDs are free to work in these areas and report them in the “other” category, but these areas do not have the visibility of the other issues. The areas of emphasis do not include the full range of areas in which the UCEDDs work, but do not seem to restrict the work of the UCEDDs.

The areas of emphasis serve two purposes: First, they provide a common language by which UCEDDs, CACs, and other network partners can talk about their work. Second, they provide ADD with a mechanism to classify the efforts being devoted to a particular area.

UCEDDs are required to address one or more areas of emphasis. All report that they have projects in at least three areas of emphasis, and several report that they have projects in all identified areas. Individual projects may address multiple areas of emphasis; each UCEDD addresses an average of seven areas of emphasis. The most common areas of emphasis are education/early intervention and health. These correspond closely to the two largest funders—DOE and NIH.

| Exhibit 2.3 Percentage of UCEDDs Reporting Work in Each of the Areas of Emphasis, Based on 2008 Annual Reports to ADD | |
|--------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|
| Category | Percentage of UCEDDs |
| Education and Early Intervention | 94% |
| Health | 89% |
| Quality Assurance | 71% |
| Employment | 60% |
| Child Care | 54% |
| Housing | 40% |
| Transportation | 32% |
| Recreation | 30% |
| Other | |
| Quality of Life | 63% |
| Other Leadership | 56% |
| Cultural Diversity | 43% |
| Assistive Technology | 40% |
| Other | 38% |
| Source: Author's analysis of 2008 UCEDD annual reports | |

If ADD is interested in maintaining the areas of emphasis as reporting devices, there are two approaches for expanding the areas of emphasis in the next reauthorization. Additional areas of emphasis such as aging caregivers, aging with a disability, postsecondary schooling, technology, abuse and neglect, integration in the generic service system, or disability studies could be added to the DD Act. Alternatively, the areas of emphasis could be replaced with more general categories that would be more inclusive of possible areas of effort, such as community living, health, education, and employment. If ADD is interested in using the areas of emphasis to guide the work of the UCEDDs, then a different approach is warranted.

f. National Training Initiatives on Critical and Emerging Needs

When appropriations exceed the sum needed to fund the core awards, ADD may award grants for “national training initiatives” (NTIs).

In accordance with the DD Act, ADD established a consultation process to identify emerging and unmet needs of people with DD. Based on the meeting, which included representatives of all network partners as well as consumers and family members, ADD identified self-determination and postsecondary education as the two most important emerging issues.

The office solicited proposals, and in October 2008, awarded Cooperative Agreements in the amount of \$800,000 to two consortia of UCEDDs. These awards served dual purposes. First, they draw on a range of disciplines and expertise available in the UCEDD network. Second, they provided an opportunity for centers to collaborate and strengthen their relationships while addressing critical national issues that face people with DD.

In addition to the NTIs, each UCEDD is eligible to compete for additional funding from ADD for PNS (including the Family Support 360 projects) funded under Title I subtitle E of the DD Act (see Chapters 5 and 6 for a discussion of these programs).

5. Accomplishments

The true “outcome” of a program is defined as a result “which otherwise would not have occurred without the program intervention” (Office of Management and Budget, 2008). However, the outcomes of the DD Act (to improve access, promote self-determination, etc.) are achieved not only through the efforts of DD network programs, but also through the combined efforts of a large number of organizations, agencies, and individuals. Thus, it is not possible to demonstrate directly that a UCEDD was solely responsible for any particular outcome.

Despite the methodological constraints, evidence suggests that the UCEDD program has been very effective in many areas:

- The ADD core funding has facilitated the development of a beachhead for research and training for DD into universities.
- UCEDDs have been on the forefront of interdisciplinary training and service for 35 years, moving practice from unidisciplinary to multidisciplinary to interdisciplinary approaches.
- UCEDDs were instrumental in the development of early intervention and early childhood programs, including the development of assessment and diagnosis, service delivery models, and personnel training. In many states they continue to play a major role in providing technical assistance to infant intervention and early childhood special education programs.
- For 35 years, the UCEDDs have prepared personnel for work in the national disability service system, from early childhood special education programs to job coaches, positive behavioral support specialists, and direct service workers in the residential/community living systems.
- UCEDDs traditionally have played a key role in providing public policy and service delivery resources in their states. Major areas of impact include special education, autism research and services, and Medicaid programs.

6. Strengths and Weaknesses

a. Long History and Stable Programs

The Federal Government has been funding interdisciplinary centers in universities to address the needs of people with DD for more than 35 years. The guaranteed funding from the DD Act supports the infrastructure and to some extent guarantees the ongoing existence of the centers. The stability of the program offers several advantages, including that the centers are:

- able to develop a long-term strategic relationship with the state and other agents of systems change.
- allowed to develop a reputation in the field, which enhances their ability to leverage additional resources.
- ensured a long-term view of the needs of people with DD and able to build the infrastructure to plan for future needs.

b. Interdisciplinary Focus

People with DD face complex medical, educational, and community issues that cannot be addressed by a single discipline. In the 1970s, the notion of interdisciplinary approach was having a neurologist, a pediatrician, an occupational therapist, and a physical therapist. Now the term encompasses educational specialists, behavioral specialists, psychologists, dieticians, occupational and physical therapists, economists, engineers, and others. This interdisciplinary approach—

- Affords researchers opportunity to work with people from different academic disciplines to address a single issue.
- Provides opportunities for students who are focusing on DD to work effectively side-by-side with professionals from other disciplines.

- Provides opportunities for students in disciplines such as medicine or economics who are not specifically focusing on DD to understand the issues and barriers faced by people living with DD, thereby expanding the reach of the DD Act into generic research and service systems.
- Stands in contrast to the categorical nature of most federal programs.

c. University Affiliation

Affiliation with a university is one of the core requirements of each UCEDD. The structure of the affiliation varies among UCEDDs. Physically, some of the centers are on campus, others are off-campus in rented space. Programmatically, some are fully integrated into the university, while others have a more distant relationship with the university and are more embedded in the community.

This affiliation is one of the strengths of the program but may also present challenges:

- Being part of the university enables the UCEDDs to influence the training of future cohorts of professionals who will be serving people with disabilities and the general population. UCEDDs can influence four types of students: (1) preservice interdisciplinary students (usually graduate students or students pursuing a professional degree) who already have shown an inclination toward participating in a disability-related field; (2) students from a variety of departments who participate in disability studies; (3) students throughout the university who may never have thought about disability as an interest or career but have been exposed to disability content in one of their classes or courses; and (4) continuing education students who may already be practicing in a disability-related field and take a UCEDD-sponsored course to upgrade their knowledge and skills.
- A UCEDD that is well-integrated with the university can infuse issues related to DD into the curricula of other departments, thereby “mainstreaming” the

issue into areas such as law, engineering, architecture, economics, and the social sciences.

- The university affiliation gives the UCEDD credibility as an objective source of information.
- The university provides a stable infrastructure that is likely to continue in the future for UCEDD research, training, and service development.

On the other hand, UCEDDs may grant certificates but are not degree-granting academic departments within universities. They are typically centers within departments, colleges, or other academic units. For example, a UCEDD may be in a medical school department of pediatrics or in a college of education, or it may be a separate entity that spans several departments or a center with an interdisciplinary institute. These administrative details may affect the visibility of the program, the status of faculty positions, the commitment of the university to provide financial support, and the ability of the center to recruit students for training. Many UCEDDs have been able to work with university departments to recruit faculty and to obtain faculty appointments and tenure. Some UCEDDs have been able to influence their universities to develop certificate and undergraduate and graduate programs in disability studies and rehabilitation sciences. Other UCEDDs continue to struggle with these issues.

d. Technical Assistance Center

The past two ADD commissioners identified AUCD as a “best practice” or a “model technical assistance program.”

In the past nine years, AUCD has promoted the capacity of the UCEDDs to work as a network or subnetworks to carry out multisite, multistate coordinated evaluations or research and development projects. This approach capitalizes on the aggregate expertise and experience contained in the network and the ease with which centers could collaborate with each other:

- SSA contracted with AUCD for assistance in assessing the determination process for children in certain populations (e.g., premature infants, teens with behavioral issues, 18-year-olds). AUCD subcontracted with eight centers to conduct interdisciplinary comprehensive evaluations (file review and face-to-face assessments) of a number of children in their states. Based on the UCEDD recommendations, SSA wrote regulations that changed eligibility guidelines.
- AUCD has a cooperative agreement with CDC in which AUCD facilitates and coordinates a grant process. Based on CDC's areas of interest, AUCD announces a research topic of interest or product development competition among the UCEDDs. The centers submit applications to AUCD, which convenes panels of reviewers and provides the scores to CDC. CDC decides which of the UCEDDs receive the grants. AUCD then manages the grant program, serving as a liaison between scientists at CDC and the funded projects.

Because of arrangements like these, AUCD's budget has grown from \$700,000 in 2000 to \$6.4 million in 2008, with almost 70 percent of funds going back to UCEDDs that participate in various efforts. These types of arrangements strengthen the UCEDD network and provide an efficient and expedient process for Government agencies to accomplish their work, as well as gain expertise and points of dissemination in the participating states. However, it carries the risk of compromising AUCD independence and ability to critique these agencies when needed to serve the public good. In addition, it excludes qualified entities outside the UCEDD network.

However, UCEDD directors and AUCD leadership believe that there are untapped opportunities for the UCEDD network to work with some of the Government agencies that fund individual UCEDDs, such as DOE, the DOL, DOJ, and HHS. By establishing models similar to those established by SSA and CDC, these agencies could use the network for the following:

- Nationwide research and development: Many UCEDDs have developed a track record in research and development that could be harnessed into a nationwide approach.
- Nationwide demonstrations: With a presence in all 50 states, the District of Columbia, and the trust territories and a history of collaborations, the UCEDD network is in a unique position to implement nationwide demonstrations focused on people with DD.
- Nationwide dissemination: The UCEDDs are connected to providers, advocacy groups, parent groups, and state governments, and could serve as credible sources to inform stakeholders of new initiatives, findings, and best practices.
- Translation of research to practice: With expertise in both research and service provision, the UCEDDs are able to quickly translate research into practice. A stronger formal connection with various research-based agencies such as NIH, the Institute for Educational Sciences, and National Institute on Disability Research and Rehabilitation would enhance this opportunity.

The value of strengthening the UCEDD network goes beyond increasing funding opportunities.

Because each UCEDD has a different focus, a well-integrated network would be able to better serve each state by providing expertise that is not available in its own UCEDD. For example, a state may need training in positive behavioral supports, but the state's own UCEDD focuses on disability policy studies and primary health care. The network could fill the gap.

An integrated UCEDD network could also better serve the PADD organizations and the DD Councils. For example, a PADD organization may want a UCEDD expert to assist in investigations or provide expert testimony against a state or school district. The state's own UCEDD wants to avoid establishing an adversarial relationship with the state that may jeopardize their funding and their ability to provide training and technical assistance

to the state. With a strong UCEDD network, the PADD could use an expert from a UCEDD in a neighboring state.

e. Consumer Input

The DD Act requires that each UCEDD have a Consumer Advisory Council (CAC). This language mandates a mechanism for consumers to influence the strategic planning process and to provide ongoing input to the UCEDD.

The nature of the UCEDD program situated in a university structure with its own governing structure and funding contingencies poses certain challenges for the CAC to represent the needs of the consumers. For example:

- The CAC works within confines of the strength and expertise of each UCEDD. If the community needs technical assistance with systems change activities but the UCEDD is focused on medical interventions, CAC recommendations may be difficult to implement.
- Given the current expertise and focus of a particular UCEDD, it may not be possible for them to garner grant funding to address the needs that the CAC deems important. Even if a UCEDD submits applications, there is no assurance that it will be funded or that its application will be successful.

On the other hand, a strong CAC can influence the professional training of a wide range of professionals who will be serving people with developmental and other disabilities for years to come. Their input into possible projects and areas of focus can influence the workforce available in their state and the type of training they receive.

ADD initiated and funded supports for the CACs through AUCD in two ways. First, AUCD's Council on Community Advocacy (COCA), an organization of CAC members, facilitates networking and information sharing among CACs from different UCEDDs. COCA has annual meetings and an electronic mailing list. Second, AUCD, with the

participation of CAC members from around the country, developed a training curriculum to introduce CAC members to their roles and responsibilities.

In the absence of a comprehensive evaluation of the role of the CACs, it is not possible to determine the extent to which each of these challenges and advantages impact the influence of the CACs.

f. Follow the Lead of the DD Act

The DD Act includes a list of 12 principles that specify values and beliefs concerning the capability and participation of individuals with disabilities and their family members, such as respect for individual and cultural differences, the benefits of services and supports provided in an individual manner, and the advantages of integration and participation (42 USC 15001).

The UCEDDs are tasked with figuring out how to best develop these principles into research, training, and practice. In addition to setting out principles that drive the research, ADD and the DD Act can put special emphasis on certain topics. For example, the DD Act of 2000 specifically identifies the need to promote positive alternatives to the use of restraints and seclusion.

UCEDDs have addressed this issue using each of the four core functions, as shown in Exhibit 2.4:

Exhibit 2.4 Core Functions of UCEDDs

Preservice Training

The universities of Oregon, Kansas, and South Florida have developed, evaluated, and disseminated Web-based instructional modules on positive behavioral supports for use in preservice training.

Community Service

UCEDDs are providing training on positive behavioral supports to a number of populations, including direct service workers and other professionals (AR); teachers (OR); consumers, families, parents, direct care staff, provider agency personnel, and staff of early intervention and other programs (UT); and brain injury specialists (VA).

Several UCEDDs provide technical assistance to schools (including onsite observation and assistance) (AZ, NJ, FL, GU); and Medicaid home and community-based waiver providers (ID).

One UCEDD is working with the state DD agency to modify language in Medicaid waivers to more effectively utilize Medicaid funding for positive behavioral supports (SC).

Research

Two UCEDDs have undertaken medical/scientific studies related to understanding behavior in order to develop appropriate behavioral support strategies. One is studying the co-occurrence of cognitive problems and difficult temperament characteristics (CA-UC Davis), and the other is developing animal and human laboratory models of maladaptive behaviors in order to understand the environmental factors that precipitate those behaviors (KS).

Dissemination

Principles, values, and approaches to positive behavioral support developed at the University of Oregon are currently being implemented in more than 4,500 schools in the United States. The UCEDD has developed Web sites that offer information about positive behavioral supports, provide fidelity monitoring, and analyze patterns of office discipline.

7. Major Issue—Funding

In 2009, each UCEDD received \$528,000. The centers use this funding for administrative costs and grant applications. They reapply for continued funding every five years in a closed competition; that is, only current grantees are eligible to apply for

funding. These funding issues—leveraging, flat funding, closed competitions, and the funding level—create both strengths and challenges for the program.

a. Leveraging

This arrangement of a “permanent” budget with time-limited, project-specific funding has advantages and disadvantages. On the positive side:

- Requiring the UCEDDs to repeatedly compete for ADD funds and to leverage resources by applying to other agencies for competitive funding ensures that their approaches are up-to-date, peer reviewed, and meeting the needs of other federal agencies.
- The UCEDDs introduce the needs of people with DD into multiple forums and federal agencies. For example, if there is funding for literacy available from the DOE, UCEDDs will try to figure out how their mission and the needs of students with DD as well as other disabilities fits with this funding, thereby mainstreaming the DD agenda.
- The funding structure promotes interagency collaboration. Awarded grants tend to be applied and field based, rather than entirely initiated by the scientist (Dowrick, 1998). For example, almost half the centers have contracts with state agencies to provide policy development/analysis and to provide direct services such as diagnostic and assessment services or case management (AUCD, 2008).

On the challenging side, the UCEDD’s portfolio of work is dictated in part by state and federal agency funding priorities, rather than necessarily by an objective review of the needs of the community or by the DD Act’s areas of emphasis. The degree to which federal and state priorities actually match the needs of people with DD is an open question and probably varies by state and national priorities at a particular time.

In addition, there is no national research agenda that identifies gaps in existing knowledge related to DD, priorities, feasibility, and timetables for priority research (U.S. Surgeon General, 2002). As a result, funding sources pursue their own agendas rather than coordinating their efforts. The real issue is the lack of a coordinated and comprehensive approach to research, training, and technical assistance. Conflicting priorities at the federal level provide a significant mixed message as to the outcomes desired by the different federal agencies. Recent attempts to coordinate across federal agencies, as in the autism area through the Interagency Autism Coordinating Council and the Office on Disability, may provide overall direction for national research and service priorities.

Many UCEDD grants are focused on a population larger than the DD population. For example, education programs may address the needs of children with a wide range of disabilities, some of which would not meet the “severity” aspect of the DD definition. Programs addressing the needs of adults may focus on the needs of adults with significant disabilities, regardless of the age of onset. Recognizing the overlapping needs between those with DD and those with other disabilities, as well as the priorities of other funding sources, the DD Act allows the UCEDDs to undertake programs that address a wide range of disabilities. As a result, although it would be natural for an evaluation of the DD Act to assess the extent to which the UCEDDs serve people with DD, it is not possible to quantify the funds that are used directly for DD.

b. Flat Funding

In contrast to the State Councils and PADDs, all UCEDDs receive the same amount of funding regardless of the size of the state. To the extent that the DD Act funds serve as a “core grant” (a platform with which to leverage additional sources), this flat funding structure is appropriate. However, to the limited extent that the funding is used to support important projects that are not funded through other state or federal entities, the flat funding poses a challenge for the UCEDDs in larger states, those with more complex issues, and those with less available state funding, although some states do have multiple UCEDDs.

c. Closed Competition

Every five years, on a rotating basis, each UCEDD must reapply for continued funding and have its proposals peer reviewed. Reviewers as well as ADD can place conditions on individual centers if the office determines that grant applications were not in compliance or had significant weaknesses. However, by statute, only existing UCEDDs may apply for funding, except in years when funds are available for adding centers to the network.

The fact that UCEDDs do not openly compete with other entities that meet certain requirements is an unusual feature of the DD Act. Most federal research and training grant competitions, such as the Rehabilitation Research and Training Centers funded by DOE, are issued as an open competition. The U.S. Government has a general policy of encouraging full, open, and fair competition for research supported by federal funding (e.g., the Competition in Contracting Act of 1985).

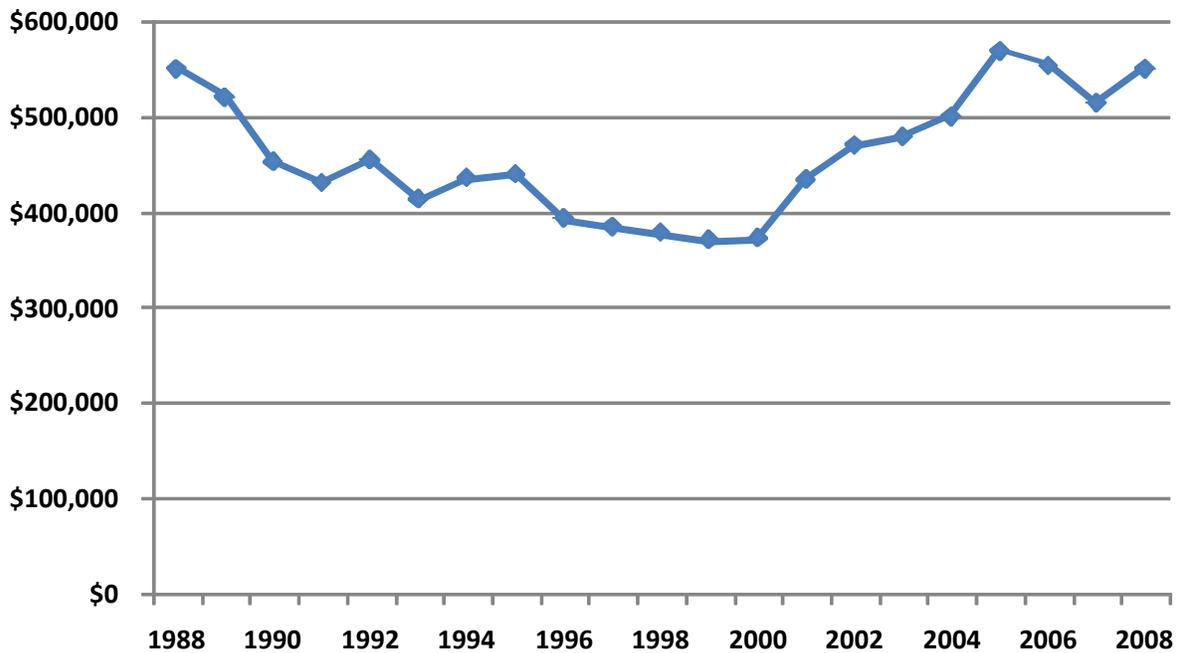
d. Funding Level

The funding level has increased steadily, from \$382,888 in 2002 (Exhibit 2.5) to \$528,000 in 2009. Nevertheless, representatives of advocacy groups, ADD, and the UCEDDs believe that the program could be more robust with additional funding.

Additional core funding would enable the UCEDDs to address issues that are not funded by other agencies or organizations. Often these are issues that do not fit squarely into the categorical nature of other agencies, such as dual diagnosis of developmental disability and mental health issues; aging with a disability; and integration of employment, housing, transportation, and recreation.

UCEDDs are able to commit only a small amount of time to projects that are not funded. Therefore, they have limited flexibility to assist other network partners. With additional core funding, UCEDDs could provide training, technical assistance, and information to other network partners.

Exhibit 2.5
Average Funding Level per Center, 1988–2009
(in inflation-adjusted 2009 dollars)*



Source: Author's calculations based on UCEDD appropriations reported in Graney, 2001; Sommers, 2008; and the Consumer Price Index for All Urban Consumers Reported in BLS, 2009.

*included core funding and related funding such as National Training Initiatives and Training Initiative Projects

An exhaustive comparison between UCEDD core funding and that of similar programs is beyond the scope of this report. However, cursory analysis suggests the UCEDD core funding is similar in size to some of the P30 grants from NIH that provide administrative support to centers that hold multiple NIH grants, but is substantially smaller than the Department of Agriculture Extension grants that fund core support and outreach and dissemination activities. This suggests that additional funding would be needed to pursue otherwise unfunded activities.

8. Current Monitoring and Evaluation Activities

ADD uses four tools to monitor and evaluate the UCEDDs: the annual report, the MTARS, the five-year application for reauthorization, and the GPRA/PART measure. These tools provide ADD with information about whether each grantee is in compliance with the law and regulations, but they do not assess the quality or impact of the individual centers or of the UCEDD program, nor do they identify short- or long-term outcomes.

a. Annual Report

The annual report includes a description of each of the projects in which the UCEDD is engaged and how those projects are related to the goals specified in the five-year plan. In addition, the report includes funds leveraged and data on the number and scope of technical assistance activities, products developed, and students trained as well as measures of trainee and consumer satisfaction.

b. Monitoring and Technical Assistance Review System

As described in Chapter 1, the MTARS brings together peers, consumers, and ADD staff to comprehensively review all network grantees (UCEDDs, DD Councils, and PADDs) in two to five states per year.

Prior to its inclusion in the MTARS process, AUCD had developed a quality enhancement system that facilitated peer-to-peer review and technical assistance. Although ADD reports that this approach did not meet its monitoring needs, many UCEDD directors mentioned that the peer review was more consistent with typical university reviews, bolstered underperforming centers, and provided a mechanism for quality improvement using methods that are well accepted in the higher education community.

c. Application for Continued Funding and Peer Review

In compliance with the language of the DD Act, ADD convenes three-person review panels to evaluate the UCEDD applications. Each panel includes a UCEDD director and may include representatives from a DD Council or PADD grantee and a family member or self-advocate. The review team assesses the extent to which the UCEDD has a sound needs assessment, goals that are tied to the needs, a practical strategy to achieve those goals, and an evaluation process to measure their effectiveness. In addition, the team looks at the involvement of the CAC in developing the strategic plan.

If the peer review team finds significant fault with the application, ADD can discontinue funding or place conditions on the grantee, which the grantee has to address before full funding is approved. To date, no UCEDD has lost its funding as a result of an inadequate application, but ADD has used its option to place conditions on grantees and require centers to submit revisions because their goals were either insufficiently measurable or not clearly related to the stated needs of the community, or because their strategies were not sufficiently articulated.

d. Performance Measures

As part of the annual performance report, ADD was required to develop goals for each grant program and report annually on progress toward those goals. The goal for the UCEDDs is to “Increase the percentage of individuals with developmental disabilities receiving the benefit of services through activities in which professionals were involved who had completed University Centers of Excellence in Developmental Disabilities state-of-the-art training within the past 10 years.”

Based on survey data collected by the UCEDDs from professionals they had trained one, five, and ten years ago, ADD estimated that in 2007, 40 percent of individuals with DD were receiving services in which UCEDD-trained professionals were involved. The value dropped to 37 percent in 2008 (Administration on Children and Families, 2008).

In theory, the performance measure quantifies an important outcome of the UCEDDs. However, the data needed to estimate the value carries so much statistical uncertainty that it is not useful, because it would be impossible to see any meaningful changes from year to year (or even decade to decade) that could be attributed to real changes in the performance of the UCEDDs rather than random variation in the measure.

9. Promising Practices

UCEDDs have developed promising practices in many topic areas. For the purpose of this report, promising practices are those that maximize the impact of their training, technical assistance, research, and information dissemination on systems change. In the first three practices, UCEDDs impact the system directly. In the last two practices, the UCEDD impacts public perceptions of people with DD, which is a critical component to changing the system.

a. Coordination with State Agencies

The University of Iowa collaborates with the state Medicaid agency to rebalance the long-term care system. The UCEDD works with state and local councils and task forces for people with disabilities and the elderly. By writing grant proposals, the UCEDD has brought in grant funding to the state from CMS (Real Choice Systems Transformation, Money Follows the Person Medicaid Infrastructure grants) and the Robert Wood Johnson Foundation (Cash and Counseling). Since 2004, the UCEDD has had at least one staff person embedded at the state Medicaid office to coordinate systems change activities. As a result of these initiatives, 651 Iowans with disabilities (including 390 with DD) have more choice in hiring direct service workers, and 528 people with DD moved from ICF/MR to the community.

b. Technical Assistance and Dissemination

The Institute for Community Inclusion (ICI) at the University of Massachusetts Boston, in collaboration with the National Association of State Directors of Developmental Disability Services, has developed a national State Employment Leadership Network where individual state Mental Retardation and Developmental Disabilities agencies can purchase a seat at the table (\$35,000 annually per member state) and be involved with the development of local and national policies and practices addressing employment of people with DD. By 2009, membership had grown to 17 states in all regions of the country. ICI provides technical assistance to the group using its long-standing research on employment strategies as well as its PNS-funded data collection efforts (Kiernan, 2008; National Association of State Directors of Developmental Disability Services & Institute for Community Inclusion, 2008). The willingness of states to contribute a substantial amount to participate in the initiatives indicates its value to the states.

c. Research, Policy, and Practice Working Together

The University of Kentucky Interdisciplinary Human Development Institute, in conjunction with another university in the state and a state agency, has undertaken a large multisite study investigating the impact of the professional development component of Kentucky's early childhood initiative, KIDS-NOW. The UCEDD has provided ongoing technical assistance and training for the initiative, and this long-standing relationship will enhance its ability to translate findings from the research into modifications to the program.

d. Outreach to the General Population

The University of Minnesota developed a year-long, 20-module curriculum fostering the social inclusion of junior and senior high school students with disabilities in school and the community. The program brings together students with and without disabilities for weekly classroom instruction and community experiences that increase understanding of the social inclusion needs and challenges of people with disabilities. Each student

with a disability is paired with another student who serves as an inclusion facilitator. The training is designed to guide teachers and community organization staff in implementing the curriculum without additional specialized training. However, technical assistance and on-site training are available from the *Yes I Can* program staff at the Institute. As of 2007, 13 states have schools and districts implementing the program (Institute on Community Integration, undated).

e. Infusing Disability Topics into a General Curriculum

At JFK Partners/University of Colorado Health Sciences Center, all pediatric residents complete a rotation in behavioral pediatrics that includes both didactic information and direct experiences with children with DD and their families.

f. Community Participation

University of Missouri Kansas City works closely with Self Advocates Becoming Empowered (SABE) to promote the inclusion of self advocates in both the UCEDD governing board and national advocacy initiatives. In addition to providing formal advocacy training, the UCEDD provides mentoring and encourages SABE members to participate in national conferences by providing financial support and personal assistance services.

10. Recommendations

- 2.1 Congress should review the funding level of university-affiliated programs that are similar to UCEDDs and increase the UCEDD appropriations to be consistent with these programs and at a level sufficient to meet the goals of the DD Act.
- 2.2 ADD should make other federal partners aware of the UCEDD network resources for multistate research, evaluation, and information dissemination activities.

- 2.3 The Secretary of HHS should establish a mechanism to coordinate federally funded research on DD and develop a research agenda.
- 2.4 Congress should direct the Government Accountability Office to identify areas in which shortages of personnel restrict access to needed supports, measure the scope of current and future training needs in those areas, assess the existing training capacity, and identify options to expand the capacity.

CHAPTER 3. State and Territorial Councils

1. Introduction

The State and Territorial Councils on Developmental Disabilities (Councils) were first established nearly 40 years ago in the Developmental Disabilities Act Amendments of 1970. When first conceived, the Councils were charged with planning a service system that would meet the medical and developmental needs of people with DD. The Councils were charged with a bold mission of coordinating the efforts of families, professionals, and state agencies to design and deliver necessary supports for all people with DD. Today, the Councils address myriad legislative, policy, programmatic, and fiscal issues through their advocacy, capacity-building, and system change activities.

The purpose of this chapter is to examine the current status of the Council program and offer recommendations designed to guide future program structures and activities that will enable Councils, state network partners, ADD, and other collaborating state and federal partners to better fulfill the mission and goals of the DD Act.

This chapter is divided into eight sections: a discussion of program goals, a review of the history and context in which the programs exist, a discussion of how the program operates, highlights of accomplishments, an overview of strengths and weaknesses, a review of the outcomes achieved, a discussion of promising practices, and recommendations.

2. Program Goals

DD Councils are federally funded programs charged with identifying the most pressing needs of people with DD in their state or territory. Councils work to promote self-determination, integration, and inclusion for people with DD through—

- Training of and technical assistance to professionals, government officials, families, and self-advocates;

- Coalition development and citizen participation;
- Information dissemination to policymakers;
- Advocacy, capacity-building, and systems change; and
- Demonstration of new approaches to services and supports.

The goals of the Councils, as defined by amendments to the Act since 1970, have in some cases modified, redirected, or refocused their original charge.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 also made major changes to the Council program. The statutory language signaled a change in the goal of the Councils from comprehensive state planning to influencing how states serve individuals and directed the Councils to engage in “advocacy, capacity building, and systemic change activities” (42 USC 15021 SEC 121). This broader mandate, in the context of the static resources, required Councils to carefully set priorities and allocate resources, collaborate with the other members of the state network, and develop strong partnerships with other advocacy groups and disability organizations in their state in order to be effective. While many DD Councils have successfully made the transition, others still struggle to meet their mandates.

3. History and Context

The 1970 reauthorization (P.L. 91-517) provided funding for Councils to coordinate and integrate the provision of services for people with DD in the least restrictive environment in their individual states.

The following is a brief history of the evolution of the Act from 1970 to the present. The changes and shifts in language and focus reflect the rising expectations that led individuals with DD and their families out of isolation and institutionalization into an era that emphasizes inclusion, independence, and family and community supports.

**Exhibit 3.1
Evolution of the Councils**

| Year/Title | Essential Changes/Shifts |
|---------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1970 (P.L. 91-517) | <p>Created and defined primary functions of the Councils.</p> <p>Conduct comprehensive planning to provide for more efficient and effective utilization of resources.</p> <p>Develop new or innovative programs to fill gaps and expand the reach of services to new groups of individuals.</p> <p>Refined types of services.</p> <p>Diagnosis, evaluation, treatment, personal care, daycare, domiciliary care, special living arrangements, training, etc.</p> |
| 1975 (P.L. 94-103) | <p>State plan requirements modified to include—</p> <p>Requirement to eliminate inappropriate placements in institutions and improve the quality of institutional care.</p> <p>New service focus</p> <p>Preschool, systems advocacy, promotion of community alternatives to large institutions.</p> <p>Requirement to review and comment on all state plans of agencies that provided services to individuals with DD.</p> <p>Establishment of Bill of Rights for Individuals with Developmental Disabilities.</p> |
| 1978 (P.L. 95-602) | <p>Definition of DD changed</p> <p><i>Developmental Disability is defined as a severe chronic disability of a person attributable to a mental or physical impairment, is manifested before age 22 years, is likely to continue, results in functional limitations in 3 or more major activities, and reflects need for lifelong services.</i></p> <p>Eliminated the 16 basic service categories</p> |
| 1984 (P.L. 98-527) | <p>Several shifts and changes</p> <p>Charged Councils with being responsible for service activities, but not actual delivery</p> <p>Purpose changed – Council purpose was to enable individuals with developmental disabilities ...”to achieve their maximum potential through increased independence, productivity, and integration into the community...”</p> <p>First definition of “supported employment”</p> <p>Non-vocational services was eliminated as a priority service and replaces with a new category of ”employment services”</p> |
| 1987 (P.L. 100-140) | <p>Continued expansion of Council responsibilities</p> <p>New focus on the role of families</p> <p>New program elements including family support and assistive technology</p> |

| Exhibit 3.1 (continued) | |
|--------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Year/Title | Essential Changes/Shifts |
| 1994 (P.L. 103-230) | <p>Refined policy principles that were aligned with the ADA</p> <p>Emphasized widespread discrimination against individuals with DD.</p> <p>Need for increased awareness</p> <p>Introduced concept of consumer choice and consumer directed services to the DD program</p> <p>Focus emphasized inclusion, independence and community living</p> |
| <p>2000 (P.L. 106-402)</p> <p>These are the last changes made to the DD Act to date.</p> | <p>Purpose of Councils changed</p> <p><i>Engage in advocacy, capacity-building, and systemic change activities... that contribute to a coordinated, consumer- and family-centered comprehensive system of community services, individual supports, and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life (42 USC 15021 SEC 121).</i></p> |

4. How the Program Operates

There are 55 Councils—one in each state, in each of the four U.S. territories, and in the District of Columbia—with annual funding levels determined by the appropriations process. In 2009, the appropriation was \$74,316,000, with awards ranging from \$6,850,939 for California to \$247,853 for each of the territories (Allotment Table in Administration on Developmental Disabilities, 2009a). In some states, the Council is positioned within the state government structure; in other instances the Councils are stand-alone 501(c) (3) organizations. Councils must spend a minimum of 70 percent of their grant on program activities to implement the plan and may use the remainder to administer the activities of the plan (Information and Technical Assistance Center for Councils, 2009).

a. Independence from State Interference

The Act specifically addresses the need for independence from state interference. Two clauses in the Act address this issue. The first is the “noninterference clause” in Section 124 State Plan, (5) Assurances, (L) which states, “the plan shall provide assurances

that the *designated State agency, and any other agency, office or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development or plan implementation of the Council,* except the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3)” (emphasis added). The second clause is found in Section 125, (c), (8) Budget, B, which states, “*such State shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the Council, to the extent that such policies would impact the staff or functions funded with Federal funds, or would prevent the Council from carrying out the functions of the Council under this subtitle*” (emphasis added).

This policy of noninterference is being tested in the current environment, in which states are experiencing severely reduced funds and are attempting to use layoffs, furloughs, and other strategies to balance their budgets. ADD has reinforced this provision with state leaders when requested by individual Councils to do so.

b. Structure and Function of the Council

As discussed in the history of the Act, members of the Council are state residents who are appointed by the governor. The governor is required to solicit recommendations from organizations representing a broad range of individuals with DD and individuals interested in those who have DD.

The Act states that the membership of the Council “shall be geographically representative of the State and reflect the diversity of the State with respect to race and ethnicity....Not less than 60% of the membership shall consist of individuals who are—individuals with developmental disabilities, parents or guardians of individuals with developmental disabilities, and immediate relatives or guardians of individuals with mentally impairing developmental disabilities who cannot advocate for themselves. Representatives of state agencies who work in this area are also included in the remaining 40% of the membership.”

The role of the Council is to—

- Promote and support advocacy, systems change, and capacity-building activities for individuals with DD and their families.
- Conduct or support programs, projects, and activities that improve the quality of life for individuals with DD.
- Develop, implement, and monitor the progress of the state plan and adapt it as necessary and appropriate.
- Periodically review the designated state agency.
- Report activities to ADD.
- Prepare, approve, and implement a budget.
- Recruit and hire a Director consistent with state law.
- Have staff to assist the Council in carrying out its responsibilities.
- Establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with DD, support opportunities for individuals with DD who are considered leaders, provide leadership training to individuals with DD, and support and expand participation of individuals with DD in cross-disability and culturally diverse leadership coalitions (Information and Technical Assistance Center for Councils, 2009).

The role of individual Council members is to assist the Council in all of its functions and to serve as a link between the Council, its consumers, and the community.

c. Five-Year Plan Guides Activities

Each Council works from a state-specific five-year plan developed through a system of community input and coordination and collaboration with other state DD partners and a broader network of state partners that includes State Departments of Developmental Services, the State Medicaid agency, transportation, housing, and education officials,

and others as needed. The reauthorization requires an analysis and reporting of existing waiting lists for services in the state. Several other major changes have been made to the planning process. The reauthorization strengthened the requirements that Councils document their efforts to coordinate their activities with UCEDDs and PADD programs within their state. Specific goals were established for the Councils' self-advocacy efforts. Finally, the reauthorization established nine areas of emphasis that must be the focus of the Councils' planning process, activities, and reporting process.

This plan is reviewed and updated on a regular basis.

d. Program Performance Report (PPR)

Each Council is required to report to ADD annually. The report contains information about the progress made by the Council in achieving the goals that each specified in their five-year plan. Among others elements, it includes a description of the extent to which the goals were achieved, the strategies used to achieve the goals, and barriers to achieving the goals.

e. Key Principles

The 2000 Act adds new or additional emphasis on many key principles. A few of these principles are described below.

Individuals and Their Families

Councils are responsible for advocating, expanding services, and new approaches to meeting the needs of both individuals with DD and their families. This emphasis recognizes the unique needs of hundreds of thousands of adults with DD, particularly individuals who reside with aging caregivers, and individuals and their families who face very long waiting lists for Medicaid waiver services and are often unable to access the services and supports that they need to remain in their home and pursue their goals of independence, productivity, and community integration.

Self-Determination

Councils are charged with ensuring that individuals with DD and their families are the primary decision-makers regarding the services and supports they receive, including choosing where to live from available options and playing decision-making roles in policies and programs. From Individualized Education Programs for special education students to Medicaid Waiver Individual Support Plans to Vocational Rehabilitation Individualized Written Rehabilitation Plans, services should be designed by and under the direction of the individual and his or her family. Although the Council system is fully based on consumer direction and control, other components of state service systems are far less inclined to allow individuals and their families to have a major voice in the design and delivery of services. This tension creates a major long-term challenge for Councils owing to their lack of direct authority over design and delivery of services.

Abuse of Individuals with Developmental Disabilities

Councils are charged with playing a role in monitoring state services for individuals with DD to ensure that those who use the services are free from abuse, neglect, sexual or financial exploitation, and violation of legal or human rights, and are not subjected to the inappropriate use of restraints or seclusion. The Act clearly recognizes that abuse of individuals with DD occurs in many forms, from children who suffer from inappropriate behavior management approaches in schools, to adults subjected to restraints or seclusion in community residential settings, to individuals victimized by Social Security representative payees.

Culturally Competent Services

Councils are charged with ensuring that services, supports, and other assistance are provided in a culturally competent manner and that individuals from diverse racial and ethnic backgrounds are fully included in all activities of the DD program. The Act recognizes that this goal is best achieved by supporting individuals from diverse ethnic and racial backgrounds to successfully advocate on their own behalf and assume leadership positions. In addition, Councils are charged with promoting the recruitment of

individuals from diverse racial and ethnic backgrounds into professions serving individuals with DD and their families.

Unserved and Underserved Populations

The term “unserved and underserved” includes populations such as individuals from diverse racial and ethnic backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with DD, including individuals who require assistive technology in order to participate in and contribute to community life.

f. Council Areas of Emphasis

Current ADD planning and reporting requirements focus on cataloging state DD Council activities into nine areas of emphasis: child care, education/early intervention, employment, health, housing, recreation, quality assurance, transportation, and formal/informal community supports. These areas of emphasis are defined in the table below.

| DD Councils’ Areas of Emphasis |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Quality Assurance: Advocacy, capacity-building, and systemic change activities that result in improved consumer and family-centered quality assurance and that result in systems of quality assurance and consumer protection that include—</p> <ol style="list-style-type: none">1. Monitoring of services, supports, and assistance provided to individuals with DD to ensure that they have the right to make choices;2. Training in leadership, self-advocacy, and self-determination for individuals with DD, their families, and their guardians to ensure that those individuals will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and3. Activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life of individuals with DD. |

DD Councils' Areas of Emphasis (continued)

Education and Early Intervention: Early intervention activities are advocacy, capacity-building, and systemic change activities provided to children and their families to enhance the ability of the individuals to maximize their potential and the capacity of families to meet their special needs.

Education activities are advocacy, capacity-building, and systemic change activities that result in individuals with DD being able to access appropriate supports and modifications to maximize their educational potential, benefit from lifelong educational activities, and be integrated and included in all facets of student life.

Employment: Advocacy, capacity-building, and systemic change activities that result in individuals with DD acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.

Health: Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of coordinated health, dental, mental health, and other human and social services (including prevention activities) in their communities.

Child Care: Advocacy, capacity-building, and systemic change activities that result in families of children with DD having access to and use of child care services, including before-school, after-school, and out-of-school services in their communities.

Housing: Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.

Recreation: Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of recreational, leisure, and social activities in their communities.

Transportation: Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of transportation.

Formal/informal community supports: Supports that enable individuals with DD to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life. They are designed to enable such individuals to control their environment; permit the most independent life possible; prevent placement into a more restrictive living arrangement than is necessary; and enable them to live, learn, work, and enjoy life in the community. Other supports may include early intervention services, respite care, personal assistance services, family support services, supported employment services, support services for families headed by aging caregivers of individuals with DD, provision of rehabilitation technology and assistive technology, and assistive technology services.

g. Leveraging Resources

DD Councils have a broad and ambitious mandate that can only be met by leveraging their resources and developing strong partnerships with other network partners and state agencies.

All DD Councils actively attempt to identify resources that are leveraged through grant investments. Leveraging can be as simple as a required grantee match or identifying long-term funds through ongoing sustainability investments made by other state, local, or private investment.

5. Accomplishments

Identifying the accomplishments of DD Councils on a national level is challenging. Because Councils have the flexibility to pursue different goals based on state needs, their accomplishments tend to be state-specific or localized. In addition, it is difficult to tease out the specific impact of Councils affecting systems change since so many forces are at work in the political and policymaking processes. Nevertheless, taken from a broad view, the activities of the DD Councils have had many accomplishments, including the following.

a. Development of a National Council Network

The DD Act, through the development of the DD Council structure, has created a national system of 55 state partners to identify issues, develop and implement strategies to address the issues, and advocate for state policy and system changes that will improve the lives of individuals with DD. This lively network shares ideas and innovations, provides Council-to-Council support and assistance, and serves as a mature resource for the nation.

b. Visibility

Forty years ago, when the DD Act was first established, individuals with DD and their issues were hidden from public view. Through the efforts of Councils and other network partners, there is now a national effort to make sure that public policymakers, legislatures, and the populace at large clearly identify and address the needs and value of these individuals.

c. Training of Self-advocates and Their Family Members

One specific reason for the improved visibility of the needs of individuals with DD is the training of individuals, family members, and other interested community members to develop advocacy skills. These skills are targeted to a wide variety of venues: legislative action, school policy and practice, and representations of individuals in institutional settings, to name a few examples.

The DD Council's Partners in Policy Making and Youth Leadership Forum training activities have been very effective in creating advocacy skills and issue knowledge within the DD community, including individuals with DD, their families, and their advocates in the greater community. These initiatives, while originating in a single Council, are now used across the country by many types of Councils and have certainly had an impact on policymakers.

d. Participation in National Disability Rights Activities

DD Councils have participated in the national disability rights movement that has created dramatic changes in the lives of individuals with DD over the past 40 years. The *State of the States in Developmental Disabilities* study, funded by ADD, highlights some of the changes in the transformation of the service system from institution-based to community-based, and Councils have played an integral role in supporting these changes (Braddock et al., 2008):

e. Historical Trends

- In 1989, community services spending in the United States first surpassed institutional (16+ people) spending.
- During 1990–2006, inflation-adjusted community spending advanced an average 7 percent per year, while institutional spending declined 2 percent annually.
- During 2000–2006, adjusted ICF/MR spending declined 1 percent per year, compared with 8 percent annual growth for the HCBS Waiver.
- With considerable funding from the HCBS Waiver, combined spending for family support, supported employment, and supported living constituted 2 percent of total intellectual disabilities/developmental disabilities (ID/DD) spending in 1988, advancing to an 18 percent share in 2006.
- The number of people with ID/DD living in settings for six or fewer people advanced 14 percent per year during 1988–2006, compared with a 3 percent annual decline in settings for 16 or more people during that period.

Braddock and colleagues also identify some states' individual efforts in 2006. Again, these are all topical areas that are reflected in DD Councils' areas of emphasis, though the results reflect the effect of myriad partners and influences.

f. Fiscal Effort

Maine, New York, Connecticut, North Dakota, and Rhode Island led the nation in fiscal effort for ID/DD services (state spending from all public sources on ID/DD community and institutional services per \$1,000 of statewide personal income).

Supported Living

The largest percentage gains in spending for supported living were reported in New Jersey, West Virginia, Louisiana, Wyoming, Iowa, Wisconsin, Virginia, Nevada, Massachusetts, and Hawaii.

Supported Employment

Strong programs were reported in Connecticut, Louisiana, Massachusetts, Oklahoma, and Washington.

Family Support

New Mexico, New Hampshire, and Arizona ranked as the top three in families supported per capita of the general population.

Use of Waiver

New York, California, Pennsylvania, Minnesota, and Florida had the largest HCBS Waiver programs, and supported more than 40 percent of the nation's Waiver participants.

Contraction of Public/Private Institutions

Indiana became the most populous state to operate its ID/DD system without reliance on a state-operated institution for 16 or more people.

6. Strengths and Weaknesses

The DD Councils have certainly had an impact on the lives of individuals, communities, and state systems. In some cases, Councils' strengths may also be their weaknesses. This section identifies both strengths and weaknesses, and areas where there are opportunities to change weakness into strength.

a. Positioning Within State Government/Independence from Interference

The DD Councils' positioning within government can be a strategic advantage, but can also show up as a weakness. If the governor is interested in issues related to DD, positioning within state government can be a tremendous advantage because it ensures a seat at the state policy table. The unique language identifying independence from interference of the governor and the state is also helpful, but can put the program in a very difficult political position, particularly if the Council chooses actions that are not supported by the governor and state agencies.

b. Flexible Resources

Each DD Council brings unique resources to its state DD community. The dollars, while small in comparison to the large state agencies it seeks to impact, are also flexible and can be tailored to the unique needs of the state. In some states, this is the only disability organization with funds that can be used for advocacy, training, demonstration, and applied research.

c. Organizational Longevity

Most DD Councils and their staffs have been working in their communities for almost 40 years, and their mission is well known. Longevity and programmatic stability allow an organization to focus on their mission rather than on name-recognition. This is a strength, though occasionally the longevity may lead to institutional lethargy, which can weaken the Councils' ability to move quickly and decisively.

d. Ability to Set State-Specific Priorities

The Act allows each state to set its own priorities through the development of the five-year plan. This creates an organizational environment that is free to address current and emerging state-specific needs as long as they fall within the broad categories of the areas of emphasis.

e. National Network Partnership

The National Network created by the Act provides a structure in which the DD Councils collaborate and coordinate activities with the other two national partners: the UCEDDs and the PADD system. This network allows the Council to focus on advocacy, public policy development, and applied research and demonstration while its partners focus on broader research, the training of professionals to work in allied fields, and the extension of protection and advocacy services on both an individual and a class basis.

f. System Navigation and Family Support

The current federal/state service system for individuals with DD is large and complex. Some programs are designed specifically for individuals with DD (e.g., supported living), others serve the entire disability community (e.g., Americans with Disabilities Act awareness), and still others serve individuals with and without disability (e.g., job search). The DD Councils are small entities in a large sea of multibillion dollar agencies; however, they continue to fill a major void in the service delivery system. Their systems advocacy efforts at the state level can help to ensure that individuals with DD are treated fairly and effectively by the large specialized and generic service providers and that their voices are heard.

7. Major Issues

a. Governor's Influence

In situations where the governor is supportive of the goals of the Act, placement within the governor's purview and his appointment of the DD Council members can be a great strength, but where the goals of the Act and the needs of individuals with DD are not a priority, the DD Council's impact can be diminished. Although the state policy of noninterference addresses these issues in policy, the day-to-day life of the Council within this environment can be difficult. As mentioned previously, severe budget

cutbacks and personnel reductions are testing this principle and the value of placement of the Councils within government.

b. Lack of National Leadership on Issues

There are certainly issues that are important to all states, although DD Councils take a state-specific approach. ADD has yet to identify and advocate on a broad range of issues on a national level that would support the state-level initiatives in the same areas. These areas include community living, employment, housing, and education at all levels.

c. Lack of Authority or Resources to Impact State and Federal Systems

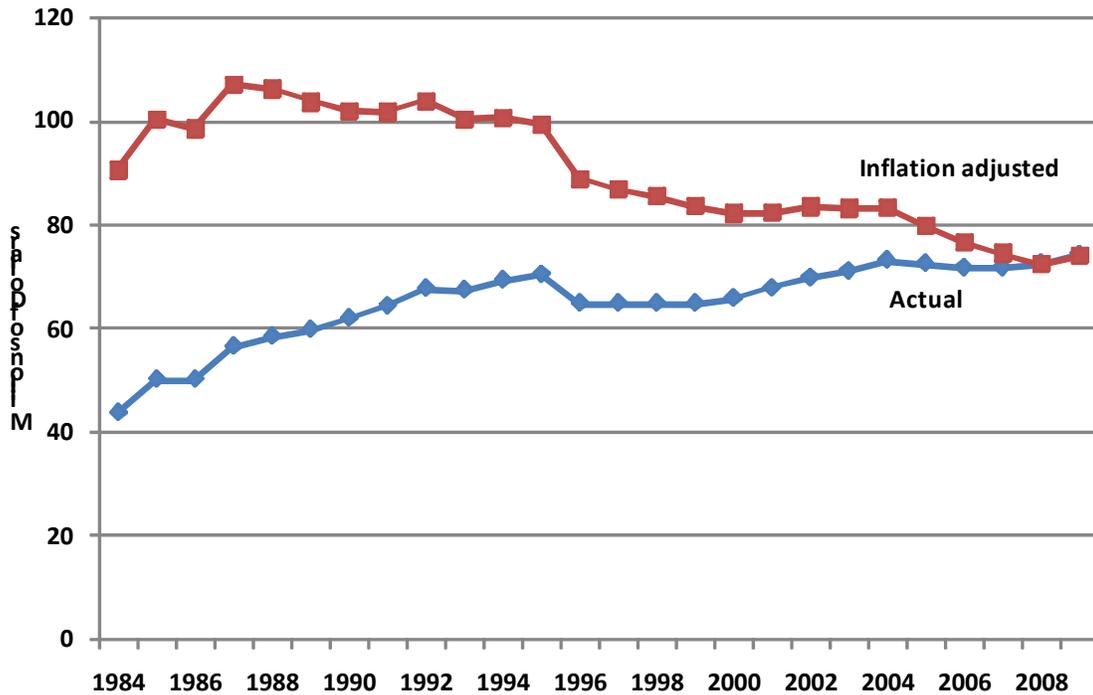
The DD Councils are a very small program with a mission to promote systemic change in very large state systems. In many states, the Council is an entity of less than \$1 million responsible for changing the policies, programs, and funding mechanisms of state DD agencies with budgets approaching \$1 billion.

This is true in policy, practice, and resource allocation issues. Councils demonstrate new strategies and identify best practices but do not have the resources or the authority to have them included in the service systems' actions. There is a structural disconnect between Councils and the system they are charged with changing, even if Councils sometimes manage to influence the larger system.

d. Funding/Resources

The prior review of the evolution of the DD Act documented the extent to which the mission and responsibilities of the DD Councils have continually expanded over the past several decades. In spite of these ever-expanding responsibilities, congressional support for the program has actually declined over the past 20 years (see Exhibit 3.2).

Exhibit 3.2
Actual and Inflation-adjusted[#] Appropriations for Councils, 1984–2008



[#] Actual refers to the nominal value of the appropriation, Inflation-adjusted refers to constant 2008 dollars.

Source: Author's calculations based on State Councils appropriations reported in Graney, 2001; Sommers, 2008; and the Consumer Price Index for All Urban Consumers in BLS, 2009

When inflation is factored in, appropriations for DD Councils peaked in FY 1987–1988 at approximately \$107 million and have declined steadily since. In contrast, during this same period appropriations for the PADD program gradually increased and have remained steady since FY 2001. Appropriations for the UCEDD programs are currently only available beginning in FY 2000. Since that time, inflation-adjusted UCEDD appropriations have increased steadily, from \$23 million in FY 2000 to a present level of \$37 million, an increase of more than 50 percent. On the other hand, inflation-adjusted funding for the Councils has steadily declined over the past 20 years, while the role and mission of the Councils has increased dramatically.

Simultaneously, the size of the Medicaid-funded state DD service systems has increased exponentially, and Councils have been charged with advocating on behalf of

individuals with DD within an ever-growing system that is creating increasingly disparate outcomes between Waiver-eligible individuals who receive large amounts of services and other individuals with DD who are restricted from access to any level of service sufficient to meet their needs. Waiting lists for services have expanded to hundreds of thousands of individuals nationwide. In many states, the Council is actively involved in implementation of the *Olmstead* decision, which requires placement of individuals in the least restrictive community setting possible, even though the system fails to provide the services and supports necessary to allow this to occur.

As the demands on the state DD systems continue to grow during hard economic times, it is imperative that Councils have sufficient resources to engage in the advocacy, capacity-building, and systemic change activities that are so critically needed.

e. Need for Improved Technical Assistance to DD Councils

Many DD Councils have done an outstanding job of engaging in collaborative activities. Councils are working closely with UCEDDs and PADDs in their states to coordinate systems change and demonstration activities. In addition to these coordination activities, in many states the Councils are very actively and successfully engaged in collaborative efforts with the major specialized and generic state agencies providing services and supports to individuals with DD, including special education, workforce development, transportation, housing, and vocational rehabilitation.

Information collected during the study indicated that in a small number of states, the DD Councils have had difficulty engaging in the type of collaborative activities that will allow them to positively affect the policies and programs of the state DD agency and other key state service providers. Many interview respondents indicated that some Councils lack the technical and policy expertise to fulfill these important functions.

8. Current Monitoring and Evaluation Activities

a. Performance Reported Through ADD Annual Report

The 2008 ADD Annual Report identified a representative sample of 77 outcome measures listed in the Councils' Program Performance Reports. It notes that DD Councils determine the issue area and outcome measures that will best serve the needs of their consumer population. Here are two examples of the outcome measure and the reported performance.

Employment: Expanding the availability of job training, inclusive work environments, and job placement for people with DD.

Thirty-seven Councils reported that they made employment more available or obtainable for 3,299 people with DD (ADD Web site, 2009).

Education: Maximizing student potential to obtain the most complete education in the most inclusive environment possible.

Thirty-eight Councils reported that they increased the knowledge, capabilities, and self-advocacy skills of 24,263 students with DD and their families, ensuring that the schools they attend are providing inclusive, appropriate, and local educational opportunities (ADD Web site, 2009).

The challenge of identifying effective outcome measures and accurately and consistently reporting performances in a meaningful way is clear. Each state must stand on its own merits, and performance may depend on state-specific issue areas and political and environmental challenges, as well as the way the Council chooses to quantify the number of people affected by a program or policy change.

For example, of the 38 states that reported on the education goal, 5 reported assisting more than 2,000 students, while 8 reported assisting fewer than 20. The disparity is

caused in large part by an inconsistent interpretation of the metric. Given the lack of consistency between the data from different Councils and over different years, the quantitative data provides little valuable information beyond the number of Councils that are addressing each area of emphasis.

b. Outcomes as Measured by GPRA Process

Some of these issues are reflected in the national evaluation process utilized by Congress, HHS, and OMB monitored through the GPRA. This process monitors and evaluates the following outcomes for the Councils:

1. Increase the percentage of individuals with DD reached by the Councils who are independent, self-sufficient, and integrated into the community. (outcome)

Outcomes Achieved: 2006, 12.05 percent; 2007, 12.46 percent; 2008, 12.47 percent; goal, 0.1 percent annual increase

2. Increase the number of individuals with DD reached by the Councils who are independent, self-sufficient, and integrated into the community per \$1,000 of federal funding. (OMB-approved efficiency)

Efficiency Achieved: 2006, 7.58 percent; 2007, 8.40 percent; 2008, 0.8.48 percent; goal, 1 percent annual increase

The report notes that measures like these are important because they attempt to measure impact and efficiency. However, the value of each measure is limited by the ability to define and measure independence, self-sufficiency, and integration into the community, and to isolate the people who are reached by the DD Councils.

There have been issues related to data quality. Changes in the performance between 2006 and 2007 reflected an attempt on ADD's part to rein in data quality by working with the DD Councils to better define the performance elements being reported. ADD

continues to analyze the changes in performance in order to improve understanding of trends and ongoing technical assistance to the state DD Councils.

It is clear that the identification of realistic and measurable goals for this program is a challenge. Application of consistent, clear definitions is an important first step. Impact is also very hard to measure using the tools currently available to ADD and their state partners. The GPRA reporting system is only a rough gauge of how well programs are actually performing. Nevertheless, it provides a long-term source for measuring trends.

9. Promising Practices

Councils all across the country are currently developing, implementing, and evaluating a wide variety of promising practices. The examples provided are designed to illustrate the scope of Council activities in the areas of leadership training, system advocacy, capacity building, and systemic change.

a. Leadership in Policymaking

Many DD Councils are highly engaged in developing the leadership and self-advocacy skills of individuals with DD and their family members. Minnesota took the lead in developing the Partners in Policymaking Program, which has now been replicated across the nation. This strategy engages self-advocates, parents, and others to learn about the policymaking process that affects their lives and to develop a set of tools that they can use in their efforts to influence human service and community systems in their state.

In Florida, the DD Council has provided leadership on health care policy and was instrumental in the development of a 30-agency statewide advocacy effort, the Partnership for Work and Healthcare. The Partnership has been advocating for a Medicaid buy-in for Floridians with disabilities and other strategies that will improve their

health care access. The Partnership received funding and support from the Health Foundation of South Florida for two years.

b. Leveraging

Leveraging resources in the current fiscal environment is essential. The New York State Developmental Disability Planning Council reports that it has leveraged its \$4,237,748 ADD grant into \$15,654,030 worth of services for individuals with disabilities in the state.

For example, a \$130,000 Council initiative funded the Office of Mental Retardation & Developmental Disability Housing Office to conduct a demonstration on utilizing the federal Low-Income Housing Tax Credit program for facilitating residential development, trained more than 90 housing staff from community based organizations, and resulted in six state-level tax credit projects of more than \$12 million in residential development. There are multiple instances of similar returns on investment, and the return amounts cited by the Council are conservative at best. The Council surveys grantees for five years post-grant activity to follow continued support and sustainability. The Council does not currently have any authority or incentive to require post-grant survey response and typically averages about a 40 percent response rate, so typically the return on investment for leveraged funds is believed to be greater than reported.

c. Systemic Change Activities

The California DD Council convened self-advocates, parents, providers, state advocacy groups, and policymakers to produce a set of recommendations to address the employment crisis among people with developmental and other disabilities. Because of the Council's efforts, the chair of the California Assembly's Human Services Committee introduced legislation in 2008 incorporating many of the Council's findings and recommendations on employment and set forth a new Employment Opportunities Initiative. Because of the Council's work, employment (along with housing) is now the top priority among disability groups in California.

d. Demonstrating New Service Approaches

The Virginia Board for People with Disabilities funded the Virginia State Government Employment Initiative, a project that promotes private and public partnerships to increase the employment of people with disabilities in state government agencies. As a result of this effort, 42 individuals with disabilities were hired in 2008–2009. This placement and training program will continue after the grant ends with state policies now in place, thanks to a governor’s Executive Order to make the disability awareness training a permanent part of human resources and management training for state employees.

Another promising practice is the development of tools that can impact access and utilization of SSA disability benefits. The Massachusetts DD Council undertook an initiative to disseminate and train SSA beneficiaries to use a benefits planning calendar to help track their earnings and reporting requirements. It provides a mechanism for individuals to record earnings and deductible expenses, and store correspondence from and to SSA. The project provided calendars and training to 1,000 working and self-employed beneficiaries in 2008 (National Association of Councils on Developmental Disabilities, 2008; New York State Developmental Disabilities Planning Council, 2008).

10. Recommendations

- 3.1 Congress should reaffirm the critical role played by the Councils in promoting the independence, productivity, and community integration of individuals with DD by raising the annual appropriations for Councils in order to restore the Councils’ capacity for systems advocacy and demonstration activities.
- 3.2 Congress should direct HHS through ADD and the DD Councils to launch a major new initiative to identify, analyze, and describe eligibility and funding inequities in the current Medicaid and state DD system, and to work collaboratively with major federal partners, state DD agencies, and state Medicaid agencies to eliminate these inequities.

3.3 ADD should redesign the required state plan development and reporting format for Councils, which focuses on activities in nine areas of emphasis, into a more relevant format that better reflects the systemic change, capacity-building, and advocacy roles of Councils and the long-term nature of their work.

CHAPTER 4. **Protection and Advocacy for Individuals with Developmental Disabilities**

1. Introduction

People with DD have rights established in the U.S. Constitution and through federal and state statutory laws and court decisions. These rights are empty in the absence of the ability to enforce them. The PADD program provides advocacy and legal support to enforce these rights and address issues of injustice. It is often at odds with other powers in the state, but is supported by the authority given to it by the DD Act.

The DD Act of 1975 authorized \$9 million (\$25 million in 2009 dollars) for the PADD program. Although funding has grown to \$40 million in 2009 (Administration on Developmental Disabilities, 2009a), this growth has not kept pace with the expansion in the purview of and demands on the PADD program. The program was originally designed to address the abuse and neglect of people in institutions. It has grown to address a broad range of issues for people in a variety of settings and provides a range of services, including individual advocacy and legal support, as well as systems advocacy and monitoring.

As the advocacy movement continues to mature and the expectations of people with DD expand, PADD grantees are being called upon to address even broader issues in self-determination and choice. Because funding is so limited, each PADD grantee must set priorities and accept cases only if they fit within those priorities.

In addition to variability in priorities and activities, many stakeholders and experts note that there is variability in the quality of the agencies. The term “quality” means different things to different people. Some stakeholders are concerned that some PADD grantees are not “aggressive” enough and fail to address systemic issues in the state. Others complain that PADD grantees focus too much on systemic advocacy and not enough on individual cases. Still others complain that programs ignore the rights and needs of

guardians or do not adequately monitor the health and well-being of individuals moved from institutions to community settings.

Despite these complaints, stakeholders interviewed for this project, with the exception of representatives from Voice of the Retarded, believed that the PADD program as a whole, with its ability to pursue legal remedies, plays a vital role in enhancing the lives of people with DD and should be supported and expanded.

Other disability groups and government agencies have also recognized the value in providing federal funds for protection and advocacy. Since the inception of the PADD program, seven other disability-related Acts have included funds for protection and advocacy (P&A). The P&A agencies that operate PADD and other protection and advocacy programs now combine their PADD funding with these other sources to provide a legal resource for people with a range of disabilities.

The DD Act gives the PADD grantees substantial legal and investigative authority. These authorities are often ignored by state agencies and are under attack by some service providers and parents. To date, PADD grantees have been able to retain their authorities, but it can be costly and time-consuming. While most attacks occur at the state level, in March 2009 the debate moved to the federal level with Rep. Barney Frank's (D-MA) introduction of HR-1255, which would limit the ability of a PADD to file a class action lawsuit against an ICF/MR.

PADD's advocacy, in conjunction with that of other organizations, has played a major role in the deinstitutionalization movement. PADD has litigated to ensure the ability of institutional residents to live in the community if they choose, and to improve the health, safety, and quality of life for people who remain in institutions. Since the PADD program began in 1977, the number of people living in large state institutions has decreased 78 percent from more than 167,000. Nevertheless, 38,000 people continue to live in institutions, and neglect and abuse continues. Currently, almost 60 percent of PADD's individual advocacy is devoted to education, raising the issue about whether the

program, with its limited funds, is able to meet its original intent of protecting people from abuse and neglect.

This chapter addresses the question of whether the policy, structure, and administration of the PADD program are appropriate given the current needs of people with DD. It describes the background, goals, history, and operation of the PADD program and explores the program's accomplishments, strengths, and challenges; ADD's monitoring and evaluation efforts; and promising practices.

2. Program Goals

According to the DD Act of 2000, the PADD program is to protect the "legal and human rights of individuals with developmental disabilities." The PADD has the authority to—

- "[P]ursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements, with particular attention to members of ethnic and racial minority groups."
- Provide information on and referral to programs and services addressing the needs of individuals with DD.
- "[I]nvestigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred." Abuse includes physical maltreatment, verbal harassment, and institutional practices that can be considered abusive. Neglect includes neglect of basic needs as well as failure to provide adequate treatment planning, discharge services, or community care.

Congress intended that PADD-eligible clients and families have an important role in determining priorities.

3. History and Context

The P&A concept was added to the DD Act in 1975 after a series of exposes by reporter Geraldo Rivera on the Willowbrook Institution in New York uncovered the appalling conditions at large institutions. Burton Blatt photographed one of these institutions on Christmas Day and published them in a book whose title summed up the situation: *Christmas in Purgatory*. Although the language in the statute was drawn broadly, the PADD systems were originally intended to protect people in facilities from this abuse and neglect.

The mission of the PADD program has evolved over the years from addressing the protection of individuals with DD who lived in institutions to responsibilities that include protecting people with DD from abuse, neglect, exploitation, and violation of their legal and human rights in both institutional settings and the community. The DD Act of 2000 added an emphasis on the “monitoring” role.

The residential landscape for people with DD has changed dramatically since the inception of the PADD system in ways that have added challenge to meeting the PADD mandate. The number of residential settings in the United States increased from 11,008 in 1977 to 167,857 in 2007. While the number of large state facilities decreased from 327 to 200, the number of small settings (one to six people) increased from fewer than 7,000 to more than 160,000 (Prouty, Alba, & Lakin, 2008).

The legal landscape has also changed. Several court cases have affirmed the rights of people with DD, most notably *Olmstead v. L.C.*, in which the Supreme Court found that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability under the ADA. However, courts have generally become more conservative in affirming states’ rights over federal mandates and school systems over parents.

The establishment of the PADD system coincided with the passage of the Education for all Handicapped Children (the predecessor to the Individuals with Disabilities Education

Act, or IDEA), which gave children with disabilities the right to a “free and appropriate education” in the “least restrictive environment.” Although never explicitly required in the DD Act, most P&A agencies rightly expanded their role to include protecting the rights of students under IDEA. With more than 100,000 schools in 13,924 school districts in the United States (National Center for Educational Statistics 2009), advocating and litigating educational cases has become a substantial portion of the PADD programs’ workload.

In advocating on behalf of individuals with DD in institutions, PADD programs have filed, joined, or intervened in class action lawsuits that have alleged inappropriate care and treatment, including abuse and neglect of residents, the rights of individuals with a disability to live in the least restrictive environment, and breaches of statutory and constitutional rights. Some of these lawsuits have resulted in moving individuals with DD from institutional care settings to group homes, apartments, and other community settings. While some parents and legal guardians of individuals involved in these suits have supported PADD efforts, a small but vocal group has opposed deinstitutionalization for 25 years and has advocated to limit the power of the PADD programs. At the request of Congress, GAO studied the issue. It found that only a small portion of PADD overall activities include litigation related to deinstitutionalization, and these lawsuits resulted in establishing quality assurance standards in institutions as well as downsizing or closing state institutions (U.S. Government Accountability Office, 2003).

Nevertheless, Congress is considering H.R. 1255, which would require that PADD programs provide notice before filing a class action against an ICF/MR on behalf of the residents and allow parents and guardians who oppose the suit to opt out on behalf of their ward. The provision is not consistent with the current federal rules of civil procedure or the rules governing class action lawsuits on behalf of people with other types of disabilities in other settings (such as people with mental illness in prisons or psychiatric hospitals, people with disabilities in nursing homes, or students with disabilities in schools).

4. How the Program Operates

a. Intervention Strategies

The P&A agencies are best known for litigating class action lawsuits. However, that strategy represents only a small portion of the activities of PADD grantees. PADD grantees work with individual clients to resolve specific issues (individual advocacy) and use a variety of systemic advocacy approaches to resolve underlying problems in the service delivery system.

Given their limited resources, PADD grantees struggle with how to divide the resources between individual and systemic advocacy. Unfortunately, ADD's reporting mechanism captures only casework and does not capture other activities of the PADD grantees, such as training, outreach, interaction with policymakers, legislative advocacy, monitoring that is not related to a specific case, and other activities related to systemic advocacy.

As shown in Exhibit 4.1, PADD grantees report that they used litigation (including class action lawsuits) in only 5 percent of the individual casework they addressed in 2008.

| Exhibit 4.1 Intervention Strategies Used in Individual Casework PADD program, 2008* | | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|----------------------------------|
| Type of Intervention | Number of Cases | Percentage of Total Cases |
| Short-term Assistance | 6,556 | 33% |
| Technical Assistance in Self-Advocacy | 5,551 | 28% |
| Negotiation | 2,632 | 13% |
| Investigation/Monitoring | 2,151 | 11% |
| Administrative Hearing | 1,080 | 5% |
| Litigation | 889 | 5% |
| Mediation/Alternative Resolution | 867 | 4% |
| Total | 19,726 | 100% |
| Source: Administration on Developmental Disabilities, 2008a. *The definition of each level of service varies somewhat among states, so this data should be considered an approximation. | | |

The National Disability Rights Network (NDRN) developed a “continuum of remedies” that describes the work of the PADD grantees more fully than the ADD reporting categories shown in Exhibit 4.1. The continuum (NDRN, 2006) includes the following strategies (with ADD reporting category shown in parenthesis).

Training Consumers and Professionals (not reported)

P&A agencies train individuals and professionals about the rights of people with DD. For example, some P&A agencies provide instruction to people with DD, parents, attorneys, service providers, police, government agencies, and others on a number of important topics.

Self-Advocacy (Technical Assistance in Self-advocacy)

The DD Act of 2000 directs PADD programs to provide training in leadership, self-advocacy, and self-determination for individuals with DD, their families, and their guardians. These programs employ different approaches to achieve this goal. For example, PADDs work with people with DD to develop grassroots peer/self-advocacy groups in facilities and in the community, and hire self-advocates to help inform their peers about their rights and how to exercise those rights. PADD programs also provide information and training on how to advocate for specific rights.

Counseling and Advice (Short-term Assistance)

One-third of the people who contact the PADD program are served with short-term assistance (see Exhibit 4.1). Describing to clients what they are entitled to, providing them information on the topic, and making suggestions on how to advocate for themselves can solve many issues.

Negotiation and Mediation (Negotiation)

PADD programs will also approach an institution, service provider, or state agency to solve a problem. This kind of contact may involve formal or informal negotiation, or using mediation to address the issue.

Administrative Action (Administrative Hearing)

Many laws require the use of an administrative approach to resolve matters. P&A agencies will follow the dictates of these laws and advocate for their clients' needs through the administrative process.

Individual Litigation (Litigation)

If counseling and advice, negotiation and mediation, and administrative action are unsuccessful, P&A agencies can file suit on behalf of individuals. For example, PADD groups have filed suits on behalf of students who were denied access to their neighborhood schools, suspended or expelled because of nondangerous behavior caused by their disabilities, or being denied the community-based services to which they are entitled.

Monitoring (Investigation/Monitoring)

The DD Act of 2000 directs PADD groups to monitor services, supports, and assistance to people with DD to ensure that they do not experience abuse, neglect, exploitation, or violation of legal or human rights, and will not be subject to the inappropriate use of restraints or seclusion.

As independent living opportunities increase, the challenges of monitoring and ensuring the appropriateness and safety of living arrangements also increase. Complicating the issue is that laws, regulations, and systems for protecting people with DD from abuse or neglect can vary significantly from state to state.

PADD groups address their monitoring mandate by conducting direct investigations of facilities and other service providers; reviewing the investigations conducted by service providers themselves or state agencies; and intervening when the process or outcomes raise questions. They also analyze trends in reported incidents in facilities, regions, or across the state and make recommendations for changes in policies and practices; routinely monitor health and safety conditions at facilities; issue public reports about inadequate systems of care and oversight and public alerts about dangerous practices;

and work with policymakers at the state level to ensure that effective standards are implemented to address these issues.

Interaction with Policymakers (not reported)

The laws that are written have a profound effect on individuals with disabilities, from changes in health care and retirement to whether there are adequate funds to provide the needed supports and services for them to live in the community. PADD lawyers and advocates must work with policymakers to ensure that the laws that are enacted are in the best interests of individuals with disabilities. For example, they may be on state task forces on education to monitor policy and implementation regarding restraints and seclusion, or they may work with policymakers to ensure that appropriate credentials are required for direct service workers. PADD staff members also participate in a variety of nongovernmental commissions and committees. They can bring to bear their legal and advocacy skills to help craft legislation that will benefit individuals with disabilities. Finally, PADD groups will monitor and comment on regulations and policies that affect the rights of and services to people with disabilities.

Class Action (Litigation)

P&A agencies have the statutory right to file class action lawsuits to address systemic issues that affect a class of individuals with disabilities. These suits have argued for increased funding for home and community-based services, increased access to public transportation, accessibility of polling places, and systemic reform to provide legally required services to students with disabilities. In a report released in 2003, GAO identified 24 lawsuits that P&As filed, joined, or intervened in related to deinstitutionalization from 1975 through 2002. Most but not all were intended to be class actions concerning large public institutions providing services to people with mental retardation and related DD (U.S. Government Accountability Office, 2003).

Legislative Advocacy (not reported)

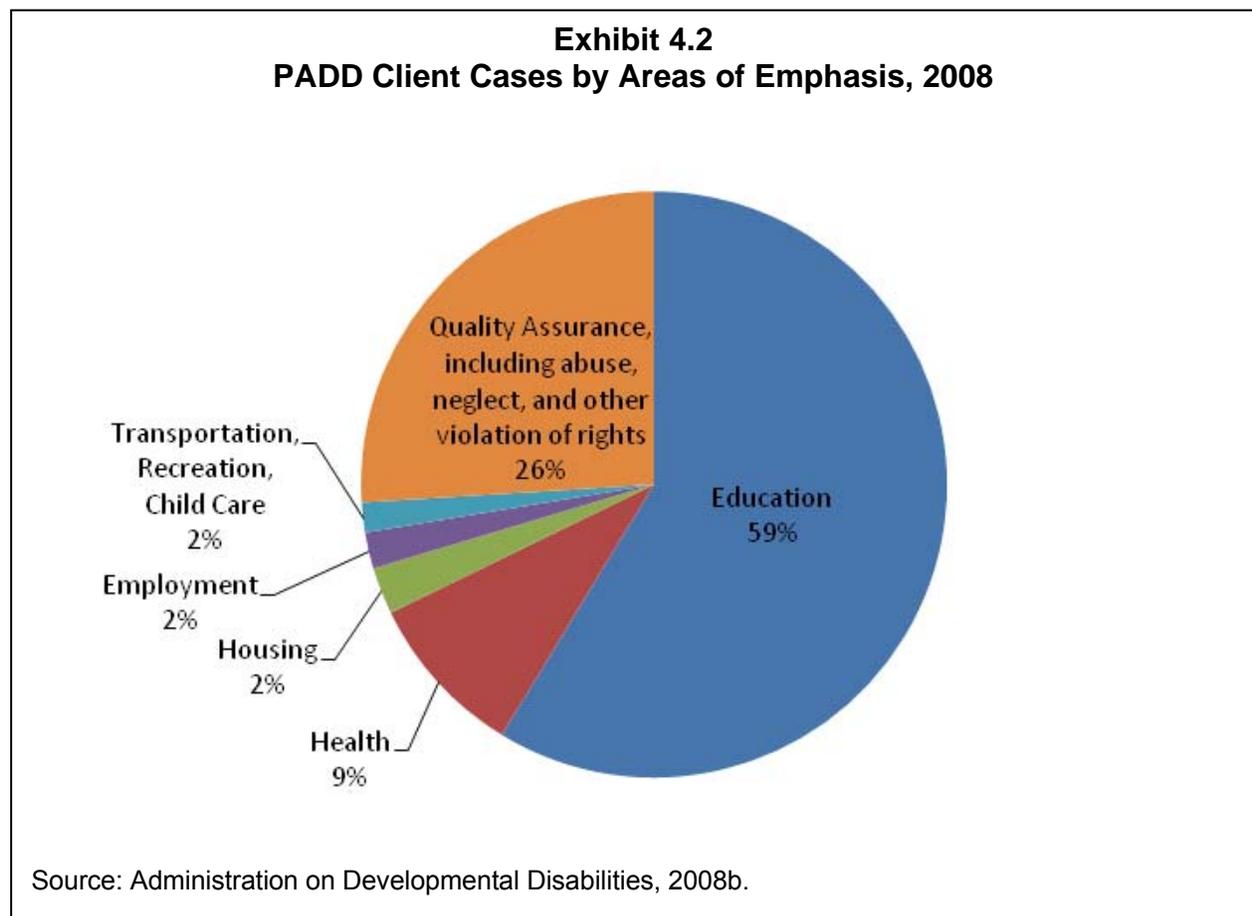
PADDs have promoted legislation that would require states to develop policies to reduce the use of seclusion and behavioral restraints in facilities, allow independent

assessor hired by parents to observe a child in his/her current educational placement, require additional slots in home and community-based waivers, ban sterilization without due process, address bullying and harassment in schools, and many other issues.

b. Areas of Emphasis

As shown in Exhibit 4.2, 59 percent of PADD clients accessed the system for education-related cases and another 26 percent for quality assurance. Employment, housing, transportation, recreation, and child care together accounted for only 6 percent of the cases.

It is unclear whether this distribution of cases and allocation of resources represents the needs of the DD community in each state. A number of factors affect the type of cases on



which each PADD grantee works. Some of these factors are observable. For example, the type of cases that a PADD grantee services is related to the priorities that it sets. If the priority-setting process represents the needs of the community, then the type of cases should also represent the needs of the community. However, if the priority-setting process fails to reach certain subpopulations, then their needs are likely to be omitted.

Some factors are more subtle. P&A agencies respond to people who seek out services. If a P&A agency has a strong reputation within a particular community (e.g., the special education community or the Medicaid advocacy community), the agency is likely to attract more of those cases. P&A agencies also reach out to the community through education and training initiatives and information dissemination. The types of cases may reflect the type of outreach.

Special Education

PADD works with families and schools to enable students to receive the supports and services they are entitled to under IDEA.

The United States spends \$78 billion to educate the nation's 6.2 million students with disabilities (Chambers, Parrish, & Harr, 2004). For those who meet the definition of DD, the P&A agency is an important legal advocate. Nationwide, 59 percent of the P&A cases address educational issues. This percentage varies among P&A agencies, from a low of 6 percent to a high of almost 90 percent. Some P&A agencies specifically limit education cases in their priorities because they are concerned that the demand will overwhelm their ability to take other cases.

Quality Assurance

Quality assurance includes protecting the rights of people with DD to live free from abuse and neglect and preserving their ability to make choices and have access to appropriate services and supports in the least restrictive setting. Quality assurance was the core mission of the PADD program at its inception in 1975. Currently, overall one-

quarter of cases address quality assurance concerns, with the percentage ranging from 5 percent in one state to 89 percent in another.

Health

Nationwide, 9 percent of PADD cases address health issues. PADD grantees are asked to intervene when a family believes that they are not receiving Medicaid services for which they are eligible or that Medicaid has denied them access to specialty care or durable medical equipment. Health cases range from none to 47 percent across different states.

c. Funding

Formula Grant

Each year, the congressional appropriation for the PADD program is divided among the existing PADD grantees based on a mathematical formula. In comparison to a competitive grant program where the office would need to re compete for the funds periodically, the formula grant guarantees the PADD grantees a somewhat stable source of funding and allows them to build capacity, take on long-term casework, and develop relationships with the state and advocacy communities.

Although this funding guarantee is critical to the viability of the PADD program, it increases the importance of the federal oversight role. In a competitive grant process, the prospect of competition would provide an incentive for an underperforming PADD grantee to enhance its services; if it failed, the grant could shift to another entity. As discussed in Section 6, unfortunately, ADD has not established any standards of performance and does not rigorously evaluate the quality of the agencies.

Multiple Sources of Funding

In 2009, each PADD grantee was allotted between \$375,316 and \$3.35 million from the DD Act (Administration on Developmental Disabilities, 2009b). Each agency combines this allotment with funds from seven other federal programs (Exhibit 4.3). Each source

of funding is used to serve the populations designated by the enabling legislation. This fragmentation has several drawbacks.

| Exhibit 4.3 Sources of Funding for Protection and Advocacy | | | | |
|------------------------------------------------------------------------------------------------------------------------------------|-------------------------|---------------|-----------------------------------------------|--------------------------------------------------------------------|
| Program | Year Established | Agency | FY 2008 Appropriation (in \$ millions) | Target Population |
| Protection and Advocacy for Persons with Developmental Disabilities (PADD) | 1975 | ACF/DD | \$38.7 | Developmental disabilities |
| Protection and Advocacy for Individuals with Mental Illness (PAIMI) | 1986 | SAMHSA | \$34.8 | Individuals with mental illness in all settings |
| Protection and Advocacy for Individual Rights (PAIR) | 1993 | RSA | \$16.2 | Individuals with disabilities who are ineligible for PADD or PAIMI |
| Protection and Advocacy for Assistive Technology (PAAT) | 1993 | RSA | \$4.26 | Individuals with disabilities who need assistive technology |
| Protection and Advocacy for Beneficiaries of Social Security (PABSS) | 1999 | SSA | \$7.0 | Social Security beneficiaries who want to work |
| Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI) | 2000 | HRSA | \$2.9 | Individuals with traumatic brain injury (TBI) |
| Protection and Advocacy for Voting Access (PAVA) | 2002 | ACF | \$5.3 | Individuals with disabilities face who want to vote |
| Client Assistance Program (CAP)* | 1984 | RSA | \$11.5 | Clients/applicants of projects funded under the Rehabilitation Act |
| Sources: Information collected from National Disability Rights Network (u.d.) and Consortium of Citizens with Disabilities (2008). | | | | |
| In addition to the federal funding sources, some P&As receive funds from state agencies and private donations. | | | | |

d. Setting Priorities

While the PADD grantees have a broad mandate, they tend to have insufficient resources to respond to all of the needs of their constituents. The DD Act and other P&A statutes require each P&A to set priorities annually using a process that maximizes consumer input.

Each P&A uses a different approach to identifying priorities. According to an MTARS report, one state conducted regional forums, surveyed clients, analyzed the client database from the previous year, reviewed the needs assessments conducted by the UCEDD and state Council, reviewed other P&A priorities, and solicited input from the PAIMI advisory council (Administration on Developmental Disabilities, 2005). Other states rely on less comprehensive approaches.

The priorities must be approved by the governing board (advisory councils for state agency P&As and Boards of Directors for private nonprofit P&As). Under the DD Act of 2000, a *majority* of each PADD governing board must be individuals with DD, their parents, family members, or other representatives. Prior law required only that the board must *include* such individuals. ADD has not undertaken an evaluation that assesses the role of consumers and families on the PADD governing boards.

5. Accomplishments

Legal representation is such an important judicial concept that one of the primary achievements of the PADD program is to ensure that people with DD have a voice. For the past 30 years, this group has had (in varying degrees) access to representation to give it a voice to challenge the service systems on which it depends. Although it is difficult to attribute specific changes in the DD system to the PADD program, in the past 30 years—

- Through use of class action lawsuits and other legal and advocacy approaches, PADD grantees have been a major factor in the closure of some institutions and improving conditions in others.
- The PADD program has played a major role in enforcing special education rights.
- The PADD program has helped to raise the discussion about adequate provision of community-based care to a civil rights issue.

In 2008, PADD grantees served almost 24,000 clients (Administration on Developmental Disabilities, 2009b). More than 90 percent of cases are closed with the complaints corrected (Office of Management and Budget, 2008).

6. Strengths and Weaknesses

The existence of an agency that carries with it the implicit threat of legal action plays a critical role in quality assurance. P&A directors relay stories of clients who were having difficulty getting access to services, but as soon as the P&A agency called, the problem was solved. As one consumer said, “the name makes people do things.” Despite this inherent strength, there are some complexities.

a. Authorities

The DD Act grants PADD grantees expansive legal and investigative authorities. However, the authorities are controversial and have been contested in both policy debates and court decisions by individuals and groups that believe that current law grants PADD groups too much authority to investigate and litigate on behalf of individuals with DD.

Investigative Authority

The DD Act grants PADD groups access to “all records of ... any individual with a DD” provided that certain conditions such as probable cause are met. But several cases

have limited that authority. For example, in *Disability Law Center of Alaska v. Anchorage School District*,¹ a court held that the PADD grantee was not entitled to the names of the parents of 10 children who had allegedly been abused in a special education classroom, on the grounds that, among other things, the Family Education Rights and Privacy Act prohibited disclosure. The Alaska decision is in direct conflict with the position taken by HHS and DOE (the federal agency that enforces the Family Educational Rights and Privacy Act),² as well as the opinions of the Second Circuit in *Connecticut Office of Protection and Advocacy v. Hartford Bd. of Ed.*³ and the Seventh Circuit in *Disability Rights Wisconsin v. Wisconsin Department of Public Instruction*, 463 F.3d 719 (7th Cir. 2006). The Alaska case is currently on appeal to the Ninth Circuit Court of Appeals.

In addition, the standing of PADD groups to bring suit on behalf of individuals with DD is increasingly being challenged (see *Missouri Protection and Advocacy v. Carnahan*⁴ and *ARC of Dallas v. Dallas Mental Health and Mental Health Retardation Center*⁵). Although many PADD groups have been able to withstand these challenges, they have had to expend significant time and resources to establish their standing and protect the rights of individuals with DD who may be retaliated against if they tried to enforce their rights on their own.

At times, the investigative authority appears to conflict with other federal laws. For example, providers claimed that the Health Insurance Portability and Accountability Act (HIPAA) prohibited them from giving records to PADD groups that were investigating abuse and neglect. The HHS Office of Civil Rights put the issue to rest when it issued a directive that HIPAA permits a covered entity to disclose protected health information, without the authorization of the individual, to a state-designated P&A system, to the extent that such disclosure is required by law and the disclosure complies with the requirements of that law.

Legal Authority

The legal standing and authority of PADD is not established as clearly in the DD Act as are PADD investigative authorities. The role of PADD agencies in class action lawsuits is controversial, and parties differ on what constitutes a “class.” In an Illinois case (*Ligas v. Maram*), the court originally affirmed that individuals with DD who are housed or at risk of being housed in residential institutions can constitute a class. However, after a settlement was reached between the plaintiffs and the state, the court received a significant number of objections to the consent decree and determined that the class definition was too broad because it did not restrict the class to individuals with DD who are “eligible for, and desire, community placement.”

The ability to bring suit against the state agency is an important power for the P&A agencies, but it has been challenged by several state agencies. The issue is currently under review in the courts and the outcome is uncertain. In the 2009 *Virginia Office for Protection and Advocacy v. Reinhard*, the Fourth Circuit Court ruled that state law prohibits the suit and that the Federal Government (e.g., the DD Act) cannot dictate whether one state agency can sue another within the state, but in the 2010 *Indiana Protection & Advocacy Services v. Indiana Family & Social Services Admin.*, the Seventh Circuit Court expressly disagreed with the Virginia decision. In June 2010, the Supreme Court agreed to review the case, so this important issue may be resolved.

b. Administrative Structure

Of the 57 P&A programs, 47 are nonprofit organizations and the remaining 10 are part of state governments. Theoretically, state P&A agencies may have much more access to government officials and can use their access for more informal advocacy in ways that are not readily available to nonprofit programs operating outside of government. The situation might also provide some financial benefit, as the state may cover some of the administrative costs. However, theoretically, it is impossible to be independent of the state if the P&A agency is part of the state and may be reluctant to sue the state

because it is afraid of the repercussions, or fears that the state may try to impede a PADD intervention.

Although available evidence does not suggest that state P&A agencies are bowing to pressure from their states, in the past 20 years nine P&A agencies have changed their designation from a state agency to a private nonprofit, and others report that they are considering this action.

c. Fragmented Funding Structure

Historically, this fragmented funding structure led agencies to work in disability-specific silos. However, most P&A agencies have restructured and now work on issues in cross-disability teams (e.g., housing, education, abuse) rather than having discrete staff serve people with a specific disability. However, the fragmentation continues to have drawbacks.

Accountability

As P&A agencies reorganize along issues and away from divisions dictated by funding source, P&A staff must carefully account for their time, and each federal program must monitor the time allocation to ensure that their populations are receiving services to the extent possible given the funding level. NDRN and others have developed software to assist in this task. The funding provided by each piece of legislation is not necessarily proportional to the size or needs of the corresponding population, which creates tension when P&A agencies must limit services because of insufficient funding.

Duplication and Efficiency

Each federal agency has its own reporting, monitoring, and evaluation requirements that are consistent with its respective legislative and administrative needs. In addition, depending on their administrative structure, P&A agencies may have reporting requirements imposed by the state or the Internal Revenue Service. These multiple

reporting requirements consume resources that could otherwise be allotted to client services.

Under the prior administration, ADD was working with other federal agencies and OMB to develop consistent reporting forms. However, no document has been produced that meets the needs of the funding agencies.

Additional Resources

NDRN has advocated for additional funding sources for specific purposes, including IDEA (through DOE); autism (through the Expanding the Promise for Individuals with Autism Act of 2007, S.937/H.R.1881); returning veterans and military families of active duty, National Guard, or Reserve personnel (through the Department of Defense); emergency preparedness; and housing. This approach would exacerbate the fragmentation but would bring additional resources to the P&A system.

d. Coordination with Other Agencies

A variety of state and federal entities are charged with protecting consumers against abuse and neglect and ensuring appropriate access to services. State entities include quality assurance mechanisms in the DD agency, adult protective services, and state departments of education. Federal entities include DOJ, HHS, DOE, and DOL.

The DD Act gives PADD grantees investigative authority that is not available to other entities and, as a result, they are a vital part of the quality assurance system. However, their resources are insufficient to investigate and monitor all cases. Some P&A agencies have found that rather than investigating individual cases, they can have a more significant impact by investigating the investigators and holding the state agencies responsible for outcomes.

The weak federal oversight of quality in state departments of education, state Medicaid agencies, and state workforce development systems puts additional demands on the

PADD grantees. Currently, ADD does not actively pursue the strengthening of these mechanisms.

7. Major issues

a. Funding Level

In 2009, Congress authorized \$40 million for 57 PADDs to safeguard the rights of 4.5 million children and adults accessing \$44 billion in residential and related community services (Braddock et al., 2008) and participating in a \$50 billion special education program (Chambers et al., 2004).

Education

As shown in Exhibit 4.2 above, 58 percent of P&A clients are requesting assistance on education issues. IDEA explicitly grants rights to students and parents. However, DOE does not have the authority to provide an enforcement mechanism. As a result, a significant portion of PADD and PAIMI funds are used to enforce these rights, leaving less funding to address issues in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems.

Monitoring

The DD Act of 2000 added monitoring to the list of responsibilities of the PADD grantees. However, the additional responsibility was not accompanied by additional funding.

Broader issues

As self-determination becomes a reality for people with DD, the PADD grantees are facing issues such as the client's opportunity and/or right to get married, have children, and retain custody of those children. They have litigated cases concerning sterilization, parental rights, and unneeded plenary guardians. Unfortunately, these types of cases are very resource intensive and, without additional funding or a reduction in

responsibilities in other areas, PADD grantees will not be able to fully address the issues.

b. National Policy for People with DD

The absence of a consistent policy toward people with DD across federal agencies affects the work of the PADD grantees. For example, recently DOJ intervened in a case regarding abuse in a large residential facility in Texas (the “fight club” case), and is asking the state to spend \$150 million to hire 1,100 staff to upgrade the quality of care in state institutions. Although the DOJ Settlement Agreement with the state of Texas includes a reference to the *Olmstead* decision and contains language in support of personal preference and community integration, the main focus of the DOJ remedy was on improving institutional care, and was not balanced by equal attention to ensuring that the state’s citizens have the community supports and services necessary for real choice between living in an institution and living in the community.

PADD systems are often asked to intervene in Medicaid cases in which ICF/MR care is an entitlement but home- and community-based care is a waiver service. This practice runs counter to rights detailed in the DD Act.

c. Support from ADD

Despite the access authority granted by the DD Act, some state agencies deny the PADD grantee access to records, facilities, and death reports. To gain access, the grantee may need to file suit. Although they often win, the process takes resources and time away from pursuing other cases. In addition, the outcome of the process is very uncertain. As noted above, the Fourth and Seventh Circuit Courts have provided conflicting decisions on the right of PADD grantees to exercise their congressionally mandated authority to access records in death investigations at state institutions (*Virginia Office of Protection and Advocacy v. Reinhard* and *Indiana Protection and Advocacy v. Indiana Family and Social Services*).⁶ At the writing of this report, the issue is in the hands of the Supreme Court. Congress established PADD groups to

investigate allegations of abuse and neglect of individuals with DD. If they are unable to go to court to enforce their access authority, their congressionally mandated authority to investigate abuse and neglect and take steps to protect individuals with DD will be rendered meaningless.

In 2005, OMB noted in the PART evaluation of a related PADD program, “The program’s effectiveness is limited by uneven cooperation from the States. The program could more effectively use its resources if States had greater understanding of and acknowledged the program’s rights to access facilities, consumers, and information involved in incidents they investigate” (OMB, 2005).

ADD project officers do not involve themselves in these conflicts. Additional federal leadership in this area is needed.

8. Current Monitoring and Evaluation Activities

Anecdotal evidence suggests that the quality and effectiveness of PADD services vary among states. Some provide needed legal protection for people with DD by effectively combining proactive strategies (e.g., educating consumers about their rights, advocating for and with groups of consumers for better services throughout the disability system) and reactive strategies (e.g., serving individuals who seek out PADD services through advocacy and litigation). Others have less comprehensive approaches.

PADD grantees are for the most part reactive entities, and they operate in different policy environments. Thus different approaches are expected. For example, a state with no institutions and strong quality assurance measures embedded in community services may engage in less litigation than a state with many large institutions or a weak service delivery system.

Interpreting quantitative data can be challenging. A large number of service requests may indicate that the PADD has a strong program to educate consumers about their

rights and a strong reputation in the community. Alternatively, it may indicate that the PADD is failing to stave off problems by advocating for system-level change.

Although setting performance standards and identifying underperforming agencies is a difficult task, it is critical that ADD hold the programs accountable and require remedial action when needed. No other entity has a vested interest in enhancing the strength of a PADD grantee. The P&A agency is designated by the governor, but the governor lacks an incentive to maintain a strong agency that can sue the state or demand legislative or administrative actions. The DD Act includes language to ensure that a governor cannot redesignate a P&A agency solely because it is too aggressive with the state, but there is no protection for the population against an ineffectual P&A agency.

Unfortunately, the ADD monitoring system does not provide this protection for people with DD. ADD requires that each PADD grantee submit annual performance reports with quantitative as well as qualitative “performance measures,” and participate in the monitoring and technical review process once every 10 years. The value of the annual performance report as a way to compare activities across states is plagued by some technical issues such as the lack of a definition of terms (e.g., the difference between “intake and referral” and “short-term assistance”). More important, however, is the absence of a standard to determine if the PADD grantee is performing adequately.

Congress, HHS, and OMB monitor PADD programs through the GPRA and PART process. The success of a program is measured by an “increase in the percentage of individuals who have their complaint of abuse, neglect, discrimination, or other human or civil rights corrected, compared to the total number of individuals assisted.” Currently, more than 90 percent of cases are corrected (OMB, 2008). However, this indicator is not, in and of itself, an accurate measure of the progress of the PADD program with respect to its mandate, since it focuses exclusively on individual representation and does not measure systemic change.

9. Promising Practices

This section describes some promising practices that maximize the impact of the P&A agencies, given their limited funds.

a. Information and Referrals

The Disability Rights Network in Pennsylvania receives roughly 10,000 phone calls per year. A well-trained support staff collects background information, identifies the issue, and enters the information into a database. Several times a day, the calls are distributed among a team of three to four attorneys and five nonattorneys who return the call. A supervising attorney retrospectively reviews some of the legal advice for accuracy. Often, the caller's needs can be met with a short conversation and information from the network's large collection of written resources. Using this approach, all callers receive some level of support.

b. Self-advocacy Skills

Equip for Equality in Illinois has set up a dedicated Special Education Clinic/Helpline for parents to access accurate, up-to-date information about their students' rights, their own rights and responsibilities, and legal advice and alternative options that they should consider to resolve differences with schools. Once parents have a basic understanding of a school's legal obligations in a specific situation and are given strategies to use in advocating for their student with school personnel, the vast majority can resolve the problem without further involvement of attorneys.

c. Individual Litigation

Disability Rights Mississippi filed a class action lawsuit against the public transportation system, including the paratransit system in Jackson, MS. The case advocated for accessible bus stops, working lifts on buses, and proper scheduling of paratransit

buses. The lawsuit was ongoing at the writing of this report but has already resulted in new lifts on all buses and some improvements in paratransit scheduling.

10. Recommendations

- 4.1 Congress should increase funding for the PADD program to meet the growing need for advocacy services of people with DD.
- 4.2 Congress should establish and authorize funding for a P&A program specific to IDEA, to be administered through DOE, to meet the critical need for legal advocacy related to education for children with DD.
- 4.3 Congress should require that ADD and the other five agencies that fund the PADD systems streamline their reporting requirements and progress indicators so that scarce resources can be used for client services.
- 4.4 Congress, in the next reauthorization, should preserve legal and investigative authorities embodied in the DD Act. Specifically, it should (1) ensure that the authorities are not superseded by state or other federal laws, (2) clarify that all PADD grantees, regardless of whether they are state or nonprofit entities, have the authority to enforce their access authority in court against both public and private providers, and (3) oppose legislation that restricts the legal authority of the PADD program to represent residents of institutions.
- 4.5 If a state does not comply with the DD Act section 143, to provide access to records, the HHS Secretary should hold ADD accountable for using its authority to support PADD grantees. Furthermore, the Secretary should request sufficient resources during the budget process to ensure that ADD can achieve its mandate.

CHAPTER 5. **Projects of National Significance**

1. Introduction

Under Title I of the DD Act, ADD may award grants, contracts, or cooperative agreements for Projects of National Significance to “support the development of national and State policies that reinforce and promote, with the support of families, guardians, advocates, and communities, of individuals with developmental disabilities, the self-determination, independence, productivity, and integration and inclusion in all facets of community life of such individuals.” Using this authority, the ADD can become an incubator for new ideas. It can provide short-term (one to five years) resources to DD network partners and other public and nonprivate entities to demonstrate new ideas that could become service models in the future.

Over the years, funding has been used for projects related to areas such as people with DD and the criminal justice system, homeownership, employment, inclusive education, assistive technology, family support, emergency preparedness, youth development, and self-advocacy.

PNS funds are also used for technical assistance to Councils, PADDs, and UCEDDs; support for small offices such as the HHS Office of Disability Policy and President’s Committee for People with Intellectual Disabilities; efforts to pursue federal interagency initiatives; and other projects that the ADD believes are needed to meet some of the increasing requirements of the Act.

For the past 30 years, PNS funding has also been used for data collection, analysis, and dissemination. This consistent funding has yielded data sources that allow the DD community to explore changes over time and disparities between states in expenditures, institutionalization, supported employment, and several important service areas. Advocates, experts, and DD network partners agree that these sources have

provided invaluable support for systems change. However, several aspects of the program limit its impact.

First, the PNS program is authorized at a substantially lower level than Congress intended when it first included it in the DD Act of 1975. At that time, “special project grants” were authorized at \$18 million (the equivalent of \$72 million in today’s dollars). In 2009, Congress appropriated \$14.2 million for PNS, requiring funds to be used for family support projects, including the National Clearinghouse and Technical Assistance Center on Family Support. When combined with existing obligations for technical assistance, data projects, and prior year grants, few funds are left to test innovative models and address emerging issues.

Second, the ADD Commissioner has broad discretion in identifying PNS priorities and determining how the budget should be spent. While this may be expedient, some stakeholders believe that a more transparent and consultative process would yield a better use of the money.

Third, PNS projects have yielded important contributions to the field. However, the impact of the program could be more substantial if the projects were better publicized among other network partners and the public so that they could stimulate further research and replication.

The sustainability of the program after the PNS funding ends has not been addressed, and there is no significant support for evaluation, dissemination, and replication.

2. Program Goals

The purpose of the PNS program is to “provide grants, contracts, or cooperative agreements for projects of national significance that support the development of national and State policies that reinforce and promote, with the support of families, guardians, advocates, and communities, of individuals with developmental disabilities,

the self-determination, independence, productivity, and integration and inclusion in all facets of community life of such individuals.” The Act specifically mentions family support activities, data collection and analysis, technical assistance to entities funded under subtitles, and other projects “of sufficient size and scope that hold promise to expand or improve opportunities for such individuals.”

3. History and Context

Since 1975, the DD Act has authorized funding for projects to develop and demonstrate innovative strategies to address national needs for people with DD, their families, and the systems that serve them. In the early days of the program, scores of PNS projects were undertaken. From 1976 to 1978, 715 special project grants were awarded—so many, in fact, that the Administration produced an annual compendium. Each was modest in size and funding, but projects in areas such as postsecondary education in community colleges and early childhood education showed substantial foresight.

In the late 1970s and early 1980s when the nation faced a recession, several researchers undertook data collection efforts to track expenditures and residential options for people with DD that could be used for advocacy purposes. PNS has continued to fund these programs, and they have produced a valuable description of the funding and deinstitutionalization effort over the past 25 years.

4. How the Program Operates

The DD Act gives ADD broad authority to choose priorities. It specifies 16 areas of potential funding, including family support, data collection and analysis, information and referral, self-advocacy, education for policymakers, federal interagency initiatives, participation of people from diverse racial and ethnic groups, and youth transition. With limited funding allocated to PNS, ADD has not been able to fund projects in all areas.

The ADD Commissioner, under the usual limitations of the Federal Advisory Committee Act and federal grant-making rules, identifies current and emerging needs, based on themes that surface from conferences and ad hoc conversations with stakeholders and network partners, and from priorities of the Administration on Children and Families. ADD then publishes a program announcement and network partners, as well as other qualified organizations, are eligible to bid. In some cases, the ADD Commissioner has the discretion to use PNS funds without going through a competitive bidding process.

This process is relatively new. Prior to the 2000 reauthorization, the DD Act required that the PNS priorities be published in the *Federal Register* and open for a 60-day public comment period before ADD released a program announcement.

Historically, ADD funded a few projects in each of many priority areas. For example, between 1998 and 2001 projects included inclusive outdoor play-spaces for children with DD; domestic violence and other crimes against people with DD; empowerment of girls of color with DD; Web-accessible information on state Medicaid programs for people with DD and their families; the College of Direct Support, the Quality Mall, Project Leadership, and NCI projects; self-advocacy for people with DD; and end-of-life care for people with DD (Grantsmanship Center, 2009; Swenson, personal communication, 2009). More recently, ADD has funded a larger number of projects in fewer priority areas and has been more prescriptive in defining the approach that each grantee should take.

5. Accomplishments

It is difficult to attribute long-term outcomes to small projects. At the time of this study, no system was evident to track the evolution of a project from a small research or demonstration through dissemination and replication. Nevertheless, several projects have evidence of success:

- State of the State, National Residential Information System Program, and Study of Financial and Programmatic Trends have provided advocates, policymakers, and researchers rich sources of information about the impact of federal and state fiscal policy and illustrate important service delivery trends in community living, public and private residential institutions, community supports, and support employment. The data, which provides national data as well as state-by-state comparisons, has been used by Congress, the courts, and in many state policy settings. As one advocate said, “Braddock and others using the PNS funds are able to capture critical statistics and we are in an age where statistics are the pieces that we need in order to educate policy makers on how far we’ve come and, more importantly, how far we’ve yet to come.” Given the paucity of data about specific disabilities available from most federal sources, these projects are vital resources and unique among disability communities.
- Anecdotal evidence suggests that the early childhood education movement that led to Part C of IDEA started with 12 demonstration programs that identified some of the methodologies and benefits of working with young children. People with DD and family members were clearly involved with this early movement.
- The family advocacy movement was strengthened by the Partners in Policy Making program and by the Home of Your Own Project, which established mechanisms for people with DD to buy their own homes.

6. Strengths and Weaknesses

The flexibility that the PNS affords the Commissioner is both a strength and potential limitation of the program. On one hand, it gives ADD the ability to respond quickly to issues as they emerge and to solicit innovative ideas. For example, ADD was able to respond to an idea generated by the youth movement and established the youth information and training centers. On the other hand, the process lacks transparency.

In addition, the small PNS grants are not well known, which limits the follow up and quick diffusion of many of these ideas. Engaging more stakeholders and DD network partners in the process of identifying PNS priorities would elevate recognition of the program and aid in the dissemination of the ideas.

7. Major Issues

Two major issues currently limit the PNS program:

First, the intent of the PNS program is to harness the creativity of the network partners, as well as the broader community, to generate innovative ideas. As shown in Exhibit 5.1, in 2009 (as in other recent years) a large part of the PNS budget has been allocated by Congress to Family Support and dedicated by ADD to the Family Support 360 programs, significantly limiting the funds available for other projects or approaches. Second, even for projects that show promise, there is often no funding from other sources for continued exploration or implementation when the short-term ADD funding of the project runs out. When PNS started, many states had the flexibility to adopt a new experimental approach with their “state-only” budgets for services to people with intellectual and DD. However, now that most services are funded by Medicaid, states have much less flexibility.

| Exhibit 5.1 Projects of National Significance, 2009 | | |
|-----------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|
| Program | Description | Funding Level (estimate) |
| <i>Family Support (discussed in Chapter 6)</i> | | |
| Family Support 360 | 26 grantees (including four military bases) develop and implement local one-stop family support centers. | \$6 million |
| National Clearinghouse and Technical Assistance Center | Develops and maintains National Clearinghouse and Technical Assistance Center on Family Support. | \$1 million |
| <i>Ongoing Data Collection and Information Dissemination</i> | | |
| State of the States in Developmental Disabilities | Ongoing annual data collection and analysis of public financial commitments and programmatic trends in state DD services and supports. | \$300,000 |
| The National Residential Information System Program | Ongoing annual data collection and analysis of state and national statistics on residential services for people with DD. | \$300,000 |
| State of the States in Developmental Disabilities: 2007–2011, A Nationwide Study of Financial and Programmatic Trends | Ongoing collection, analysis and dissemination of state-level data on employment services, outcomes, and economic status of people with DD. | \$300,000 |
| <i>Youth Programs</i> | | |
| Youth Information, Training, and Resource Centers | 21 grantees (15 in 2004–2007) design and implement centers projects that assist youth and emerging leaders with DD with transition, empowerment, and advocacy issues | \$2.5 million |
| <i>Medicaid</i> | | |
| The Medicaid Reference Desk | Maintains and expands a Web-based interactive information resource of state and national level Medicaid information for adults and children with DD, their families, and others. | \$150,000 |
| <i>Technical Assistance and Other PNS Budget Items</i> | | |
| Technical Assistance | Technical assistance (TA) to UCEDDs, Councils, Family Support 360, and Youth Information and Training Centers. | \$2.2 million |
| Developmental Disabilities Program Performance Evaluation (DDPIE) | External Evaluation of the UCEDD, P&A, and state Council programs as recommended by the Performance Assessment Rating Tool (PART). | \$1.5 million |
| Program Support | PNS program administration (monitoring and TA). | \$562,000 |
| Sources: ADD Web site and Administration for Children and Families, 2009 | | |

8. Current Monitoring and Evaluation Activities

The goal of most PNS projects is to demonstrate a new idea and assess whether it merits additional research and replication. Unfortunately, measuring the ultimate impact of these types of programs is plagued by an issue that is shared by many federal grants. The Federal Government has not established a system that can track an idea from research or small demonstration through additional research, larger demonstration, small-scale dissemination, and eventually full-scale implementation. As a result, although PNS projects predated some of today's accepted practices, the system lacks "hard evidence" of the projects' exact role.

ADD monitors the programs to ensure that they meet their contractual obligations and requests that the projects evaluate themselves. However, most projects are not evaluated for their effectiveness.

a. Monitoring and Technical Assistance

ADD uses several approaches to monitor the PNS grantees:

- ADD requires grantees to provide quarterly and semiannual reports that identify accomplishments and challenges. To the extent possible given their current staffing level, ADD provides technical assistance in response to these identified challenges.
- ADD has contracted with Technical Assistance Centers to provide state-to-state TA for multisite projects (family support and youth transition).
- Grantees participate in quarterly TA conference calls and share their accomplishments and challenges with ADD.

b. Evaluation

ADD requests that grantees develop logic models and other methods to evaluate their program. However, the demonstrations are not required to have an evaluation component. Although the lack of evaluation limits access to information about the usefulness and impact of a project, in general, requiring evaluation in the design of the demonstration is costly. Without additional funding, an evaluation component could consume a large portion of the grant funds.

In the multisite demonstrations, a number of small entities are testing slightly different models within the context of different state environments. Teasing out the lessons learned and promising practices is not an easy task. Other federal entities such as CMS (HHS) and ODEP (DOL) use the use the Technical Assistance Centers to perform some of these evaluation tasks. Unfortunately, the Technical Assistance Centers are not contracted to take an active role in evaluating the grantees or the programs as a whole.

At the writing of this report, ADD has no additional plans to evaluate the PNS program, as it is not included in the DDPIE evaluation.

9. Promising Practices

Stakeholders and experts consistently identified four PNS projects that had a significant impact on service delivery and systems change:

a. State of the States in Developmental Disabilities

With 25 years of data collection, this project allows state-by-state examination of the effects of important societal events such as the *Olmstead* decision. Although data is affected by state differences in eligibility definitions, as well as imprecision and inconsistencies in state data collection practices, the information allows an unparalleled examination of national trends across multiple years (Stoneman, 2009).

The State of the States project has produced more than 170 articles contributing to the field's understanding of the evolving character of DD service delivery systems in the United States, including eight books, 28 book chapters, 49 journal articles, 67 monographs and technical reports, nine congressional and judicial testimonies, and 10 newsletters and brief reports. The project's research findings have also been disseminated through an extensive program of 439 presentations delivered in 43 states and seven foreign countries (Coleman Institute, undated).

b. Residential Information System Project

For more than 25 years, the National Residential Information System Program (RISP) has gathered, maintained, and disseminated annual state-by-state and national statistics and other program- and policy-relevant information on residential and Medicaid-financed services for people with DD. RISP is the principal national source of annual statistics on residential and Medicaid services for people with DD, and as such it is widely used in policy development, evaluation, and advocacy. RISP gathers and disseminates national and state-by-state statistics on state and nonstate institutional and community- and home-based residential services for people with DD by size, operator, and type of living arrangement; recipients of and expenditures for Medicaid ICF/MR, HCBS, and Nursing Facility programs; and people waiting for services. It conducts periodic special surveys of state DD directors. For example, in 2009 it is collecting information about the number of children with intellectual or developmental disabilities living in places other than their family home or a family foster setting. RISP also conducts analyses of existing data sets, such as the National Core Indicators Survey, to examine the associations between personal characteristics, living arrangements, financing and support models, state and other factors on inclusion, self-determination, well-being, and other outcomes.

RISP maintains clearinghouses of information and resources on community living costs and outcomes and the direct support workforce. Its information collection and analysis activities are supported by a comprehensive dissemination program of annual reports, Policy Research Brief, Community Services Reporter; the QualityMall.org Web site; the

“Trends and Milestones” feature in *Intellectual and Developmental Disabilities*; and other publications and presentations. The Quality Mall provides Web-based information on person-centered supports in 20 “stores” and 78 “departments.” It has 1,700 products and averages 12,000 visitors per month. RISP also provides ongoing technical and informational assistance to government agencies; professional, advocacy, and provider organizations; individuals; families; the media; researchers; and others. These activities ensure ongoing access to current information on the status, trends, and outcomes of residential and Medicaid-financed services and on effective and innovative policies and programs for their delivery. The vast majority of RISP publications are disseminated online at no cost through the Institute on Community Integration Web site (<http://ici.umn.edu/>) or through the Research and Training Center on Community Living Web site (<http://rtc.umn.edu/main>).

c. Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Intellectual and Developmental Disabilities

For 20 years, the Access to Integrated Employment project has described trends and issues related to employment and day supports for individuals with intellectual and developmental disabilities. The project goal is to contribute to a comprehensive understanding of the factors that influence employment outcomes at individual, employment support, service provider, and state policy levels. Funded by ADDs, the project has taken an approach that considers multiple perspectives, including a regular survey of state DD agencies, periodic surveys of community rehabilitation providers, case studies of high-performing states, and descriptions of state-level promising practices. This varied approach, along with secondary analysis of data from other sources, including the Rehabilitation Services Administration, the U.S. Census Bureau, DOL, and SSA, has allowed the project to both describe trends and explore the factors that influence employment outcomes.

Since 2006 core data from the project has been available at www.StateData.info. This Web site allows users to create custom graphs and tables at the state and national levels covering a 20-year period. The annual companion State Data report, the National

Report on Employment Services and Outcomes, provides a comprehensive overview of the status of employment and economic self-sufficiency for individuals with intellectual and developmental disabilities in print and PDF formats.

The Access to Integrated Employment trend data and case studies of high-performing states provided a catalyst for the development of the State Employment Leadership Network (SELN). ICI formed the SELN in partnership with the National Association of State Directors of Developmental Services. Sixteen state intellectual and developmental disabilities agencies are currently members, with a commitment to developing policy and strategy that improves employment outcomes. Nationally, data suggests that since 2001 the percentage of agency customers engaged in integrated employment has begun to decline, but some states have achieved significant results. Over the past several years, there has been a growth in attention to employment outcomes, including the development of employment-first policy at the state level. ICI has supported and informed policy change at the state and federal levels, and researchers, policymakers, and advocates request custom data analyses. Project data has supported policy and advocacy, including informing the leadership of the Alliance for Full Participation's initiative on employment.

d. Partners in Policymaking

The Minnesota DD Council created a model of leadership training designed for self-advocates and parents. Partners in Policymaking provides timely and current knowledge about disability issues and teaches its participants the leadership skills they need to become effective advocates in influencing policy at all levels of government.

The program has been replicated in 47 states, and by 2007, more than 15,000 people have graduated from the program. Many are now part of a growing national and international network of community leaders serving on policymaking committees. Many report that the program has enabled them to be more successful in their personal advocacy for more inclusive school environments, community employment, in-home supports, and other services (MN Governors Council, 2007).

e. Home of Your Own

In 1993, ADD funded demonstration projects in three states to offer technical assistance to people with DD and their families in securing homes of their own and developing replicable approaches to identify resources and strategies. ADD expanded the program by entering into a five-year cooperative agreement with the Institute on Disability at the University of New Hampshire to build coalitions of people with disabilities, families, representatives of financial institutions, housing and disability organizations, and human services providers. The result was the creation of a national information and technical assistance center on homeownership, control, and personalized support, and a 23-state National Home of Your Own (HOYO) Alliance. From 1993 to 1999, Alliance members assisted more than 900 individuals to purchase homes (Klien, 2000).

Two aspects of the HOYO initiative were especially promising practices. First, it did not rely predominantly on ADD; rather, it facilitated access to existing private and Government resources from Fannie Mae, U.S. Department of Housing and Urban Development, Federal Home Loan Banks, and private mortgage companies. By 1996, Fannie Mae had developed a new mortgage product, Home Choice, tailored specifically to the needs of people with disabilities. The Fannie Mae Home Choice coalitions that have developed around the country are built on the HOYO coalitions. Second, as part of their strategic plans, each state established outcome measures to evaluate the effectiveness of their work. Outcome measures included the number of individuals owning their homes, policy issues that needed to be addressed, ongoing technical assistance needs, and public awareness needs.

10. Recommendations

- 5.1 ADD should develop a transparent system for identifying PNS priorities that includes consumers, policymakers, and network partners.

- 5.2 ADD should develop an evaluation approach to track the follow up and outcomes of PNS programs in order to identify their effectiveness and the value of PNS grants.
- 5.3 ADD should fund additional data collection initiatives in areas such as health care access, direct care workforce issues, and educational outcomes.

CHAPTER 6. Family Support

1. Introduction

The majority of the approximately 5 million Americans with intellectual and developmental disabilities live at home with their families. Although many families find strength in having a member with a disability, having such a member may also impose significant physical, emotional, and financial demands.

Providing support to families can reduce the need for costly, unnecessary, and unwanted out-of-home placements and can allow the family to guide the member with a disability toward achieving life goals. However, although family support programs exist at both the state and federal levels, they are generally underfunded, fragmented, and restrictive.

Title II of the DD Act of 2000 was supposed to provide systems change grants to states to address some of these underlying problems. Although it was authorized, it was never funded. However, beginning in 1999, ADD received appropriations of \$5–\$6 million for PNS that were earmarked for family support initiatives to pursue statewide systems change consistent with Title II. ADD used the PNS funding for three initiatives:

- **Demonstration grants to states:** ADD gave states wide latitude in designing and developing these initiatives, which tended to be consistent with Title II and focused on statewide systems change activities. However, since the grant program was never evaluated, it is not possible to assess if any results were achieved. The extent to which the initiatives had a long-term impact on state policy or were sustained beyond the grant funding period is unknown.
- **Family Support 360 program:** The Family Support 360 program funds one-stop centers for families. The program grantees are meeting the goals identified in the program announcement and are helping the families they serve. However, stakeholders express significant concerns about the

program. First, by providing direct services to a small number of families rather than targeting statewide systems change, it is inconsistent with the intent of Title II. In addition, the programs are not well integrated with existing federal and state family support programs and do not address the most compelling issues facing the family support movement.

- **National Clearinghouse and Technical Assistance Center on Family Support:** In 2008, ADD funded the Academy of Educational Development to develop the National Clearinghouse and Technical Assistance Center on Family Support. The program has the potential to help families learn about available services and supports and to strengthen the ability of families to influence family support policy. However, some stakeholders believe that the program would have had a wider audience had it coincided with and supported the other two family support initiatives. In addition, in 2008 ADD funded a contractor for two years, but no plan is in place to evaluate the efficacy of the technical assistance initiative to determine whether the funding should continue beyond 2010.

This chapter provides a short history of family support and Title II of the DD Act; reviews ADD family support programs; and recommends actions that Congress, ADD, and other federal agencies should consider to strengthen the nation's approach to supporting families.

2. Program Goals

Title II of the DD Act of 2000 authorizes ADD to make grants to states to “support *systems change activities* designed to assist states to develop and implement, or expand and enhance, a **statewide system** of family support services for families of children with disabilities” [42 USC 15093] (emphasis added).

3. History and Context

Family support consists of a range of services or supports, including direct cash payments to families and vouchers, reimbursement, or direct payments to service providers, that helps people with disabilities and their families achieve the following goals:

- Assisting families to stay intact until such time as the minor member with a disability becomes an adult and leaves the family home;
- Enabling families to provide needed supports at home to their family member with a disability;
- Assisting families to enhance their family quality of life and be included in their communities; and
- Assisting families as they guide the member with a disability toward achievement of the nation's goals for people with disabilities: equal opportunities, economic self-sufficiency, independent living, and full participation (Beach Center, 2007).

It generally includes the following types of services:

| | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none">• Assistive and medical technology• Medical and related professional services, including specialized therapies• In-home assistance (personal care services, homemaker support, nursing services)• Behavioral supports• Case management/service coordination• Cash subsidy/financial support• Crisis intervention• Home modifications | <ul style="list-style-type: none">• Psychological/emotional support (counseling, parent-to-parent, sibling support, self-help groups, etc.)• Family education and training (disability information and/or advocacy training)• Financial and life planning assistance• Prevocational training/supported employment• Recreation/leisure (day, evening, summer day camp, sleep away camp)• Respite• Transportation |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Family support has proven to be an effective approach to reducing out-of-home placements (Heller & Caldwell, 2005). Nevertheless, only a fraction of public long-term spending is directed toward family support initiatives. In 2006, \$2.3 billion, or 6 percent of community DD funding (5 percent of total intellectual and developmental disabilities spending) was allocated to family support services across the nation (Braddock et al., 2008). As one stakeholder said, “the service system rests on the back of family caregivers who by and large receive nothing. When the family can’t do it anymore, we spend thousands and thousands of dollars a year on residential support. This expectation that families can just provide care for decades and decades without support is just not smart.”

Prior to the 1970s, families had only two choices: place their loved one in an institution or assume the responsibility for their family member with no government assistance. Over the past three decades, fewer people have chosen institutions, and federal and state governments have moved toward establishing systems to support children and adults living at home.

In the early 1970s, Pennsylvania developed one of the earliest state-funded family support initiatives for children with intellectual disabilities, and over the next two decades, all other states and the District of Columbia fielded some type of family support for children. Each offered different types of services and supports, but most intended to do “whatever it takes” to ensure that children could grow up with their families.

Although all states have family support initiatives in either cash subsidy or other family support activity, there is wide variation in services, service options, and spending. In 2006, more than 426,000 families received family support services nationwide, with the average spending per family ranging from \$232 per year in Alabama to over \$10,000 in 12 states (Rizzolo, Hemp, Braddock, & Schindler, in press).

The language in Title II of the DD Act of 2000 was originally developed in 1994 as the Families of Children with Disabilities Supports Act of 1994. The language was

formulated at a time when state-funded family support programs were in their infancy. In the meantime, family support has evolved in the following areas.

a. Expansion of Target Population

Most state programs were originally designed for families who have children younger than 18 with disabilities. Many have expanded to include families who have adult members with disabilities living in the family home.

The expansion into a different population requires a rethinking of the nature of families. The two populations (families of children and families of adults) need not only different types of supports but also different philosophies. For families of young children, family direction is a key principal. For families of adults, the key principal may be self-direction.

b. Growth in the Demand for Services

The number of people with DD has grown, as has the number living with their families well into their adult years, creating an unprecedented demand for services.

c. Wider Variation in the Age of Caregivers

Because states are increasingly targeting individuals from birth to any age and people with disabilities are living longer, families include support givers of varying ages, some young and others past retirement age.

d. Increasing Cultural Diversity

The intellectual and developmental disabilities community is becoming more culturally diverse, which requires that service systems accommodate varying languages and customs.

e. Evolution of the Meaning and Structure of “Family”

A person with intellectual and developmental disabilities may live in a “traditional” family with two parents and perhaps brothers and sisters, or may live in a household headed by a single parent, siblings, grandparents, or other extended family members.

f. Change in Expectations

Family support services have historically been provided and directed by public and private service agencies. More recently, consumers, families, and advocates have demanded that services be more consumer-centered or consumer-directed. Twenty-four states have responded by establishing consumer-directed cash subsidy programs, and Medicaid allows states to develop consumer-directed options (Braddock et al., 2008).

g. Increased Reliance on Medicaid

States have been trying to maximize the federal funds for family support by expanding their use of the Medicaid Home and Community-Based Waiver authority. As a result, Medicaid has become the primary provider of family support. In 2006, the waiver financed 70 percent of all family support services in the United States, almost triple the proportion it funded in 1998 (Braddock et al., 2008; Parish et al., 2000).

As states rely more heavily on Medicaid to fund in-home supports, family support services are changing. Medicaid will fund only certain types of services, thereby limiting the state’s ability to do “whatever it takes” to keep the family together. In fact, Medicaid does not pay for family support per se since the Medicaid beneficiary—not the beneficiary’s family—must be the recipient of services.

h. Addition of Other “Players” in the Service System

Other federal and state agencies provide services important to families of people with all types of disabilities, including DD. (1) The Supplemental Security Income (SSI) program provides cash assistance to families who meet financial eligibility requirements and who have children with severe disabilities. (2) Part C of IDEA authorizes state and local educational agencies to provide appropriate early intervention services, including other supports such as parent training and family resource centers. (3) The Rehabilitation Act offers independent living and home care services to people with disabilities in some states. (4) Temporary Aid to Needy Families offers a range of family support services to families eligible for the program. (5) The Department of Housing and Urban Development, in combination with local housing authorities, may provide subsidized housing. (6) The Department of Labor funds some targeted job-training programs. Each program has its own application procedures and eligibility requirements. As a result, families are challenged to learn what programs are available, how to access them, and how to coordinate their services across multiple agencies.

i. Increased Attention to Parent/Caregiver Training and Family-to-family Groups and Networks

A variety of federal agencies provide funds to help families understand and navigate the fragmented system. (1) SAMHSA funds small Statewide Family Network grants for families of children with mental illness. (2) The Maternal Child Health Bureau funds family-to-family health information centers through the Title V block grant for Children with Special Health Care Needs. (3) AoA funds the National Family Caregiver Support Program, targeting caregivers responsible for someone over age 60 or caregivers who are at least age 60 and are responsible for a child or a person with a disability. (4) AoA and CMS jointly fund the Aging and Disability Resource Centers to help families navigate the long-term care system. (5) State Departments of Education often have family support networks to involve parents in the education system.

4. How the Program Operates

No funding was appropriated for Title II. However, in 1999, Congress appropriated \$6 million in Title I of the DD Act for PNS. Through committee report language, Congress directed these funds for states to develop statewide systems of family support consistent with Title II. Using these funds, ADD has launched three family support initiatives: Demonstration grants to states, the Family Support 360 program, and the National Clearinghouse and Technical Assistance Center on Family Support.

a. Demonstration Grants to States

Between 1999 and 2003, ADD funded 54 family support projects nationwide, including projects in 49 states, four U.S. territories, and the District of Columbia. The size of the grants varied between \$100,000 and \$200,000 per year for one to three years. States had wide latitude in designing and developing initiatives that would enhance the statewide system of support for families of individuals with disabilities.

b. Family Support 360 Programs

ADD awarded grants to UCEDDs, state agencies, and nonprofits to develop family-driven, one-stop family support centers targeting unserved or underserved populations. In 2003, ADD funded 31 planning grants, and in 2004, 21 of these grantees were awarded \$250,000 per year for five years in implementation grants. ADD also awarded nine planning grants in 2004, but insufficient funding prevented any of the grantees from receiving implementation grants.

Each of the 21 implementation projects is required to work with at least 50 targeted families a year. Project personnel work with each family to determine the services needed and the best way to access those services. Families participate in writing a family service plan, which describes the services they may receive as well as the steps to be taken to secure the services. Through the plan, families may be assisted with a broad range of needs such as accessing health care, child care, early intervention,

education, employment, marriage education, transportation, housing, respite care, and assistance in maintaining parental rights. In 2008, ADD began funding four five-year Family Support 360 projects for military families on bases.

c. National Clearinghouse and Technical Assistance Center on Family Support

In 2008, ADD launched a Center to develop and disseminate information to families of children with disabilities. During the two-year grant period, the Center is to provide leadership training to help families become “informed and knowledgeable partners in working with State and local agencies in designing, expanding and improving family-centered policies and practices” (Administration on Developmental Disabilities, 2008c).

In September 2008, ADD entered into a two-year \$1.9 million cooperative agreement with AED to develop a National Clearinghouse and Technical Assistance Center on Family Support (FedBizOps.gov, 2008). AED is to assess the technical assistance needs of families of children with disabilities and address these needs by providing expert knowledge and leadership development using multiple dissemination methods. AED is expected to proactively disseminate information, especially to unserved and underserved populations, as well as respond to questions and requests from families who contact the Center (Administration on Developmental Disabilities, 2008c). In addition, AED is to develop teams of family members in each state who will be “the next generation of family support” and provide technical assistance and support to these teams to develop and implement family support action plans for their community or state.

5. Accomplishments

Together, the three independent initiatives do not represent a coherent approach to realizing the goals of Title II. However, the family support programs have provided information, training, and other forms of technical assistance to families of people with DD. Examples are as follows:

a. Demonstration Grants to States

Based on a review of ADD documentation (Administration on Developmental Disabilities, 2001), states pursued the following initiatives:

- Modified laws and policies to expand the availability of family support and developed family-centered policies (e.g., a family support Medicaid waiver, policy guidelines for family support programs, increased cash subsidies);
- Provided information and training to parents for better access and effective use of available supports (e.g., awareness of what supports are available, how to work with collaborative teams, how to manage resources in a consumer-directed cash subsidy program);
- Developed family leadership to become more involved in the policymaking process (e.g., develop family councils, provide information and technical assistance); and
- Developed and support family-to-family networks to share information on family support, advocacy, and systems change.

ADD did not track the outcomes of these initiatives. As a result, it is unclear which, if any, had lasting impacts.

b. Family Support 360 Programs

In FY 2008, the Family Support 360 programs received \$4.1 million and provided comprehensive assistance to 1,426 families. An additional 4,681 families benefited from casual assistance and various Center activities. “Family navigators” worked with families to blend together resources around families involving supports from public agencies, various community resources, and the families themselves. In addition, the Centers developed opportunities for families to provide support to one another (Agosta, Melda, & Bradley, 2009).

c. National Clearinghouse and Technical Assistance Center on Family Support

AED established the Family Support Center on Disabilities: Knowledge & Involvement Network in January 2009. To date, it has established a Web site with information, links to other resources, and forums. The grantee has recruited 411 people for state action teams, provided technical assistance to the teams, and convened a conference for state team members. The Web site is set up to function as a centralized location where families and people with disabilities can access information about resources, and the state action teams provide a mechanism for people to become involved and connect with other families.

6. Strengths and Weaknesses

a. Demonstration Grants to States

The demonstration grants allowed states to experiment with different options to address the most compelling issues facing family support in the state. The grant program was consistent with Title II of the DD Act and had the potential to affect change. However, the demonstration grants were never evaluated. So it is not possible to report on their impact, their sustainability, or the lessons learned from the experience.

b. Family Support 360 Programs

The grantees identified and tapped a wide range of community resources. Using peer or family navigators, grantees were able to help families access multiple social service systems such as Medicaid, food stamps, housing assistance, and energy assistance. They found that navigators could harness community resources to complement government-provided services.

However, the initiative had some major limitations:

- The initiative was not consistent with Title II of the DD Act. Title II specified that ADD should provide grants for statewide systems change activities. The Family Support 360 projects provided direct service to a relatively small number of people in local areas.
- The projects had limited family and state DD agency collaboration. With only a few exceptions, state DD directors had little or no interaction with the Family Support 360 programs. ADD did not maximize the potential partnership between the Family Support 360 programs and state DD programs.
- The projects were required to adhere to a one-stop concept that constrained their flexibility to experiment with other models. While the one-stop concept had a great deal of value, stakeholders noted that the opportunity to experiment with different types of models was not realized.

c. National Clearinghouse and Technical Assistance Center on Family Support

Information for families is scattered among many government and nongovernment service providers, advocacy groups, and other entities, with no central repository of information that is easily accessible to families. As a result, the Center had the potential to fill an important gap. However, it is not well integrated with other ADD family support initiatives. ADD has opted not to continue funding the Center beyond the original two-year grant.

7. Major Issues

The title was never funded.

8. Current Monitoring and Evaluation Activities

a. Demonstration Grants to States

ADD required grantees to produce annual reports, but it does not appear that the grantees were closely monitored, and ADD did not evaluate the programs.

b. Family Support 360 Programs

ADD required the grantees to produce quarterly reports and monitored the reports to ensure that grantees were meeting the requirements of the request for proposals (RFP) and to identify additional technical assistance needs. ADD, and its TA contractor BETAH Associates, Inc., facilitated conferences, webinars, and work groups to address the information needs of grantees and navigators. Because the programs were designed as short-term demonstration projects, they were not included in the formal independent evaluation. As a result, their impact is unknown.

c. National Clearinghouse and Technical Assistance Center on Family Support

No evaluation component was included in the Center plans.

9. Promising Practices

A number of the state demonstration grantees and Family Support 360 programs have provided valuable support to the people they reached. A practice can be seen as promising if it is easily replicable or sustainable beyond the end of the ADD grant funding. The fact that a program can sustain itself or garner funding from another entity indicates that consumers view the program as having value.

The funding for grantees ended in September 2009. At the writing of this report, it was unclear which programs would be able to find ongoing support. ADD identified the following models as either easily replicable or likely to find support:

a. Family Navigators Located with Local Programs Model

In Colorado, family navigators are located in the same office as the staff of Denver Options, who work with Temporary Assistance for Needy Families recipients.

b. Culturally Sensitive Mobile Services Model

The New Mexico grantee has partnered with a Native American nonprofit organization to provide an array of culturally appropriate services and supports. Project staff members travel to five participating Pueblos, working with tribal leaders and visiting families in their own homes. This project also recognizes the sensitive need to balance tribal sovereignty with state and federal laws.

c. Faith-Based Model

The Minnesota grantee subcontracted with a church in a low-income area to promote the availability of the services and resources of the Center. This model builds on the natural community and resources of the church.

d. Leveraging Medicaid Waiver Funds

The Division of Developmental Disabilities in South Dakota administers the grant program, People Leading Accessible Networks of Support (PLANS). The state has hired five professional coordinators in different regions to assist families to develop a plan to access a broad range of supports and services in their communities. PLANS offers a limited pool of funds for direct services. The state intends to continue the PLANS program beyond the end of the ADD grant funding by using Medicaid Waiver funds.

10. Recommendations

Each state is at a different stage in its development of family support services. Given this variability, states and localities should be allowed to pursue different approaches. At

the same time, it is possible to identify overarching goals and strategies that are relevant for all states and could be the core of a refocused effort to ensure that the system supports families of children with DD.

Family support services, policy, and philosophy have evolved since the mid-1990s, when the family support provision was originally written. It is important to Title II to consider both the type of programs it supports and the guidance it can give to state DD agencies as they modify their family support systems.

- 6.1 ADD should convene a meeting of experts, stakeholders, and government representatives to identify changes in family support services, policy, and philosophy that have occurred since the family support provision was written and recommend changes to Title II before the DD Act is reauthorized.
- 6.2 Congress should provide direct funding of Title II to ensure that funds are used consistent with the intent of the Act, rather than funding family support through PNS. The funding should be at a level of at least \$15 million.
- 6.3 ADD should coordinate through intra- and interagency groups, i.e., involve other HHS agencies, divisions, and external federal partners that are working on family support issues.

CHAPTER 7. Direct Support Workers

One of the greatest challenges to providing community supports for people with DD is finding and retaining qualified direct support workers (DSWs). Some call DSWs the “backbone of the long-term care system.” DSWs provide services in residential settings, family homes, their own homes, community job sites, vocational and day training settings, schools, and other settings. The positions may include special education paraprofessionals, supported employment counselors, community home staff, home health aides, and a host of other position titles. Their jobs require them to help children and adults with DD with basic health and self-care needs, but they also play a central role in assisting people with DD to gain skills, participate in community life, develop social relationships, make decisions and judgments, and become more independent.

The absence of reliable data to measure the supply of DSWs who work in a variety of settings makes it difficult to quantify the extent of the shortage and turnover rates. However, estimates suggest that 625,000 DSWs support people with DD. The vacancy rate is 6 to 17 percent, and the turnover rate is 52 percent per year (Hewitt & Larson, 2007).

This shortage is expected to be problematic over time as the need for services increases. The growing U.S. population, increasing life expectancy for people with DD, aging of family caregivers, national commitment to and steady expansion of community-based and home services combine to increase the demand for DSWs. Factors affecting the shortage and high turnover rate of qualified DSWs include low wages, few benefits, lack of recognition, and the lack of quality training and career advancement opportunities.

Between the high turnover rate and the expanded need for services and supports, DD programs need to recruit and train more than 300,000 DSWs per year nationwide. With Medicaid accounting for almost 80 percent of total spending for DD through waivers, ICF/MR, and related Medicaid spending (Braddock et al., 2008), involvement by the

CMS and the state Medicaid agencies can have an impact on Medicaid spending and quality of care.

This challenge is not unique to people with DD and their families. Community care services for people who are aging or have physical disabilities or mental illnesses/psychiatric disabilities also rely on DSWs. The roles of the DSW vary by sector, as do the needs, location of services, and funding sources. Despite these differences, all sectors face the common challenge of recruiting and retaining a quality workforce to support the expansion of home- and community-based services.

Title III of the DD Act of 2000 concentrated on the training component of the issue. It authorized \$800,000 per year for three years to develop a Web-based training course for DSWs and \$800,000 per year for six years to fund scholarships for DSWs. Congress failed to appropriate any additional funds for the Title. However, a congressional appropriation in the late 1990s earmarked seed money for the University of Minnesota UCEDD to develop the College of Direct Support, an online training center that provides training for DSW supervisors, managers, and executive directors as well as frontline DSWs. It continues to update its curriculum and currently sustains itself with user fees. It currently serves 136,000 learners in 25 states, and over the past five years has provided almost 2 million hours of training.

Some states have begun to address other aspects of the recruitment and retention challenge. With initiatives in UCEDDs and DD Councils, as well as those funded by the CMS, AoA, and DOL, states have enhanced wages and benefits, developed health insurance options, expanded training opportunities, developed recruitment initiatives such as worker registries and coordination with one-stop employment centers, or established career ladders and credentialing. As a result, states vary in terms of their current needs, competencies, and infrastructure.

This chapter discusses ADD past initiatives to address the shortage of DSWs and provides background information to identify an appropriate role for ADD and the DD Act in addressing this issue in the future.

1. Program Goals

As Congress noted in the DD Act, “as increasing numbers of individuals with developmental disabilities are living, learning, working, and participating in all aspects of community life, there is an increasing need for a well trained workforce that is able to provide the services, supports, and other forms of direct assistance required to enable the individuals to carry out those activities” [P.L. 106-402-OCT. 30, 2000 114 STAT. 1679 14].

2. History and Context

In institutions, DSWs were primary caretakers who carried out structured programs of health, safety, training, and basic care. In the community, DSWs are expected to meet peoples’ basic health, safety, and care needs, but they also support people to develop and achieve personal goals; to balance risks with choices; to find and keep jobs; to connect with peers, friends, and family members; and to be full and active citizens in their communities. In institutions, DSWs could turn to supervisors and peers for daily support, but in the community, DSWs often work alone with little supervision (Hewitt & Larson, 2007).

While given expanded responsibilities (often through regulations), DSWs have not been required to meet increases in qualifications, education, or training. Today, many states only require DSWs to have a driver’s license, a high school diploma or general equivalency diploma, and to pass a criminal background check. DSWs consistently report that their training is insufficient to prepare them for their job responsibilities (Hewitt & Larson, 2007). To address this need for training, the DD Act of 2000 includes the following initiatives:

- **Reaching Up Scholarship Program** to provide grants to enable eligible entities to provide vouchers (of no more than \$2,000 each) for postsecondary education to DSWs who assist individuals with DD.

- **Staff Development Curriculum** to fund the establishment, evaluation, and dissemination of a staff development curriculum and related guidelines for computer-assisted, competency-based, multimedia, interactive instruction relating to service as a DSW.

Even in the absence of this appropriation, ADD has funded initiatives to recruit, retain, train, and develop best practices for DSWs through DD Councils, UCEDDs, and direct funding (through the PNS authority) to the College of Direct Support. Unfortunately, it is difficult to identify and track these initiatives on a national level because the direct support workforce is not an “area of emphasis.” Thus, UCEDDs and DD Councils do not have a vehicle in which to report the results of these initiatives in an easily identifiable and consistent manner.

3. How the Program Operates

Title III was never implemented because appropriations never materialized.

4. Accomplishments

Title III was never implemented because appropriations never materialized.

5. Strengths and Weaknesses

Title III would have provided short-term funds to enhance training opportunities. However, it did not address some of the broader issues that must be addressed to ensure that the DSW workforce is able to meet the needs of the DD community:

- **Recruitment and retention:** Research and demonstrations by ADD-funded entities and others have identified a number of strategies to recruit and retain DSWs, such as providing health benefits, establishing backup systems, creating marketing campaigns, developing computer-based worker registries

and matching systems, and developing career lattices. However, most states have no mechanism to implement these strategies.

- **Wages and benefits:** Wages and access to benefits are consistently identified as strong predictors of DSW turnover. Although inadequate data precludes an exact measure, researchers estimate that the average wage of a DSW working with people with DD is under \$10 per hour, and a high proportion rely on public assistance to make ends meet (Hewitt et al., 2008).
- **Ongoing training and curriculum development:** Because of the high turnover rate, there is a constant need to train new DSWs. In addition, existing DSWs need to learn new skills as their job demands change and they take on additional responsibilities as supervisors and managers. Currently, most of this training is funded by states and social service agencies that pay a fee to the College of Direct Support or the UCEDD in their state to provide training. In times of budget constraints, these funds may be at risk.
- **Data needs:** Federal data systems do not provide sufficient information about DSWs working in the DD field to facilitate informed policy decision.
- **Coordination with other government agencies:** A number of federal agencies, including CMS, AoA, the DOE National Institute on Disability Rehabilitation and Research, and SAMHSA, focus predominantly on the needs of one sector of the population, such as people with physical disabilities, mental health issues, or aging. As state and federal strategies are established, the unique needs of people with DD need to be considered.

6. Major Issues

Title III was never implemented because appropriations never materialized.

7. Current Monitoring and Evaluation Activities

None.

8. Promising Practices

Because Title III was not implemented, no promising practices have evolved from it.

9. Recommendations

- 7.1 Congress should rewrite Title III to provide grants to states to develop, implement, and evaluate comprehensive workforce development programs to attract, retain, and train DSWs who provide support to individuals with DD.
- 7.2 Congress should add recruitment, retention, and training of the direct care workforce to the areas of emphasis in the DD Act.
- 7.3 ADD should develop and help fund partnerships with other federal agencies to create a unified approach to ensure an adequate direct care workforce to serve the needs of people who are aging or have disabilities.

Conclusion

This report set out to answer three basic questions:

- What has the DD Act accomplished in the past 40 years?
- What are the strengths and weaknesses of the current structure?
- Is the current structure suited to address the current and future social and policy environment?

1. Accomplishments

Without a doubt, the past 40 years has been a time of sustained and significant progress for people with DD. The quality of their lives and their control over their lives has seen monumental progress. The DD Act has contributed to this progress, but the extent of its contribution is unclear. Limitations in data, monitoring, and evaluation hamper our ability to come to any firm conclusions. Moreover, the results of the DD Act vary across the states. The nature, extent, and implementation of activities all differ from state to state. Assessing and adding up the components of programs under the DD Act is simply not possible.

But while a fine-tuned assessment of the legislation is beyond our capabilities, enough evidence exists to suggest that the DD Act has been a positive force. Together with private and public sector stakeholders, the Act has changed lives for the better, through various programs and the leaders they have fostered. Instead of being institutionalized, marginalized, and forgotten, people with DD have made huge steps in taking their rightful place in society—in schools, workplaces, and the public square, and even within their own families. And while significant progress still needs to be made, that progress seems more inevitable, due to a large extent to the burgeoning and sophisticated self-advocacy movement that has been nurtured in no small measure by the DD Act.

2. Strengths and Weaknesses

The DD Act has many strengths, but at times those strengths are dampened by institutional arrangements. For example, Councils have been the source of much important innovation in service delivery models, but their lack of direct authority and lack of a statutory relationship to state agencies limit their influence. P&A programs provide essential legal representation and were integral to both deinstitutionalization and enforcement of IDEA, but lack of resources undermines their effectiveness. The UCEDDs generate and disseminate important information and help create the next generation of leaders, but their funding mechanism can at times prevent them from responding directly to community needs. The PNS have produced very important sources of data, but funding limitations prevent them from being the source of innovative ideas envisioned in the original DD Act. One clear shortcoming is the lack of funding for Titles II and III, Family Support and Direct Support Workforce, two initiatives that have great potential for helping people with disabilities and their families.

3. Structure

The DD Act has a clear vision for the development of services for people with disabilities, and ADD is supposed to spearhead that vision. However, ADD is structurally disjointed from the other federal agencies that fund services for people with DD. This hampers ADD's ability to direct funds and influence the development of services. Instead, other agencies that are not tied to that vision, such as CMS, are making critical policy through funding and regulatory mechanisms.

The recommendations set forth in this report aim to address these issues and offer a way forward when the reauthorization process begins.

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APPENDIX A. Interviews

Interviews with Individuals and Organizational Representatives

John Agosta, Vice President, Human Services Research Institute

Karen Armstrong, Protection and Advocacy for Individuals with Mental Illness
Program Coordinator, State Planning and Systems Development Branch,
Division of State and Community Systems Development, Center for Mental
Health Services, Substance Abuse and Mental Health Services Administration

Robert Bacon, Director, Center for Disabilities and Development, University of Iowa

Ruthie-Marie Beckwith, Executive Director, Tennessee Microboards Association,
Inc.

Stephen Bennett, President and CEO, United Cerebral Palsy

Peter Berns, Executive Director, The Arc of the United States Veteran Affairs

Peter Blanck, University Professor and Chairman of the Burton Blatt Institute:
Centers of Innovation on Disability, Syracuse University

David Braddock, Executive Director, University of Colorado, Coleman Institute for
Cognitive Disabilities

John Butterworth, Project Director, Institute for Community Inclusion, University of
Massachusetts Boston

Grace Chang, Sibling, Maryland

Henry Claypool, Director, Office of Disabilities, Health and Human Services

Doreen Croser, Executive Director, American Association on Intellectual &
Developmental Disabilities

Steven Eidelman, Robert Edelsohn Chair in Disabilities Studies, University of
Delaware

Suellen Galbraith, Director for Government Relations, ANCOR

Bob Gettings, Executive Director, Retired, National Association of State Directors of
Developmental Disability Services

Erika Hagensen, Director of Disability Rights, Family and Technology Policy,
Partnership of the Arc and United Cerebral Palsy

Tamar Heller, Director of the Rehabilitation Research and Training Center on Aging
with Developmental Disabilities, Department of Disability and Human
Development, University of Illinois-Chicago

Amy Hewitt, Senior Research Associate/Training Director, Research and Training
Center on Community Living, Institute on Community Integration, University of
Minnesota

Tammie Hoop, Director of Government Relations and Advocacy, Voices of the
Retarded

Peter Kinzler, Chair, Legislative Committee, Voices of the Retarded

Sherri Larson, Senior Research Associate, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota

Stephanie Lee, Senior Policy Advisor, National Down Syndrome Society National Policy Center

Joe Meadours, President, People First of California

James McGaughey, Executive Director, Protection and Advocacy for Persons with Disabilities, Connecticut

John M. Morrow, Chief, State Planning and Systems Development Branch, Division of State and Community Systems Development, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration

Ari Ne'eman, President, Autistic Self Advocacy Network

Margaret Nygren, Associate Executive Director for Program Development, Association of University Centers on Disabilities

Susan Parish, Assistant Professor, School of Social Work, University of North Carolina

Ed Preneta, Director, Connecticut Council on Developmental Disabilities

Joe Razes, Acting Division Director, Center for Medicare and Medicaid Services, U.S. Department of Health and Human Services, Center for Medicaid and State Operations, Disabled and Elderly Health Programs Group, Division of Advocacy and Special Initiatives

Suzanne Ripley, Director, Family Support Center on Disabilities: Knowledge and Involvement Network, Academy of Education Development

Nicholas Rose, Program Planner, New York State DD Planning Council

Debbie Robinson, President, Self-Advocates Becoming Empowered

Ricki Sabia, Associate Director for the National Down Syndrome Society Policy Center

Jeff Sell, Vice President, Advocacy & Public Policy, Autism Society of America

Ilene Shane, Executive Director, Disability Rights Network of Pennsylvania

Nancy Thaler, Executive Director, National Association of State Directors of Developmental Disability Services

Rud Turnbull, Co-Founder, Co-Director, Distinguished Professor, Beach Center on Disability, University of Kansas

James Ziruolo, Vocational and Rehabilitation and Employment Division Chief, U.S. Department of Veterans Affairs

Grantee Focus Group Participants:

Executive Directors of State and Territorial Councils, Convened by the National Association of Councils on Developmental Disabilities (NACDD)

Mary Sword, Idaho State Council on DD
Alan Kerzin, California State Council on DD
Holly Riddle, North Carolina Council on DD
Roger Webb, Texas Council for DD
Becky Harker, Governor's DD Council (IA)
Mary Gordon, Nebraska Planning Council on DD
Ed Preneta, Connecticut Council on DD
Jane Rhys, Kansas Council on DD
Jennifer Ondrejka, Wisconsin Board for People with Developmental Disabilities
Wanda Willis, Tennessee Council on DD
Susan Pritchard-Green, Missouri, Planning Council for DD
Bill Lynch, Oregon Council on DD
Suellen Jackson-Boner, Governor's Council for People with DD (IN)

Executive Directors of Protection and Advocacy Organizations convened by the National Disability Rights Network (NDRN)

Charles Hausch, West Virginia Advocates, Inc.
Curt Decker, National Disability Rights Network
Elmer Cerano, Michigan Protection and Advocacy Services, Inc.
Ilene Shane, Disability Rights Network (PA)
Marsha Hockensmith, Kentucky Protection and Advocacy
Richard Cohen, Disability Rights Center (NH)
Sylvia Piper, Iowa Protection and Advocacy
Zena Naiditch, Equip for Equality (IL)
Virginia Knowles, Maryland Disability Law Center

Center Directors of University Centers for Excellence in Developmental Disabilities convened by the Association of University Centers on Disabilities (AUCD)

Ansley Bacon, Director, Westchester Institute for Human Development, New York
Robert Bacon, Director, Center for Disabilities and Development, University of Iowa
Leslie Cohen, Director, Sonoran UCEDD, University of Arizona
Michael Gamel-McCormick, Associate Director, Center for Disability Studies,
University of Delaware
Bill Kiernan, Director, Institute for Community Inclusion, University of Massachusetts
Boston

Barbara LeRoy, Director, Developmental Disabilities Institute, Wayne State University,
Michigan
Jan Nisbet, Director, Institute on Disability, University of New Hampshire

Interviews with the Staff of the Administration on Developmental Disabilities

Pat Morrissey, former Commissioner
Faith McCormick, Acting Commissioner
Elsbeth Wyatt, Program Specialist
Jennifer Johnson, Program Specialist
Ophelia McClain, Program Analyst
Lisa Kennedy Osaka, Program Specialist
Sara Newell, Program Specialist
Jackie Ezell, Program Specialist

APPENDIX B. **Mission of the National Council on Disability**

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency, composed of 15 members appointed by the President, by and with the consent of the U.S. Senate.

The purpose of the NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, and that empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

To carry out this mandate, we gather public and stakeholder input, including that received at our public meetings held around the country; review and evaluate federal programs and legislation; and provide the President, Congress and federal agencies with advice and recommendations.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better

promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the DOE, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

Statutory History

NCD was established in 1978 as an advisory board within the DOE (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

Endnotes

1. *Disability Law Center of Alaska v. Anchorage School District*, No. 3:07-cv-0131(D. Alaska, Sept. 26, 2007).
2. Amicus Brief filed by the United States at the invitation of the Second Circuit in *Connecticut Office of Protection and Advocacy v. Hartford Bd. of Ed.*, 464 F.3d 229 (2nd Cir. 2006).
3. *Connecticut Office of Protection and Advocacy v. Hartford Bd. of Ed.*, 355 F. Supp. 2d 649 (D. Conn. 2005), *aff'd*, 464 F.3d 229 (2nd Cir. 2006).
4. *Missouri Protection and Advocacy Services, Inc., et al. v. Carnahan, et al.* 499 F.3d 803 (8th Cir. Aug. 23 2007).
5. *Arc Dallas v. Dallas County Mental Health & Mental Retardation Center Board of Trustees*, 19 F.3d 241 (5th Cir. 2000).
6. *Virginia Protection and Advocacy v. Reinhard*, 568 F.3d 110 (4th Cir. 2009), *rehearing and rehearing en banc denied*, July 30, 2009); *Indiana Protection and Advocacy Services v. Reinhard*, ___ F.3d ___, 2009 WL 2224807 (7th. Cir., July 28, 2009).