***Rising Expectations: The Developmental Disabilities Act Revisited***

The following contains excerpts from the National Council on Disability’s Report *Rising Expectations: The Developmental Disabilities Act Revisited*. The full report is available online at <http://www.ncd.gov/publications/2011/Feb142011#toc1>

**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.

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.

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| **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 | |

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.

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| |  | | --- | | **DD Councils' Areas of Emphasis** | | **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—   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; and 3. 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. | | **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. | |

**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.