



The Developmental Disabilities Act

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Summary

The Developmental Disabilities Assistance and Bill of Rights Act (commonly known as the DD Act) provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities. The DD Act defines developmental disabilities (DD) as severe, life-long disabilities attributable to mental and/or physical impairment. The aim of the DD Act is to help individuals with DD maximize their potential through increased independence, productivity, inclusion, and integration into the community.

Title I of the DD Act authorizes appropriations for (1) State Councils on Developmental Disabilities (SCDDs) that are tasked with developing state-wide plans on delivering services to individuals with DD; (2) Protection and Advocacy (P&A) systems, which investigate reported incidents of abuse and neglect of individuals with DD; (3) University Centers for Excellence in Developmental Disabilities (UCEDDs) that engage in applied research on DD; and (4) Projects of National Significance (PNS), which fund public nonprofits focused on enhancing the independence, productivity, and social inclusion of individuals with DD.

Title II of the DD Act authorizes competitive grants to help states strengthen their family support programs for families with a severely disabled family member. Title III of the DD Act authorizes one scholarship program to provide vouchers for post-secondary education for direct support workers who assist individuals with DD either through an institution of higher education or state agency. Title III also authorizes a grant program for the development, evaluation, and dissemination of a staff development curriculum.

Authorization of appropriations for the DD Act programs expired at the end of FY2007, although Congress has continued to provide appropriations for the programs. The 111th Congress has not considered legislation to reauthorize the DD Act. This report provides background and funding information on DD Act programs, discusses evaluation activities, and summarizes recent legislative efforts related to the DD Act.

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Background

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities (DD). The aim of the programs established by the DD Act is to help persons with DD maximize their work potential, facilitate their ability to live independently, and foster their integration into the community. The protection of the legal rights of individuals with DD is another major objective of the DD Act. Current law encourages coordination and collaboration among the State Councils on Developmental Disabilities (SCDDs), various independent living centers, and its state Protection and Advocacy (P&A) programs to support the legal rights of individuals with DD. Although the DD Act does not provide direct services, its programs are intended to plan and better coordinate the delivery of services and to advocate on behalf of individuals with DD. The Administration on Developmental Disabilities (ADD), part of the Administration for Children and Families (ACF) in the Department of Health and Human Services (HHS), is the federal agency that oversees all DD Act programs.

The DD Act was originally Title I of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P.L. 88-164). It was renamed the Developmental Disabilities Assistance and Bill of Rights Act by P.L. 95-602 in 1978, and was completely reorganized by P.L. 98-527 in 1984. Congress last reauthorized the DD Act¹ (P.L. 106-402) in 2000. Authorizations of appropriations for the DD Act programs expired at the end of FY2007, although Congress has continued to provide appropriations for the programs. Legislation to reauthorize the DD Act has not been introduced in the 111th Congress.

Based on data from the U.S. Census Bureau, there are an estimated 4.6 million individuals with developmental disabilities in the United States.² Although the term “developmental disability” originally specified disabling conditions such as mental retardation and cerebral palsy, the current definition is based on functional limitations that manifest prior to adulthood. Section 102(8)(A) of the DD Act defines “developmental disabilities” as

“a severe, chronic disability of an individual that (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency; and (v) reflects the

¹ All sections referenced in this report are part of this DD Act unless otherwise noted. It is codified in 42 U.S.C. § 15001 et seq.

² Precise counts on the number of individuals with developmental disabilities are difficult to attain. The U.S. Census Bureau annually conducts the National Health Interview Survey (NHIS) on the civilian non-institutionalized population of the United States. In 1994 and 1995, a special two-year Disability Supplement was added to the NHIS to gather nationally representative data on the characteristics of individuals with disabilities in the U.S. The data revealed that the overall prevalence of individuals with mental retardation and/or developmental disabilities in the non-institutionalized population was estimated to be 14.9 per 1,000 people in the United States (see ‘Table 3’ in Sheryl Larson et al., *Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D*, Institute on Community Integration, MR/DD Data Brief, Minneapolis, MN, April 2000, p. 7, <http://rtc.umn.edu/docs/dddb2-1.pdf>). Assuming that the prevalence has remained relatively constant over time, there are an estimated 4.6 million individuals with developmental disabilities in the United States, based on the July 2009 U.S. population census estimate of 307,006,550.

individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.”

The DD Act also specifies that “an individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described ... if the individual, without services and supports, has a high probability of meeting those criteria later in life.”³

Without appropriate services and supports, the choices open to some people with DD, including where they live, work, and play, may be minimal. Many may be isolated rather than fully integrated and included in the mainstream of society. Others may require individually planned and coordinated services and supports (e.g., housing, employment, education, civil and human rights protection, health care) from many providers in order to live in the community.

This report describes the major programs authorized under Title I of the DD Act. Federal funds for these programs are used to help state governments, local communities, and private sector organizations provide health care services, educational opportunities, P&A, and employment training to persons with developmental disabilities. A list of P&A programs and their respective administering agencies is provided in **Table 1**. A funding history for each of these programs is included in **Table 2**. **Table A-1** and **Table A-2** in **Appendix A** detail allotments for SCDDs and for P&A programs, respectively, by state and U.S. territory. **Appendix C** lists the full names of the acronyms used in this report.

DD Act Programs

State Councils on Developmental Disabilities

Each state and U.S. territory receives federal funding to establish a SCDD, which is expected to develop and implement a comprehensive statewide plan for delivering services to individuals with DD—and their families—especially those not otherwise served under existing health and welfare programs.⁴ Members of a state’s Council are appointed by the governor and must be geographically, ethnically, and racially representative of the state as a whole. At least 60% of the members of the Council must be individuals with DD, immediate relatives of persons with a DD, or legal guardians to such individuals. Representatives from relevant state agencies are also required to sit on each SCDD. SCDDs are given wide latitude to use the DD Act funding they receive. Each is permitted to engage in advocacy activities that promote independent living and social integration. These efforts may include, but are not limited to

- training,
- technical assistance,
- barrier elimination,⁵

³ § 102(8) of the DD Act (42 U.S.C. 15002(8)(B)).

⁴ §§ 121-129 of the DD Act (42 U.S.C. §§ 15021-15029).

⁵ An environmental factor that hinders an individual with a disability from functioning in his or her daily life can be considered a “barrier.” For example, lack of access to smooth surfaces, such as a continuous path of sidewalks, could (continued...)

- coalition development and citizen participation,
- informing policymakers,
- advocacy, capacity building and systems change, and
- demonstration of new approaches to services and supports.⁶

Funds are allotted to states and territories based on population, the need for services for individuals with DD, and the financial need of each state or territory (see **Appendix A, Table A-1**).⁷ The DD Act of 2000 (P.L. 106-402) amended the previously established minimum allotments for states and territories. P.L. 106-402 stipulates that in years when total appropriations for SCDDs are less than or equal to \$70 million, each state will receive at least \$400,000 from this program and each territory will receive \$210,000. When appropriations exceed \$70 million, minimum allotments for states and territories will be \$450,000 and \$220,000, respectively.⁸ Matching funds are required on a 75% federal-25% state basis, except in the case of projects in “poverty areas,” where the federal share may be up to 90%. For projects conducted by Council members or staff to implement state plan activities,⁹ the federal share may be up to 100% of the aggregate necessary cost of such activities.

Protection and Advocacy

As a condition for receipt of grant funds for SCDDs, states must have in effect a system of programs to protect and advocate for the rights of individuals with DD. P&A programs provide information and referral services and investigate reported incidents of abuse and neglect of individuals with DD.¹⁰ These programs have the authority to pursue legal, administrative, and other appropriate remedies to protect and defend the legal and human rights of individuals with DD. There are 57 P&A systems in the United States. Each state (50), each U.S. territory (5), the District of Columbia (1), and American Indian tribes (1) receive P&A funding. Appropriations for all entities are detailed in **Table A-2 of Appendix A**.

(...continued)

be considered a physical environmental barrier for a person with DD who has impaired balance and wishes to take daily walks in order to maintain a physical fitness program. An example of a social barrier is the unavailability of public transportation for a person with a DD to use to get to work.

⁶ For additional information about the role of SCDDs, see ADD Mission Statement, available at <http://www.acf.hhs.gov/programs/add/>.

⁷ Two-thirds of the amount appropriated is allotted to each state based on relative population, weighted by the relative per capita income for each state. One-third of the amount appropriated is allotted according to the percentage of individuals in the state, aged 18-65, receiving benefits under the Childhood Disabilities Beneficiary Program [§202(d)(1)(B)(ii) of the Social Security Act (42 U.S.C. 402(d)(1)(B)(ii))]. Data used to compute the allotments are supplied annually by the Social Security Administration and the U.S. Department of Commerce.

⁸ When the DD Act was reauthorized in 2000 (P.L. 106-402), minimum allotments were also constrained so that a state would not be given “less than the amount received by the State for the previous year.” The Birth Defects and Developmental Disabilities Prevention Act of 2003 (P.L. 108-154) amended the minimum allotment so that each state would receive at least as much money as was appropriated in the previous fiscal year for its SCDD, or it would receive “the amount of Federal appropriations” received in FY2000, FY2001, or FY2002, whichever is greater.

⁹ “State plan” activities include, but are not limited to, outreach activities, training for persons with DD, technical assistance, public education efforts, interagency coordination activities, and research that would inform policy makers about the needs of persons with DD.

¹⁰ §§121-129 of the DD Act (42 U.S.C. 15001-15029).

Funds for P&A systems are allotted on the same basis as the SCDDs, except no matching funds are required. The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (P.L. 103-230) set the minimum allotments under this program at \$200,000 for states and \$107,000 for territories in fiscal years when the total amount appropriated for the program is at least \$20 million, and current law maintains those minimum allotments.¹¹

Although the DD Act provides a mandate for protection and advocacy of persons with DD, other federal laws have similar mandates for P&A programs for similarly vulnerable populations. **Table 1** lists other P&A programs and the federal agencies that administer them. Together, these programs form a state, territorial, or tribal P&A system that focuses on securing the rights of persons with all types of disabilities wherever they reside.¹² The DD Act is unique in that it charges the SCDDs with coordination of services with the other programs in the P&A system.¹³

Table 1. Protection and Advocacy Programs

Program	Administering Agency
P&A for Individuals with Developmental Disabilities (PADD)	Administration on Developmental Disabilities, Department of Health and Human Services
P&A for Voting Access (PAVA)	Administration on Developmental Disabilities, Department of Health and Human Services
P&A for Individuals with Mental Illness (PAIMI)	Center for Mental Health Services, Department of Health and Human Services
P&A for Individual Rights (PAIR)	Rehabilitation Services Administration, Department of Education
P&A for Assistive Technology (PAAT)	Rehabilitation Services Administration, Department of Education
P&A for Beneficiaries of Social Security (PABSS)	Social Security Administration
P&A for Individuals with Traumatic Brain Injury (PATBI)	Health Resources and Services Administration, Department of Health and Human Services

Source: HHS, ACF, ADD, *State Protection and Advocacy Agencies Systems Fact Sheet*, <http://www.acf.hhs.gov/programs/add/states/pnafactsheet.html>.

Note: One other program considered part of the state Protection and Advocacy System, the Client Assistance Program (CAP), established by the 1984 Amendments to the Rehabilitation Act, provides services such as assistance in pursuing administrative, legal, and other appropriate remedies to persons receiving or seeking services from state rehabilitation agencies under the Rehabilitation Act. A CAP agency may provide assistance and advocacy with respect to services that are directly related to employment for the client or client applicant. For additional information about Protection and Advocacy/CAP System, see the National Disability Rights Network (NDRN) at <http://www.napas.org/>.

¹¹ When appropriations for the P&A program are not at least \$20 million, the minimum allotments are \$150,000 for each state and \$80,000 for each territory.

¹² For additional information about the system of Protection and Advocacy for Individuals with Disabilities, see National Disability Rights Network (NDRN) at http://www.napas.org/aboutus/PA_CAPext.htm.

¹³ §143(a)(D) of the DD Act (42 U.S.C. 15043).

University Centers for Excellence in Developmental Disabilities Education, Research, and Service

Formerly known as “university-affiliated programs,” University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) are interdisciplinary research and public service units of universities or public, not-for-profit entities associated with universities. They provide training and technical assistance, and engage in scientific research that is intended to be directly applicable to meeting the needs of people with DD. These centers are in a unique position to facilitate the flow of research findings and disability-related information from the university environment to the public at-large. UCEDDs educate policy makers, employers, and community leaders about opportunities for persons with disabilities in an effort to increase the capacity of such individuals to live independently and lead economically productive lives.¹⁴

UCEDD discretionary grants are awarded on a competitive basis for a period of five years. According to statute, existing UCEDDs receive first priority when DD Act funding is being distributed.¹⁵ In FY2010, there are 67 such UCEDDs, with at least one center in every U.S. state, the District of Columbia, Guam, Puerto Rico, the U.S. Virgin Islands, receiving \$542,000 per year in federal funding.¹⁶

Projects of National Significance

This program funds grants or contracts to public nonprofit institutions to enhance the independence, productivity, and social inclusion of people with DD. Projects of National Significance (PNS) differ from the SCDDs and P&A programs because PNS activities focus on emerging areas of concern, on issues that transcend the border of particular states and territories.¹⁷ Such projects may (1) provide support services for families of individuals with DD; (2) involve data collection and analysis; (3) support the advocacy, planning, and training functions of SCDDs; or (4) fund other projects, such as conferences and special meetings that may have an impact on federal or state policy. Examples of PNS projects include studies of racial disparities in access to services used by individuals with DD, or research that explores the transition from school to work for the DD population. PNS grants are administered by ADD at the federal level. Funding for the PNS grants in FY2010 was expected to support 46 grants for: youth activities, family support activities, data collection, evaluations of all DD Act programs, and programs focused on emerging issues of concern for the disability community such as Medicaid services available to adults and children with developmental disabilities.¹⁸

¹⁴ §§125-129 of the DD Act (42 U.S.C. 15062).

¹⁵ §152 of the DD Act, (42 U.S.C. 15062). If each of the existing Centers receives a minimum funding level of \$500,000 per fiscal year, and there are adequate funds remaining from the annual appropriation, other activities specified under the DD Act would be funded. The activities identified in the DD Act as appropriate recipients of the additional funding are (1) National Training Initiative and (2) grants for additional Centers, or increased funding for Centers that operate in areas of high need.

¹⁶ A complete directory of UCEDDs is available online at the Association of University Centers on Disabilities (AUCD), <http://www.aucd.org/directory/directory.cfm?program=UCEDD>.

¹⁷ §§161-163 of the DD Act (42 U.S.C. 15081-15083).

¹⁸ See **a** for a list of active PNS grant recipients by category.

New Programs Authorized

In addition to reauthorizing the existing programs described above, the DD Act of 2000 authorized three new programs. Title II authorized competitive grants to help states strengthen their family support programs for families with a severely disabled family member.¹⁹ Title III authorized one scholarship program to provide vouchers for post-secondary education for direct support workers who assist individuals with DD as well as a grant program for the development, evaluation, and dissemination of a staff development curriculum.²⁰

Funding

In FY2002, the following amounts were allocated for DD Act programs: \$66.9 million for the SCDDs, \$31.9 million for P&A programs, \$24.0 million for the UCEDDs, \$11.7 million for PNS, and \$800,000 each for the new scholarships and staff development curriculum grants.²¹ Although authorization for the staff development curriculum lapsed after FY2003, the act authorized such sums as may be necessary for the other DD programs through FY2007, including a separate family support program that came into existence in FY2003. Known as *Family Support 360*, this program only received funding in FY2003 (for planning) and FY2004 (for implementation). Since FY2005, ADD has funded the family support program using monies appropriated for PNS.²²

Congress appropriated \$168.4 million for DD Act programs for FY2010. **Table 2** shows the recent history of total funding allocations for the programs authorized by the DD Act. Total allocations for all the DD Act's programs have increased from \$134.5 million in FY2002 to \$168.4 for FY2010. **Table A-1** and **Table A-2** in **Appendix A** provide FY2002-FY2011 funding allotments for the SCDDs and for P&A programs, respectively, by state and territory.²³ Although FY2011 appropriations have not yet been finalized, estimates are provided.²⁴

¹⁹ §§202-212 of the DD Act (42 U.S.C. 15091-15101). For program details, see <http://www.acf.hhs.gov/programs/add/Factsheet.html>.

²⁰ §§304-305 of the DD Act (42 U.S.C. 15114-15115). No additional funds were appropriated for Title II or Title III, personal communication, ADD, February 24, 2009.

²¹ Funding allocations for P&A exclude: 1) any funds withheld for P&A technical assistance centers under §142(a)(6) of the DD Act, and 2) any unused P&A funds reallocated under §142(c) of the DD Act.

²² Twenty-one states and territories have established and continue to maintain this type of program. For details, see http://www.acf.hhs.gov/programs/add/states/pns_map.html.

²³ P&A figures and Total figures exclude: 1) any funds withheld for P&A technical assistance centers under §142(a)(6) of the DD Act, and 2) any unused P&A funds reallocated under §142(c) of the DD Act.

²⁴ The President's FY2011 budget request for DD programs matches FY2010 levels (see *Budget of the United States Government: Appendix Fiscal Year 2011*, p.498, lines 01.19-01.22 at <http://www.gpoaccess.gov/usbudget/fy11/pdf/appendix/hhs.pdf>). However, a March 16, 2010 ACF announcement on FY2011 Estimated Allotments for SCDDs and P&A programs contained figures that were lower than the budget request (see *Federal Allotments to State Developmental Disabilities Councils and Protection and Advocacy Systems Formula Grant Programs for Fiscal Year 2011* at <http://www.acf.hhs.gov/programs/add/adddocs/HHS-2011-ACF-ADD-ADDDDC-0079.pdf>). Allotment figures from the ACF announcement are reported in **Table 2**, **Table A-1** and **Table A-2** for FY2011.

**Table 2. Developmental Disabilities Programs:
Appropriations, FY2002 - FY2011 (est.)**

(in millions of dollars)

Fiscal Year	State Councils on Developmental Disabilities (SCDDs)	Protection & Advocacy ^a (P&A)	University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)	Projects of National Significance ^b (PNS)	Total ^a
2002	66.9	31.9	24.0	11.7	134.5
2003	71.1	35.5	24.9	12.4	143.9
2004	73.1	37.6	26.8	11.6	149.1
2005	72.5	37.3	31.5	11.5	152.8
2006	71.8	37.9	33.2	11.4	154.3
2007	71.8	37.9	33.2	11.4	154.3
2008	72.5	38.2	36.9	14.2	161.8
2009	74.3	39.2	37.9	14.2	165.6
2010	75.1	40.2	38.9	14.2	168.4
2011 ^c	72.5	38.2	38.9	14.2	163.8

Sources: Department of Health and Human Services, Budget Tables at <http://www.acf.hhs.gov/programs/olab/budget/index.html> and Final Allotment tables at <http://www.acf.hhs.gov/programs/add/grantsandfunding.html>.

- P&A figures and Total figures exclude: 1) any funds withheld for P&A technical assistance centers under §142(a)(6) of the DD Act, and 2) any unused P&A funds reallocated under §142(c) of the DD Act.
- PNS funding also includes appropriations for Family Support 360 from FY2005 to FY2010. See the 'Family Support 360' section in Appendix B for specific information on ADD family support programs.
- FY2011 allotments figures are estimates provided by the U.S. Department of Health and Human Services.

Program Evaluation

In accordance with accountability requirements of the DD Act,²⁵ as well as those of the Government Performance and Results Act (GPRA) of 1993²⁶ and the Program Assessment Rating Tool (PART),²⁷ the Developmental Disabilities Program Independent Evaluation (DDPIE) project has been developed to assess the overall effectiveness of the DD Act programs. The DDPIE project was divided into two phases. Phase One of the DDPIE involved (1) the development of evaluation tools, and (2) the implementation of a pilot study to test the accuracy, feasibility, and utility of the evaluation tools.²⁸ Phase One included an advisory panel of relevant stakeholders, such as individuals with DD; families of individuals with DD; other consumers; advocates; researchers; and representatives from various DD networks to provide input and review draft

²⁵ §104 of the DD Act.

²⁶ P.L. 103-62.

²⁷ OMB, Assessing Program Performance, at <http://www.whitehouse.gov/omb/expectmore/part.html>.

²⁸ Lynn Elinson, Pei-Shu Ho, Linda Lynch, Cynthia Thomas, Karen R. Stewart, Martha B. Palan, Bibi Gollapudi, and William D. Frey (hereafter Elison, et al.), "Developmental Disabilities Program Independent Evaluation (DDPIE) Project, Final Report", Westat: Rockville, MD, November, 2008. Institutional review board (IRB) approval was obtained for the pilot study to protect the rights and welfare of human subjects who participated in the study, p. xiii.

materials.²⁹ A working group of DD program representatives from SCDDs, P&A programs, and UCEDDs was established to incorporate DD program input; address concerns, such as potential duplication of data collection; and facilitate collaboration between DD program components in the development and piloting of evaluation tools.³⁰

Phase One Evaluation

Phase One evaluation activities, occurring between 2005 and 2008, were guided by the principles of the Centers for Disease Control and Prevention's (CDC's) Framework for Program Evaluation in Public Health and the American Evaluation Association.³¹ The DDPIE program evaluation process included identification of DD program key functions, with the development of measurements for each key function.³² A select, geographically diverse group of SCDDs, P&A programs, and UCEDDs piloted these evaluation measures.³³

Several findings emerged from the Phase One evaluation activities, including recommendations on (1) benchmarks and indicators to be used in a full-scale evaluation, (2) logistics for data collection, and (3) ways of making use of existing data that is reported from DD Act programs to ADD.

National Council on Disability Evaluation

A separate DD program evaluation effort has been initiated by the National Council on Disability (NCD). This one-year project is designed to study the effectiveness of services established by the DD Act and to develop recommendations for improvements that will enhance the quality of life and opportunities for people with DD. Specifically, it will

- examine how the ADD administers, supports, monitors, evaluates, and holds accountable the programs and services under the DD Act, and
- evaluate select programs and services authorized under the DD Act.³⁴

²⁹ Ibid, pp. 3-2 to 3-6.

³⁰ Ibid, p. 3-6.

³¹ CDC, "Framework for program evaluation in public health", MMWR, 1999, 48 (No. RR-11), p. 1-40, at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr4811a1.htm>, accessed September 13, 2010.

³² Elison, et al., DDPIE Project, Final Report, Westat: Rockville, MD, November, 2008. The measurement matrix of key functions included benchmarks, indicators, and performance standards. "Benchmarks were considered to be general standards or key expectations for each key function. Performance standards, more objectively defined than benchmarks, were statements of the expectations or requirements that DD Network programs should be achieving, doing, or having at a nation level. Indicators were what would be measured to determine whether the benchmarks and performance standards were being met", p. x. Phase One took place from September 2005 through September 2008. Report available at <http://www.acf.hhs.gov/programs/add/pns/task7.html>.

³³ Ibid, pp. 3-20.

³⁴ NCD, "Developmental Disabilities Assistance and Bill of Rights Act: Implementation Evaluation and Recommendations for Reauthorization", National Council on Disability Prerelease Notice of Funding Opportunity for a Cooperative Agreement, May 12, 2008, at http://www.ncd.gov/research_opportunity/042908prerelease.html, accessed September 13, 2010. Applications for proposals to implement this evaluation project were due June 20, 2008. The estimated period of performance was September 15, 2008 - September 14, 2009. As of the date of this CRS report, the NCD study has concluded and is in the editing stage. A final report is expected in Fall 2010.

Recent Legislative Efforts

Legal Representation of Individuals with Developmental Disabilities

Legislation that directly related to the DD Act was considered, but not enacted, in the 110th Congress. In June 2007, H.R. 2839 was introduced by Representative Barney Frank. This bill would have amended the DD Act to require SCDDs and P&A programs to obtain authorization from individuals or their legal guardians before pursuing legal remedies on their behalf. In effect, litigants would have to “opt-in” to lawsuits filed on their behalf by DD Councils or P&A programs.

In October 2007, H.R. 3995 was also introduced by Representative Frank. Intended as a substitute for H.R. 2839, it would have extended the right of individuals or their legal guardians to “opt-out” of any proposed class action lawsuits. H.R. 3995 would have required federally funded organizations representing plaintiffs in a class action to give notice to any Intermediate Care Facility for the Mentally Retarded (ICF/MR) that was named in said lawsuit.³⁵ In turn, this ICF/MR would be obliged to give notice of the proposed action to its residents or their legal guardians.

Paralleling the bills introduced by Representative Frank, the ADD proposed a new rule that would modify the implementation regulations for the DD Act.³⁶ Specifically, HHS sought comment on “...whether the current process involving class action lawsuits provides adequate protection for individuals with developmental disabilities,” and on what criteria should be applied, or what clearance process should be followed, to include an individual as a member of a “class.”³⁷ In addition, HHS asked for feedback about how to handle situations in which there is a difference of opinion between the individual with a DD and his or her guardian regarding whether to become a member of a class action lawsuit. The public comment period for this notice of proposed rulemaking closed on September 29, 2008. Final rules were never issued.

Issues Surrounding H.R. 2839, H.R. 3995, and Proposed Regulations

The underlying objective of bills introduced in the 110th Congress and the proposed regulations discussed above was to address some concerns that have been raised about the activities of some federally funded DD Act programs. Specifically, Voice of the Retarded (VOR), an advocacy organization, has argued that P&A organizations have been complicit in the neglect, and even death, of some individuals with severe mental retardation by bringing class action lawsuits, which have ultimately led to the closure of some ICFs/MR.³⁸ VOR has contended that some low-

³⁵ An ICF/MR is an institution whose primary purpose is to provide health or rehabilitation services to individuals with mental retardation or related conditions. ICFs/MR must meet standards outlined in federal regulations (42 CFR Part 483, Subpart I, §§483.400-483.480). In addition, all ICFs/MR residents must be financially eligible for the Medicaid program.

³⁶ HHS, “Notice of Proposed Rulemaking (NPRM), Developmental Disabilities Program,” 73 *Federal Register* 19707-19741, April 10, 2008.

³⁷ *Ibid* p. 19709.

³⁸ For evidence of higher mortality rates among persons with DD who were transferred out of ICFs/MR, see Robert (continued...)

functioning persons would have preferred to remain in an institutional setting and would have been able to do so, if P&A programs had been required to secure the approval of the families or guardians of these individuals with DDs before filing class action suits “on their behalf.”³⁹ In contrast, organizations such as American Disabled for Attendant Programs Today (ADAPT) have argued that the administrative burden associated with “opting-in” to a lawsuit is unreasonable and would only delay or hinder efforts to deinstitutionalize services for individuals with disabilities. Moreover, they contend, by limiting the number of class action suits brought against ICFs/MR, the “opt-in” provision in H.R. 2839 would have insulated facilities that provide substandard care, making it more difficult to penalize these institutions. ADAPT and other advocacy groups welcomed Representative Frank’s substitution of H.R. 3995 for H.R. 2839.⁴⁰

Individuals with Autism

Additionally during the 110th Congress, the Expanding the Promise for Individuals With Autism Act of 2007 (S. 937, H.R. 1881), sponsored by Senator Hillary Rodham Clinton and Representative Mike Doyle, would have awarded additional grants to UCEDDs to (1) provide services and address the unmet needs of individuals with autism and their families, (2) make grants to P&A programs to address the needs of individuals with autism and other emerging populations of individuals with disabilities, and (3) award a grant to a national nonprofit organization for the establishment and maintenance of a national technical assistance center for autism services and information dissemination. Although individuals with autism already receive services funded under the DD Act, these bills would have given additional monies to SCDDs and P&A programs for the purposes of funding services specifically geared towards individuals with autism.⁴¹

In the 111th Congress, Representative Doyle also introduced the Training and Research for Autism Improvements Nationwide Act (H.R. 5756), cosponsored by Representative Christopher Smith. H.R. 5756 would award grants to UCEDDs to provide interdisciplinary training, continuing education, technical assistance, and information to parents and healthcare professionals for the purpose of improving services to individuals with autism and their families.

(...continued)

Shavelle, David Strauss, and Steve Day, “Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care,” *Journal of Data Science*, vol. 3 (2005), pp. 371-380.

³⁹ Mary McTernan, *The Need for Immediate Reform*, VOR, Elk Grove, IL, January, 2007.

⁴⁰ Personal communication with Tom Wilson, ADAPT Board Member, May 22, 2008.

⁴¹ Funding for autism research was also addressed late in the 110th Congress by Representatives Chris Smith and Mike Doyle. They worked to secure funds for research to improve treatment and intervention for individuals with autism spectrum disorders (ASDs) in the Research and Development account for the Department of Defense, Defense Health Program in the “FY2009 Consolidated Security, Disaster Assistance, and Continuing Appropriations Act” (P.L. 110-329). For additional information, see http://doyle.house.gov/newsrel_2008/20081030AutisminFY09DoDApprops.shtml.

Considerations for the 111th Congress

Legislation Related to the Protection and Advocacy Systems Authorized Under the DD Act

In the 111th Congress, the House has passed H.R. 911, the Stop Child Abuse in Residential Programs for Teens Act of 2009. Similar legislation (H.R. 6358) also passed the House during the 110th Congress. H.R. 911 requires standards and enforcement provisions to prevent child abuse and neglect in public and private residential programs that serve children with emotional, behavioral, or mental health problems or disorders; or problems with alcohol or substance abuse.⁴² Among other provisions, H.R. 911 would direct the Assistant Secretary of Children and Families in HHS to (1) implement an ongoing review process for investigating and evaluating reports of child abuse and neglect at covered programs; (2) establish public websites with information about each covered program, as well as a national toll-free telephone hotline to receive complaints; (3) establish civil penalties for violations of standards; and (4) establish a process to ensure that complaints received by the hotline are promptly reviewed by persons with appropriate expertise. H.R. 911 would require the Assistant Secretary to develop a process to immediately notify the state, appropriate law enforcement, and appropriate P&A system of any credible complaint of child abuse and neglect at a covered residential program.

Reauthorization of the Developmental Disabilities Act

Should reauthorization of the DD Act be considered in the 111th Congress, advocates have identified a need to address expanded funding for the UCEDDs to meet the needs of individuals with DD and their families across the lifespan.⁴³ There are indications that individuals with DD are now living longer.⁴⁴ Also, there is increased recognition and appreciation of the impact of early life experiences on later life. Therefore, clinicians, families, and people with disabilities are increasingly recognizing the importance of long term planning for individuals with developmental disabilities who are living beyond childhood.⁴⁵ The need to address the transition from pediatric health care services to adult care services for youth with chronic health conditions or disabilities was also identified in the 2007 Institute of Medicine report on *The Future of Disability in America*.⁴⁶ The National Association of Councils on Developmental Disabilities

⁴² H.R. 911.EH. For additional information about vulnerable youth, see CRS Report RL33975, *Vulnerable Youth: Background and Policies*, by (name redacted).

⁴³ Association of University Centers on Disabilities (AUCD), Priority Disability Recommendations, Issue Paper for Obama Transition Team, Silver Spring, MD, December 17, 2008, <http://www.aucd.org/docs/policy/AUCD%20Disability%20Recommendations%20-%202012-16-08.pdf>.

⁴⁴ For example, see Matthew P. Janicki, Arthur J. Dalton, C. Michael Henderson and Philip W. Davidson, "Mortality and Morbidity Among Older Adults with Intellectual Disability: Health Services Considerations," *Disability and Rehabilitation*, vol. 21, no. 5/6, (1999), pp. 284-294.

⁴⁵ Institute of Medicine, *The Future of Disability in America*, Washington, DC: The National Academies Press, 2007, p. 139, at http://www.nap.edu/catalog.php?record_id=11898.

⁴⁶ Institute of Medicine, *The Future of Disability in America*, Washington, DC: The National Academies Press, 2007, p. 117, at http://www.nap.edu/catalog.php?record_id=11898. For additional information about meeting the health care needs of individuals with DD across the lifespan, see for example: HHS Public Health Service, Office of the Surgeon General, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*, Rockville, MD, 2002 at <http://www.surgeongeneral.gov/topics/mentalretardation/> and The Arc of Massachusetts, *Left Out in the* (continued...)

recommended reauthorization of the DD Act; increased funding for SCDDs; provisions that would address community-based employment of individuals with DD; and the appointment of executive branch officials who have knowledge of DD as priorities for the incoming administration.⁴⁷

As of the date of this CRS Report, no bills to reauthorize the Developmental Disabilities Act have been introduced in the 111th Congress.

(...continued)

Cold: Health Care Experiences of Adults with Intellectual and Developmental Disabilities in Massachusetts, December, 2008, at <http://www.arcmass.org/ArcMassHome/WhoWeAre/ServicesatTheArc/HealthCareProject/HealthCareProjectReport2009/tabid/848/Default.aspx>.

⁴⁷ Michael Brogioli, Chief Executive Officer, National Association of Councils on Developmental Disabilities (NACDD), NACDD Policy Concerns for President-elect Obama's Transition Team, available at <http://www.nacdd.org/index.html>.

Appendix A. Allotments for State Councils on Developmental Disabilities and Protection and Advocacy Programs, FY2002 - FY2011 (est.)

Table A-1. State Councils on Developmental Disabilities Allotments, FY2002 - FY2011 (est.)

(in dollars)

States	FY2002	FY2003	FY2004	FY2005	FY2006	FY2007	FY2008	FY2009	FY2010	FY2011^a
Alabama	1,316,694	1,312,274	1,315,925	1,305,392	1,209,711	1,287,350	1,304,421	1,351,459	1,363,915	1,304,421
Alaska	20,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Arizona	965,108	1,144,633	1,285,145	1,274,859	1,260,522	1,257,240	1,342,090	1,440,524	1,483,202	1,342,090
Arkansas	768,612	805,462	805,462	799,015	790,029	787,972	787,972	790,801	801,192	787,972
California	5,876,564	6,517,570	6,795,666	6,741,276	6,665,465	6,648,112	6,653,416	6,850,939	6,917,900	6,653,416
Colorado	732,816	769,862	836,106	829,414	820,086	817,950	841,994	896,393	915,259	841,994
Connecticut	678,461	650,630	690,715	685,216	677,542	675,805	695,612	720,427	725,688	695,612
Delaware	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
District of Columbia	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	46,2315
Florida	2,856,147	3,509,166	3,641,185	3,612,042	3,571,422	3,562,124	3,583,358	3,694,231	3,726,609	3,583,358
Georgia	1,657,371	1,885,140	1,904,329	1,889,087	1,867,842	1,862,979	1,962,493	2,118,374	2,173,986	1,962,493
Hawaii	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Idaho	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Illinois	2,656,686	2,669,813	2,669,813	2,648,445	2,618,661	2,617,997	2,624,831	2,625,937	2,638,168	2,624,831
Indiana	1,465,626	1,514,002	1,514,002	1,501,884	1,484,994	1,484,670	1,488,546	1,488,546	1,500,563	1,488,546
Iowa	795,933	756,826	774,177	767,980	765,470	772,161	774,177	774,177	774,177	774,177
Kansas	610,953	621,286	621,286	616,313	609,382	612,988	614,589	614,589	614,589	614,589
Kentucky	1,218,231	1,205,456	1,225,694	1,215,884	1,202,210	1,199,080	1,220,209	1,261,526	1,273,371	1,220,209
Louisiana	1,414,383	1,358,920	1,385,313	1,374,225	1,360,252	1,372,141	1,375,723	1,397,179	1,414,387	1,375,723
Maine	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315

States	FY2002	FY2003	FY2004	FY2005	FY2006	FY2007	FY2008	FY2009	FY2010	FY2011^a
Maryland	926,442	1,026,488	1,026,488	1,018,272	1,006,820	1,005,535	1,008,160	1,008,160	1,008,160	1,008,160
Massachusetts	1,311,359	1,308,789	1,367,725	1,356,778	1,341,520	1,338,027	1,363,763	1,395,337	1,406,159	1,363,763
Michigan	2,378,843	2,477,214	2,540,965	2,520,628	2,492,281	2,485,792	2,508,955	2,582,152	2,598,084	2,508,955
Minnesota	1,007,871	1,041,526	1,041,526	1,033,190	1,021,571	1,022,625	1,025,295	1,025,295	1,025,295	1,025,295
Mississippi	938,115	944,426	948,925	941,330	930,744	928,320	928,320	957,347	965,076	928,320
Missouri	1,326,270	1,385,181	1,385,181	1,374,094	1,358,641	1,355,103	1,355,103	1,357,989	1,378,273	1,355,103
Montana	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Nebraska	425,955	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Nevada	420,477	450,000	462,315	458,614	457,115	461,111	469,691	487,981	499,458	469,691
New Hampshire	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
New Jersey	1,493,616	1,587,659	1,589,253	1,576,533	1,558,803	1,554,744	1,555,332	1,582,012	1,598,824	1,555,332
New Mexico	462,147	514,035	521,855	517,678	511,856	510,523	510,523	510,523	510,523	510,523
New York	4,150,337	4,110,221	4,263,616	4,229,491	4,181,927	4,171,039	4,237,731	4,353,557	4,374,416	4,237,731
North Carolina	1,817,454	1,989,293	1,989,293	1,973,371	1,951,179	1,946,099	194,609	2,059,063	2,127,809	1,946,099
North Dakota	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Ohio	2,870,118	2,866,334	2,891,529	2,868,386	2,836,129	2,839,309	2,846,721	2,858,996	2,870,875	2,846,721
Oklahoma	912,780	914,772	914,772	907,450	897,245	894,914	897,250	897,250	897,250	897,250
Oregon	703,155	756,326	785,280	778,994	770,233	768,227	770,874	816,531	832,498	770,874
Pennsylvania	3,111,570	3,040,598	3,113,657	3,088,736	3,054,001	3,046,050	3,068,727	3,135,633	3,150,765	3,068,727
Rhode Island	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
South Carolina	1,059,459	1,132,839	1,132,839	1,123,772	1,111,134	1,108,241	1,108,241	1,110,259	1,142,792	1,108,241
South Dakota	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Tennessee	1,443,822	1,516,063	1,517,325	1,505,181	1,488,254	1,484,379	1,487,918	1,505,443	1,518,718	1,487,918
Texas	4,290,573	4,509,851	4,775,777	4,737,553	4,684,275	4,672,079	4,813,721	5,035,776	5,106,030	4,813,721
Utah	521,763	570,336	602,828	598,003	591,278	589,738	613,228	656,015	679,021	613,228
Vermont	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Virginia	1,374,780	1,524,134	1,524,134	1,511,935	1,494,932	1,498,018	1,501,929	1,501,929	1,501,929	1,501,929

States	FY2002	FY2003	FY2004	FY2005	FY2006	FY2007	FY2008	FY2009	FY2010	FY2011^a
Washington	1,066,152	1,165,304	1,196,582	1,187,005	1,173,656	1,170,600	1,189,607	1,240,323	1,259,859	1,189,607
West Virginia	765,828	676,145	772,441	766,258	757,640	755,667	769,832	785,287	788,440	769,832
Wisconsin	1,284,774	1,309,753	1,309,753	1,299,270	1,284,658	1,289,797	1,293,164	1,297,538	1,304,275	1,293,164
Wyoming	420,477	450,000	462,315	458,614	457,115	461,111	462,315	474,013	478,797	462,315
Subtotal	63,681,761	67,838,327	69,611,287	69,054,150	68,259,090	68,310,060	69,012,025	70,821,657	71,561,693	69,012,025
Territories										
American Samoa	220,752	234,348	240,761	238,834	240,458	240,134	240,761	246,853	249,344	240,761
Guam	220,752	234,348	240,761	238,834	240,458	240,134	240,761	246,853	249,344	240,761
Northern Mariana Islands	220,752	234,348	240,761	238,834	240,458	240,134	240,761	246,853	249,344	240,761
Puerto Rico	2,373,546	2,358,881	2,506,931	2,488,866	2,478,738	2,500,404	2,506,931	2,506,931	2,506,931	2,506,931
Virgin Islands	220,752	234,348	240,761	238,834	240,458	240,134	240,761	246,853	249,344	240,761
Subtotal	3,256,554	3,296,273	3,469,975	3,430,950	3,430,950	3,460,940	3,469,975	3,494,343	3,504,307	3,469,975
Total	66,938,315	71,134,600	73,081,262	72,496,352	71,771,040	71,771,000	72,482,000	74,316,000	75,066,000	72,482,000

Sources: U.S. Department of Health and Human Services, Administration for Children & Families final allotment tables at <http://www.acf.hhs.gov/programs/add/grantsandfunding.html>.

a. FY2011 allotments figures are estimates provided by the U.S. Department of Health and Human Services.

Table A-2. Protection and Advocacy Allotments, FY2002 - FY2011 (est.)

(in dollars)

States	FY2002	FY2003	FY2004	FY2005	FY2006	FY2007	FY2008	FY2009	FY2010	FY2011 ^a
Alabama	544,401	599,332	627,475	622,778	629,409	624,790	623,313	648,587	665,926	623,973
Alaska	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Arizona	454,324	529,268	579,111	581,737	605,431	626,294	645,537	660,675	690,420	651,551
Arkansas	323,364	367,922	387,602	384,321	387,406	385,083	386,366	401,965	413,642	387,025
California	2,776,552	2,978,192	3,181,700	3,162,573	3,247,585	3,269,611	3,303,228	3,352,715	3,429,091	3,268,601
Colorado	344,211	387,881	415,010	411,660	414,511	419,637	429,360	446,725	461,063	433,976
Connecticut	326,619	357,896	378,592	377,613	379,833	378,401	377,744	387,497	397,033	377,168
Delaware	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
District of Columbia	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Florida	1,404,766	1,603,400	1,745,277	1,731,237	1,786,357	1,818,094	1,808,235	1,832,104	1,871,977	1,785,318
Georgia	766,845	861,232	933,374	919,045	953,198	982,659	1,022,625	1,067,277	1,108,738	1,040,545
Hawaii	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Idaho	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Illinois	1,113,210	1,219,417	1,284,415	1,268,725	1,307,848	1,291,826	1,305,530	1,339,000	1,363,241	1,304,468
Indiana	631,366	691,560	727,760	722,012	736,909	735,665	740,328	762,544	787,922	744,045
Iowa	320,978	352,266	371,121	369,484	371,021	366,994	367,599	377,062	385,684	369,868
Kansas	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Kentucky	503,612	550,505	577,979	572,605	579,004	581,840	589,182	610,814	628,980	593,187
Louisiana	557,936	620,599	646,343	644,750	642,178	645,244	615,577	637,589	646,370	621,757
Maine	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Maryland	427,672	468,934	498,207	491,083	488,306	483,737	484,293	490,432	498,544	479,784
Massachusetts	550,395	597,599	621,094	611,440	614,644	599,590	614,459	625,832	638,605	610,465
Michigan	1,047,124	1,131,229	1,190,195	1,170,213	1,187,867	1,176,513	1,197,768	1,251,870	1,286,252	1,206,328

States	FY2002	FY2003	FY2004	FY2005	FY2006	FY2007	FY2008	FY2009	FY2010	FY2011^a
Minnesota	434,873	475,743	502,232	495,058	502,831	499,792	499,343	512,529	526,142	503,534
Mississippi	387,714	431,326	453,210	445,401	445,181	445,745	447,394	464,679	474,353	448,781
Missouri	574,279	632,709	665,767	658,178	674,067	673,574	679,800	706,635	728,532	686,026
Montana	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Nebraska	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Nevada	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
New Hampshire	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
New Jersey	658,758	725,127	764,947	758,472	765,027	758,626	765,642	780,926	791,726	754,969
New Mexico	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
New York	1,680,809	1,876,815	1,959,198	1,933,163	1,970,656	1,952,446	1,965,064	1,981,903	2,009,118	1,933,353
North Carolina	810,417	908,709	976,006	966,905	1,004,238	1,026,804	1,045,773	1,083,780	1,124,261	1,058,062
North Dakota	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Ohio	1,207,229	1,309,037	1,369,182	1,352,955	1,377,843	1,359,530	1,373,317	1,403,949	1,438,424	1,379,227
Oklahoma	380,649	417,943	437,177	433,566	429,420	426,890	426,025	437,322	443,924	424,360
Oregon	329,527	365,481	390,425	388,767	396,665	396,213	399,911	417,392	430,091	403,866
Pennsylvania	1,263,351	1,388,495	1,443,211	1,429,450	1,446,328	1,426,488	1,429,202	1,462,797	1,489,586	1,423,902
Rhode Island	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
South Carolina	465,271	517,436	549,365	541,745	551,953	557,541	563,354	583,782	604,012	571,416
South Dakota	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Tennessee	619,765	692,425	732,439	720,876	733,173	733,221	743,002	770,304	795,921	757,679
Texas	1,860,544	2,060,863	2,232,558	2,212,680	2,289,093	2,313,870	2,377,703	2,431,616	2,498,017	2,372,501
Utah	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Vermont	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Virginia	637,072	696,222	739,346	734,200	740,794	737,259	746,864	759,024	776,734	746,746
Washington	487,689	532,454	567,799	561,124	575,851	589,007	607,232	616,802	634,479	609,722
West Virginia	338,198	371,782	390,425	390,577	390,830	388,670	389,196	395,722	404,155	389,808
Wisconsin	548,445	598,214	629,285	620,380	623,948	621,843	627,494	654,724	670,147	635,125

States	FY2002	FY2003	FY2004	FY2005	FY2006	FY2007	FY2008	FY2009	FY2010	FY2011^a
Wyoming	314,319	345,429	365,940	365,940	365,940	365,940	365,940	375,316	384,693	365,940
Subtotal	30,121,702	33,535,735	35,554,747	35,271,693	35,836,325	35,880,417	36,184,380	37,112,262	38,037,584	36,184,056
Territories										
American Samoa	168,175	184,802	195,775	195,775	195,775	195,775	195,775	200,791	205,808	195,775
Guam	168,175	184,802	195,775	195,775	195,775	195,775	195,775	200,791	205,808	195,775
Northern Mariana Islands	168,175	184,802	195,775	195,775	195,775	195,775	195,775	200,791	205,808	195,775
Puerto Rico	897,039	1,077,750	1,114,058	1,096,931	1,112,264	1,084,348	1,080,265	1,107,303	1,136,896	1,080,589
Virgin Islands	168,175	184,802	195,775	195,775	195,775	195,775	195,775	200,791	205,808	195,775
Subtotal	1,569,739	1,816,958	1,897,158	1,880,031	1,895,364	1,867,448	1,863,365	1,910,467	1,960,128	1,863,689
American Indian P&A	168,175	184,802	195,775	195,775	195,775	195,775	195,775	200,791	205,808	195,775
Total	31,859,616	35,537,495	37,647,680	37,347,499	37,927,464	37,943,640	38,243,520	39,223,520	40,203,520	38,243,520

Sources: CRS table using data from the U.S. Department of Health and Human Services, Administration for Children & Families final allotment tables at <http://www.acf.hhs.gov/programs/add/grantsandfunding.html>.

Notes: Total figures exclude any funds withheld for PNS technical assistance centers under §142(a)(6) of the DD Act. Total figures exclude any unused funds reallocated under §142(c) of the DD Act. American Indian Consortiums are eligible to receive an allotment under §142(a)(6)(B) of the DD Act.

a. FY2011 allotments figures are estimates provided by the U.S. Department of Health and Human Services.

Appendix B. Current Projects of National Significance (PNS)

Project title, brief abstract, institute location, project period and annual funding amounts

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
Ongoing Data Collection and Information Dissemination				
The State of the States in Developmental Disabilities	A comparative nationwide longitudinal study of public financial commitments and programmatic trends in developmental disabilities services and supports.	The Coleman Institute Department of Psychiatry University of Colorado	9/30/2007 – 9/29/2012	300,000
State of the States in Developmental Disabilities: 2007 – 2011, A Nationwide Study of Financial and Programmatic Trends	Extends 17 years of research describing day and employment services for individuals with developmental disabilities.	Institute for Community Inclusion University of Massachusetts Boston	9/30/2007 – 9/29/2012	299,999
The National Residential Information System Program: Ongoing Data Collection and Information Dissemination on Residential Services for Persons with Developmental Disabilities	Continues more than 20 years of analysis of annual state-by-state and national statistics on residential services for people with developmental disabilities (DD), including state and non-state institutional settings and community and home-based residential services	Research and Training Center on Residential Services and Community Living Institute on Community Integration (UCEDD) University of Minnesota	9/30/2007 – 9/29/2012	300,000
Family Support 360				
Family Support 360: Implementing a One-Stop Center, A Project of National Significance from the Administration on Developmental Disabilities (ADD)	Serves military families who have children with developmental disabilities and who are assigned or connected to Fort Richardson Army Installation and Elmendorf Air Force Base, as well as those attached to National Guard units that are activated and/or deployed.	Stone Soup Group, Anchorage, Alaska	9/30/2009 – 9/29/2014	200,000
Project Pendleton - For Military Families, San Diego State University Research Foundation	The goal of the project is to empower and strengthen a military family's capacity to assist their child with developmental disabilities in maximizing their independence, productivity, integration, and inclusion into the community.	San Diego State University Research Foundation Interwork Institute, San Diego, California	9/30/2008 – 9/29/2013	200,000

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
SE Florida Project 360 for Military Families	In collaboration with U.S. Army Garrison Miami, armed with technology and a newly developed family assessment tool, Mailman Center for Child Development (MCCD) will connect military families living in Southeast Florida to the local resources, support and services they need using technology.	University of Miami, SE Florida Project 360 for Military Families, Coral Gables, Florida	9/30/2009 – 9/29/2014	199,979
Parent to Parent of Georgia's Navigator 360 Project	An human service model that is designed with and involves families, is easily replicated and is based in the strengths of private-public partnerships. The vision is that these partnerships will work collaboratively with families with developmental disabilities so support systems needed are integrated and accessible when families need them and ultimately help families stay together and thrive.	Parent to Parent of Georgia, Inc., Atlanta, GA 30349-3720	9/30/2009 – 9/29/2014	200,000
The Navigator's Compass - For Military Families, University of Guam	To enhance the capabilities of families to assist their children with developmental disabilities to achieve their maximum potential; support the increasing ability of children with disabilities to exercise greater choice and self-determination and to engage in leadership activities in their communities; and ensure the protection of children with disabilities' legal and human rights.	University of Guam Center for Excellence in Developmental disabilities, Education, Research & Service, Mangilao, Guam	9/30/2008 – 9/29/2013	200,000
Iowa Family Support 360 Center	To coordinate and enhance access to Iowa's fragmented system of services to children with developmental disabilities and their families by building a network of navigators with accurate, consistent and broad based information and resources, who will serve a local one-stop access points for families.	Iowa Department of Human Services, Des Moines, Iowa	9/30/2009 – 9/29/2014	200,000
Family Access to a Center of Excellence for Support Services (FACESS)	Family support 360 Centers empower and strengthen families by increasing community responsiveness to the immediate needs of families who have children with developmental disabilities and promoting community partnerships.	The University of Southern Mississippi, Hattiesburg, Mississippi	9/30/2009 – 9/29/2014	200,000
Military Family Support 360 Project - For Military Families	This project will develop, implement, and evaluate a military and community based, coordinated and seamless multi-agency one-stop center, to assist military families who have children (up to 25 years old) with a developmental disability.	The University of Southern Mississippi, Hattiesburg, Mississippi	9/30/2009 – 9/29/2014	200,000

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
Strengthening Military Families with Children who have Developmental Disabilities: One Stop for Family Support - For Military Families	This project will provide effective family support to active duty military families with children who have developmental disabilities who are connected to Camp Lejeune Marine Base. Military families living off base within the state of North Carolina will be able to access needed support.	The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina	9/30/2009 – 9/29/2014	200,000
NJ 360 Family Support Center	Designed to serve teenagers and young adults with developmental disabilities and their families. The Center's primary objective will direct services to persons within the Latino/Hispanic community of the City of Perth Amboy who because of cultural, economic and social barriers are traditionally underserved.	Cerebral Palsy Association of Middlesex, Inc., Edison, New Jersey	9/30/2009 – 9/29/2014	200,000
Statewide Parent Advocacy Network of New Jersey (SPAN) Military Family 360 Center - For Military Families	The Statewide Parent Advocacy Network (SPAN) will provide support and assistance to a minimum of 30 military families who have children with developmental disabilities in 2009-2010, and 40 families each year in 2010-2014.	Statewide Parent Advocacy Network of New Jersey, Newark, New Jersey	9/30/2009 – 9/29/2014	200,000
Nevada's Family support 360 Center	Children in the target population are either served in one system that is able to address only part of their problem or they are the "unclaimed" children who fall through the cracks and do not get the services that they require. Because of the complexity of their needs, rarely can one system provide the comprehensive services and supports the children and their families require.	Nevada P.E.P., Inc, Las Vegas, Nevada	9/30/2009 – 9/29/2014	200,000
Fort Hood 360 - For Military Families, The University of Texas at Austin	For military families caring for children with developmental and other disabilities, to enhance their capability to navigate social service and educational systems that assist children to achieve their maximum potential.	Texas Center for Disability Studies University of Texas at Austin, Austin, Texas	9/30/2008 – 9/29/2013	200,000
Utah Military Family Support 360 - For Military Families	This project will assist with enhancing and strengthening the capacity of Hill Air Force Base personnel and coordinating communication between military and civilian systems, The project will identify the military and civilian supports and services and guide a coordinated effort based on lessons learned through Utah's 360 Support for Families.	Utah State University, Logan, Utah	9/30/2009 – 9/29/2014	200,000

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
Family Support 360 Family to Family Network in Virginia	The Partnership's Center for Family involvement will house the greater Richmond Virginia Family to Family Network, a one-stop center where families who have children aged birth to 26 years with developmental disabilities can receive information and referral regarding education, early intervention, health care, disability services and various other community resources.	Virginia Commonwealth University, Richmond, Virginia	9/30/2009 – 9/29/2014	200,000
Wraparound 360 Family Support Project	The ARC of King County will establish a Family Support Center for low income individuals who are underserved by virtue of poverty, race, language, or immigration status.	The Arc of King County, Seattle, Washington	9/30/2009 – 9/29/2014	200,000
PAVE 360 - For Military Families, Washington PAVE	Through coordination with its partners, Washington PAVE will identify families in need of a higher level of support and assistance than can be provided through current military and civilian resources.	Washington PAVE, Tacoma, Washington	9/30/2008 – 9/29/2013	200,000
Youth Information, Training, and Resource Centers				
Northwest Arkansas Youth Center	The Center's primary goal will be to help people complete their high school education, pursue post high school education or job training, seek and maintain employment, build personal assets or otherwise improve their lives.	Northwest Arkansas Youth Center, Springdale, Arkansas	9/30/2007 – 9/29/2010	99,997
Set Yourself Free	Southwest Institute for Families and Children with Special Needs (SWI) proposes to expand the role of the Arizona Youth Action Council (YAC-AZ) to initiate the <i>Set Yourself Free</i> project. Established in 2003, YAC-AZ, organized youth and emerging leaders with disabilities and special health care needs. YAC-AZ is virtually linked, has a governance structure, assesses needs and wants, engages in recreational activities, and participates in AZ Legislative Awareness events.	Southwest Institute for Families and Children, Scottsdale, Arizona	9/30/2007 – 9/29/2010	149,792
Center for Emerging Leadership: Empowering Youth, Building Community, and Enhancing Lives (CEL)	The overall goal of the Center for Emerging Leadership: Empowering Youth, Building Community, and Enhancing Lives (CEL) is to improve community inclusion outcomes for youth (aged 13-17) and emerging leaders (aged 18-30) with developmental disabilities through a replicable Empowerment Model of Peer Mentorship.	Center for Emerging Leadership Interwork Institute/San Diego State University Research Foundation, San Diego, California	9/30/2007 – 9/29/2010	149,636

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
National Consortium on Leadership and Disability for Youth (NCLD/Y)	The Institute for Educational Leadership (IEL) serves as a national youth-led information, training, and resource center. IEL has a four-pronged focus on working on developing leaders, developing the capacity of centers for independent living to serve those leaders, the capacity of the staff working directly with the leaders, and supporting the cadre of youth with disabilities-related organizations.	NCLD-Youth Institute for Educational Leadership, Washington, DC	9/30/2007 – 9/29/2010	99,995
Training and Resource Self Advocacy Empowerment Center	This project builds on the success of the Training and Resource Self-Advocacy Empowerment Center for Youth and Emerging Leaders in the District of Columbia. This initiative provides District of Columbia youth and emerging leaders training, opportunities and information on employment, education, housing, and transportation in the city.	Inclusion Research Institute, Washington, DC	9/30/2007 – 9/29/2010	100,000
Youth Information, Training and Resource Center	In its implementation of the Youth Information, Training and Resource Centers program, The Family Café will provide youth and emerging leaders with disabilities in Florida with the information, supports and resources they need to move from passenger seat to the driver's seat when it comes to navigating their own transition planning.	The Family Café, Inc, Tallahassee, Florida	9/30/2007 – 9/29/2010	150,000
My Voice, My Choice	“My Voice, My Choice” will create a Youth Information, Training, and Resource Center to infuse self-advocacy into existing adult self-advocacy activities in Hawaii and the region. The center will respond to the following areas of emphasis: education, employment, and quality assurance (self-advocacy). The purpose of the Center is to improve education and employment outcomes for youth by giving them a greater voice in the development of policies and services that affect their choices.	University of Hawaii, Honolulu, Hawaii	9/30/2007 – 9/29/2010	100,000
Center for Youth Information, Education and Leadership for Developmental Disabilities (YIELDD)	Current AYLP Chicago members and emerging leaders of the YIELDD leadership training will come together to choose an issue that affect persons with developmental disabilities. The new groups will hold forums and network with other organizations to address the issue(s). The overall outcome is to ensure the independence of future generations of people with developmental disabilities.	Access Living of Metropolitan Chicago, Chicago, Illinois	9/30/2007 – 9/29/2010	100,000

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
The Pathways Center	The primary areas of focus will be employment, education, housing, and quality assurance. The Pathways Center will expand eligibility for Pathways Center activities to all youth and emerging leaders with developmental disabilities (DD) in North Minneapolis. The Pathways Center will provide youth friendly products via the IPSII Inc. website, national, state, local forums and other partners.	IPSII, Inc, Richfield, Minnesota	9/30/2007 – 9/29/2010	100,000
Youth LEAD: Leadership, Education, and Advocacy for Youth with Disabilities	The overall goal of this project is “to create a sustained community infrastructure through which to support the leadership development of youth and merging leaders with developmental disabilities.” The focus areas of this project are continuing education, inclusive recreation, and community employment via person centered planning and mentoring.	Curators, University of Missouri, Kansas City, Missouri	9/30/2007 – 9/29/2010	150,000
Youth Information, Training, and Resource Centers, Project TRIAD (Training, Resources and Information for the Advancement of Degrees)	The primary purpose of this project is to assist youth that are transitioning from school to adult life in accessing postsecondary training opportunities that will focus on the academic and leadership development skills necessary for employment, self-determination, and community engagement and leadership. The center will focus on unserved and underserved youth and emerging leaders enrolled in post-secondary institutions.	University of Southern Mississippi, Hattiesburg, Mississippi	9/30/2007 – 9/29/2010	150,000
Montana Transition Training, Information and Resource Center	The MT-TIRC activities and outcomes will focus on education, employment, and inclusive recreation and housing. Through collaboration with the Montana Advocacy Program, Developmental Disabilities Council, Office of Public instruction, Parent Training and Information Center, ADAPT, MonTECH and the Developmental Disabilities Program, MT-TIRC will increase access to employment and inclusive community living for young people with developmental disabilities.	Rural Institute on Disabilities, University of Montana, Missoula, Montana	9/30/2007 – 9/29/2010	150,000
Youths for Advocacy (Y4A)	Youth 4 Advocacy (Y4A) is a three-year Youth Information, Training and Resource Center project designed to link youths with developmental disabilities and emerging leaders across North Carolina, empowering youths to transition successfully from school to adult life in their communities.	University of North Carolina – Chapel Hill, Chapel Hill, North Carolina	9/30/2007 – 9/29/2010	100,000
Center on Youth Empowerment Services (YES)	YES will serve as a source of information and referral for youth and young adults with developmental disabilities. YES will also provide leadership and self-advocacy training to 15 young people annually, aged 16-24 through its Youth Leadership Series, and also enroll them in two transition related planning and support systems.	Institute on Disabilities University of New Hampshire, Concord, New Hampshire	9/30/2007 – 9/29/2010	139,186

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
El Poder de Los Jovenes (Empowerment of Youth)	The Arc of New Mexico goal is to promote positive outcomes for young people with developmental disabilities in the areas of education, employment, transportation, and healthy lifestyles.	The Arc of New Mexico, Albuquerque, New Mexico	9/30/2007 – 9/29/2010	100,000
Oklahoma Alliance for Youth	The Oklahoma Alliance for Youth (OKAY) proposed to create new exemplary practices and products to support youth and adult with developmental disabilities in self-advocacy, leadership, health, and transportation.	Oklahoma Alliance for Youth National Center for Disability Education & Training, University of Oklahoma, Norman, Oklahoma	9/30/2007 – 9/29/2010	100,000
Oregon Emerging Youth Leaders Consortium	This project will address the need for full participation in daily life and active community engagement by youth and young adults using a multi-agency, multi-model approach. The project will develop a community and web-based youth information, training, and resource center that address multiple areas.	Incight Company, Portland, Oregon	9/30/2007 – 9/29/2010	100,000
National Youth Leadership Network (NYLN), National Youth Information Center (NYIC)	The NYIC will serve as a support for state YIC development in North Carolina, New York, and Idaho; for curriculum and resource development; for organizational collaboration, public awareness, education, , and outreach; and for information exchange, empowerment, full inclusion and accessibility. These efforts will place specific emphasis on outreaching to and including young people with underrepresented disabilities (i.e., cognitive, psychological, emotional), culturally diverse youth, and areas of need (i.e., areas of low socioeconomic status, rural communities).	National Youth Leadership Network, Pierre, South Dakota	9/30/2007 – 9/29/2010	150,000
Becoming Leaders for Tomorrow (BLT)	The three areas of emphasis for the BLT project are education, employment, and health. The targeted communities that would most benefit from this project are youth (aged 13-17) and young adults (aged 18-30) with developmental disabilities and their families who have completed the application process for the Division of Services for People with Disabilities, but have been placed on the "waiting list."	Center for Persons with Disabilities, Utah State University, Logan, Utah	9/30/2007 – 9/29/2010	100,000
Virginia Center for Self-Advocacy Leadership	The Virginia Center for Self-Advocacy Leadership will provide information, training, and resources to increase self-advocacy leadership skills. The target groups are youth (aged 13 to 17) and young adults (aged 18 to 30) who are emerging leaders, including individuals living in poverty or from unserved or underserved communities.	Partnership for People with Disabilities Virginia Commonwealth University, Richmond, Virginia	9/30/2007 – 9/29/2010	147,184

Project Title	Brief Abstract	Institute	Period	Funding/year (\$)
Wisconsin Youth Information Training and Resource Center	The Wisconsin Youth Information and Training and Resource Center (YITRC) is a three-year project, built on a collaborative partnership of four core agencies: Wisconsin Family Assistance Center for Education & Training Support, Inc, Independence First, a Developmental Network Partner, and Department of Vocational Rehabilitation. WI FACETS proposed to establish a community-based center which will (1) deliver intensive training, information and support to Milwaukee area young adults with developmental disabilities (aged 13-30) and (2) build community awareness and capacity so that young adults with developmental disabilities are able to pursue self-directed adult lives which are independent, healthy and rich with community involvement.	WI FACETS, Milwaukee, Wisconsin	9/30/2007 – 9/29/2010	112,500
Medicaid				
The Medicaid Reference Desk: A Web-Based Information Resource for Adults and Children with Developmental Disabilities, Families, Service Brokers, Service Providers, and Policymakers	The Medicaid Reference Desk Project continues the design and implementation of an interactive website to provide people with developmental disabilities, their families, and others with timely, accurate state and national level information on Medicaid services. The project will serve as a nationwide resource by providing research, translation, and audio/video recording of comprehensive Medicaid information for each state and territory.	The Arc of the United States, Silver Spring, Maryland	9/30/2007 – 9/29/2012	150,000

Source: U.S. Department of Health and Human Services, Administration for Children & Families.

Notes: This CRS table excludes information on PNS technical assistance centers. PNS abstracts have been shortened in this CRS report for brevity. For full abstracts on active PNS grants see <http://www.acf.hhs.gov/programs/add/pns/pns.html>.

Appendix C. Acronym Glossary

Acronym	Term
ACF	Administration for Children and Families
ADAPT	American Disabled for Attendant Programs Today
ADD	Administration on Developmental Disabilities
AUCD	Association of University Centers on Disabilities
CDC	Centers for Disease Control and Prevention
DD	Developmental Disabilities
DDPIE	Developmental Disabilities Program Independent Evaluation
FY	Fiscal Year
GPRA	Government Performance and Results Act
HHS	Health and Human Services
H.R.	House of Representatives
ICF/MR	Intermediate Care for the Mentally Retarded
NCD	National Council on Disability
P&A	Protection and Advocacy
PART	Program Assessment Rating Tool
P.L.	Public Law
PNS	Projects of National Significance
SCDDs	State Councils on Developmental Disabilities
UCEDDs	University Centers for Excellence in Developmental Disabilities
VOR	Voice of the Retarded

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