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.
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

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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/ddd2-1.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 307,000,550.

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