

Introductory Brief on NCD's Long-Term Services and Supports Report

The National Council on Disability (NCD) is an independent federal agency required by its authorizing statute to advise Congress regarding laws and issues that affect people with disabilities. This introductory brief is the first of a number of upcoming monthly two-page briefings highlighting major points in NCD's report, *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities* (http://www.ncd.gov/newsroom/publications/2005/longterm_services.htm).

Presently, about 1.6 million people live in nursing homes, group homes, and other institutional facilities. In addition, over 2 million people on waiting lists are in need of some type of long-term services and supports (LTSS). Though LTSS consumers have indicated a clear preference for receiving LTSS in home- and community-based settings, a federal institutional bias remains.

The current LTSS system is funded by state and federal programs, primarily Medicaid. Medicaid paid for 45 percent of the \$137 billion this country spent on LTSS in FY 2000. Yet, despite the amount of money that state and federal programs allocate to LTSS, individuals and their families still pay out of pocket for nearly one-third of LTSS expenses. The impending wave of aging baby boomers, increasing life expectancy, and rising disability rates in people under 65 will significantly increase the demand for LTSS in the coming decades.

Few Americans think of LTSS for individuals under the age of 65 with significant disabilities who are living and working in the community. Many people do not realize that there is no LTSS public policy for individuals of moderate to middle income of any age. Private long-term care insurance, on average, is capped at a specific dollar amount, provides coverage for about three years, and is not specifically designed to address the needs of working Americans with disabilities. Ninety percent of Americans do not have long-term care insurance, and many do not have the financial savings to cover the costs of aging.

NCD has grown increasingly concerned about (a) the lack of a coherent national LTSS public policy for all people with disabilities; (b) the fragmented nature of service and support delivery systems, with uneven access and services provisions; and (c) increasing LTSS costs, which are fast becoming unsustainable. No single federal program, federal agency, or Congressional committee is charged with the responsibility for the management, funding, and oversight of LTSS. More than 20 federal agencies and almost 200 programs with varying policy objectives provide a range of assistance and services to people with disabilities. Currently, no single entry point at a community level exists for individuals with disabilities and seniors to learn about and access service and support options, nor is there an integrated delivery system to provide portability across states.

People who are elderly and people with disabilities desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence. Without significant reform, current financing mechanisms will

become unsustainable in the near future. With the changing demographics of the United States, an opportunity to explore the possibilities of a universal approach to the design and financing of supports is emerging.

America needs a coherent and comprehensive framework for its LTSS policies, programs, and funding. To achieve this crucial goal, NCD offers the following recommendations to Congress:

- Decouple eligibility for Home- and Community-Based Services (HCBS) under an HCBS waiver from a determination of nursing home eligibility. Remove the institutional bias in the Medicaid program to give Medicaid beneficiaries greater choice in how financial assistance is provided to cover a range of LTSS.
- Increase support for families and significant others in their role as informal and unpaid caregivers. Eligibility for LTSS and the scope and intensity of covered services varies significantly from state to state. Despite state variability in criteria for Medicaid eligibility and scope of benefits, in all states, individuals with disabilities are dependent on informal caregivers, including parents, family members, and significant others. The estimated benefit of informal caregiving exceeds \$200 billion annually. Services should be designed to support, not supplant, the role of the family and actions of informal caregivers.
- Improve the supply, retention, and performance of direct support workers to meet increasing demand. Funding should be authorized for collaborative demonstration projects between the U.S. Departments of Labor and Health and Human Services that promote collaboration between community colleges and disability-related organizations to develop a high-quality set of competencies to be taught in a new support worker certificate program that expands supplies of quality workers to meet market demand in home- and community-based settings.
- Mandate coordination and collaboration among federal agencies to align public policy and transform infrastructure to be responsive to consumer needs and preferences for a comprehensive system of LTSS. Congress should consider holding hearings to evaluate possible options for improvement of multiple department collaboration to provide access to information and supports and services to meet the long-term needs of people with disabilities. Congress should also consider establishing an Interagency Council on Meeting the Housing and Service Needs of Seniors and Persons with Disabilities.

NCD is available to provide you with advice and assistance pertaining to these and other issues of importance to people with disabilities and welcomes any inquiries. Please contact NCD's Congressional Liaison, Mark Seifarth at mseifarth@ncd.gov, or reach NCD by telephone at (202) 272-2004 (v), (202) 272-2074 (tty).