

National Council on Disability: Long Term Support Service

Seniors and people with disabilities need a coherent and comprehensive framework of long-term services and supports across states. Congress should authorize federal interagency coordination of essential public policies, programs, and funding.

Lead Agency:

National Council on Disability

Agency Mission:

The mission of the National Council on Disability is to promote the full inclusion, independent living, and economic self-sufficiency of people with disabilities of all ages and backgrounds by providing advice, analysis, and recommendations on disability policy to the President, Congress, and other federal agencies

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General Description:

The NCD report called attention to America's changing demographics—growing numbers of people age 65 and people with disabilities. More than 20 federal agencies and nearly 200 programs with varying policy objectives provide assistance and services. Elders (people who are seniors) and people with disabilities need choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence. Significant reform should explore possibilities of a universal approach to the design and financing before existing financing mechanisms become unsustainable. NCD (1) analyzed the state of long-term services and supports, future market demand and system reform needs; (2) surveyed promising state practices and local innovations; (3) solicited suggestions and comments from an expert panel of public and private stakeholders; and offered 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. Authorize funding 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.

Excellence: What makes this project exceptional?

This is the most comprehensive policy analysis of LTSS that evaluates federal LTSS laws, regulations, policies, and programs for people over 65 years of age (with and without disabilities) and people with disabilities under 65 years of age who use LTSS .

Significance: How is this research relevant to older persons, populations and/or an aging society?

NCD undertook research for this report because it had grown increasingly concerned about the (a) lack of a coherent national long-term services and supports (LTSS) public policy for all people with disabilities; (b) fragmented nature of service and support delivery systems, with uneven access and services provisions; and (c) LTSS costs of 22 percent or more of state budgets, which are

fast becoming unsustainable. Additionally, NCD noted in undertaking research for this report that no single federal program, federal agency, or congressional committee was charged with the responsibility for the management, funding, and oversight of LTSS; however, 23 federal agencies were actively involved in LTSS using the NCD definition.

Effectiveness: What is the impact and/or application of this research to older persons?

As demonstrated in the findings of this NCD report, the United States needs a coherent and comprehensive framework for its LTSS policies, programs, and funding based on five inter-related realities. First, that people who are elderly and people with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence. Second, the current financing mechanisms (public and private) will become unsustainable in the near future without significant reform. The system must be affordable to all Americans regardless of income levels and must consider opportunities to leverage public and private support in new ways without impoverishing beneficiaries. Third, there is an opportunity with the changing demographic picture of the United States to explore the possibilities of a universal approach to the design and financing of supports that is responsive to individuals under the age of 65, as well as Americans over 65 who may or may not have disabilities, without sacrificing individual choice and flexibility. Fourth, formal and informal care giving must be sustained, including examination of family needs and workforce recruitment and retention challenges. Fifth, the approach to quality must include consumer direction and control of resources in addition to traditional external quality assurance mechanisms.

Innovativeness: Why is this research exciting or newsworthy?

This is the first federal analysis of the issue of long-term services and supports (LTSS) which is based on an operational definition of LTSS identical to the one used by the American Association for Retired Persons. It is the first federal analysis that looks at LTSS for people over 65 years of age (with and without disabilities) and people with disabilities under 65 years of age who use LTSS. It is the first to review federal government LTSS policies, laws, and programs for both population groups. And it is the first to codify Executive Branch and Congressional operations involving LTSS initiatives.