



December 18, 2013

Chairman Bill Nelson  
Senate Special Committee on Aging  
Dirksen G31  
Washington, DC 20510

Ranking Member Susan Collins  
Senate Special Committee on Aging  
Dirksen G31  
Washington, DC 20510

Dear Chairman Nelson and Ranking Member Collins:

Thank you for holding this very timely hearing on the future of long-term care policy. The Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD) offer the following set of consensus principles for reform that we hope provide a framework on essential elements to a reformed system, from the consumer, family and long-term services and supports (LTSS) worker perspective.

Together, LCAO and CCD include over 150 organizations representing older adults, people with disabilities, and providers of health, housing and supportive services. Our consensus on a new direction for financing and delivering these services puts millions of Americans behind the push for reform.

An estimated 11 million Americans currently have needs for LTSS. The number of individuals needing LTSS is projected to increase to 27 million by 2050. However, the nation lacks a coordinated, national public-private system for delivering LTSS. Nearly half of all funding for these services is now provided through Medicaid, which is a growing burden on states and requires individuals to become and remain poor to receive the help they need. While the situation has improved, the institutional bias in Medicaid persists whereby the majority of LTSS funding is directed toward nursing homes and other institutions instead of preferred community-based services and supports.

The principles adopted by CCD and LCAO call for national solutions. Consumers should have access to a broad array of affordable, quality support options, including a range of home and community-based supportive services. The financing system(s) should facilitate universal access so that individuals of all ages and disabilities can obtain LTSS. The financing system should promote independence and dignity across the lifespan by ensuring individuals the right to control and choose what services they receive, how and where they are delivered, and who provides them. Any system must also put in place strategies for supporting the central role of family caregivers and attracting and retaining an adequate number of direct care workers to deliver high quality services.

We look forward to working with you to advance this discussion and develop policies to improve LTSS in this country. Please do not hesitate to contact us if we can be of assistance.

Sincerely,

Richard J. Fiesta  
Chair  
LCAO

Katy Beh Neas  
Chair  
CCD

## **Principles for Long-Term Services and Supports**

For too long, our nation has ignored the urgent need to address in a bipartisan fiscally responsible manner the emerging long-term services and supports (LTSS) crisis facing older adults, baby boomers, people of all ages with disabilities, and family caregivers. LTSS should offer consumers access to a broad array of support options, including an array of home and community-based supportive services, as well as residential options, as needed. Our current system forces people into institutions, requires many to spend-down into poverty before receiving the help they need, fails to provide realistic opportunities for personal planning, and fails to support family caregivers adequately. America can and must do better.

The following principles for LTSS are intended to provide a framework for focusing attention, generating discussion and crafting solutions to the problem in the near future. In the interim, the members of the Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD) will work toward a strong Medicaid program and advocate for additional resources and opportunities for home and community-based services and individual planning.

### **Financing**

**National Problem, National Solutions** – Recognize that financing for LTSS is a national problem that requires national solutions, although states, communities, families, and individuals have important roles to play.

**Universal Access** – Facilitate universal access so that individuals of all ages and disabilities can obtain LTSS. Create a system that does not exclude individuals or groups.

**System Organization and Integration** – Develop a well-organized system that aligns payment and services to promote optimal care and service delivery. Community-based long-term services and supports should be seamlessly integrated with acute, ambulatory, advanced and palliative care to ensure efficient and effective coordination of care across the continuum.

**Affordability**– Make costs affordable by using tools such as broad pooling of risk and appropriate low-income subsidies so that all people, regardless of income, age, gender, disability and health status, have access to LTSS. Ensure that any new system(s) protects the financial security of individuals and families and does not force people to impoverish themselves to get the services and supports they need.

**Public/Private Partnership** – Promote personal planning and private sector options with a strong foundation of consumer protection. Support both public and private insurance options, including new alternatives to Medicaid, and enhance the feasibility of private LTSS solutions.

**Fiscal Responsibility** – Provide actuarially sound funding for LTSS that builds reserves over time sufficient to pay for future needs in a way that is affordable to individuals and to society as a whole.

**Relieve Pressure on Medicaid** – Provide additional LTSS funding mechanisms that will help take the pressure off future Medicaid expenditures, while preserving and enhancing the guaranteed safety net.

**Housing, Transportation and Technology** –Include a strategy to meet the housing and

transportation needs of older adults and people with disabilities, as well as to finance technological supports that enable independence.

### **Consumers and Family Caregivers**

**Consumer Choice** – Promote independence and dignity across the broad array of services and supports by ensuring individuals the right to control and choose which services they use, how and where those services are delivered and who provides them including education about and the use of advance directives, and individual care planning.

**Consumer Control** – Ensure consumer services and supports are flexible, consumer driven, person-centered and tailored to the individual’s needs and preferences. Develop mechanisms to connect consumers who want to hire their own direct care professionals with available candidates. Improve the ability of consumers, caregivers, and healthcare professionals to plan for and understand the full array of long-term services and supports including advanced care and end-of-life planning through education and other supports.

**Support Family Caregivers** – Recognize and support the central role family caregivers play in planning for and providing LTSS. Develop strategies to support caregivers who are otherwise employed to maintain their financial security. Assess the needs of family caregivers and provide information, training, counseling, respite and other supports to address their needs. Guard against designing a system that relies too heavily on family caregivers in lieu of developing a viable system of long term services and supports.

### **Quality of Life, Quality of Care**

**Invest in Quality** – Provide adequate funding to support quality care, including sufficient training, protections, and compensation for the LTSS workforce. Invest in the development of quality standards for home and community-based services and supports. Provide additional funding to strengthen oversight, enforcement, and advocacy programs that ensure quality of life and improve quality of care in all settings.

**Quality Standards** – Support strong quality standards that include quality measures and assessment of the consumer experience including oversight, enforcement, and robust advocacy programs.

**Quality of Life** – Promote community inclusion and engagement that allows individuals to participate in activities, events and work to the extent they desire throughout their lives, including the end of life. Acknowledge that disability, chronic disease and advanced illness bring their own set of criteria for quality of life, including psychosocial support, pain relief, and person-centered planning.

### **Workforce**

**Professionals in LTSS** – Recommend strategies to bolster the professional long-term services and supports workforce through recruitment, opportunities for professional education and training for those specializing in aging or disability work, including loan forgiveness and grants; competitive compensation; and practice-based research.

**Stabilize and Strengthen the Direct-Care Workforce** – Recognize the essential role of direct-care workers in providing LTSS, promote a plan for attracting an adequate number of workers to direct-care positions to meet consumer demand, as well as for addressing the causes of high-rates of turnover. Recommend mechanisms for stabilizing and strengthening the direct-

care workforce through training and credentialing, data collection, and improved compensation.

###