



March 4, 2016

The Honorable Fred Upton
Chairman
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Frank Pallone
Ranking Member
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Upton and Ranking Member Pallone:

The Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD) are extremely pleased that the Energy & Commerce Subcommittee on Health held the hearing, *Examining the Financing and Delivery of Long-Term Care in the U.S.* on March 1, 2016. The United States lacks a comprehensive system to finance and deliver long-term services and supports (LTSS), and we urge Congress to work with stakeholders to develop a viable solution.

CCD is a coalition of over 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

LCAO is a coalition of 72 national nonprofit organizations concerned with the well-being of America's older population and committed to representing their interests in the policy-making arena.

Together we represent millions of Americans who either receive or are at risk of needing long-term services and supports (LTSS).

For older adults and people with disabilities who need LTSS, their freedom is tied to the need for assistance with activities of daily living, such as eating, bathing, or getting dressed. Every American is at risk of one day requiring LTSS. This can happen at any age, not just Americans over 65.

The lack of a comprehensive LTSS finance and delivery system today translates into a crisis for American families that places enormous financial, emotional, and physical strain on family caregivers as well as the person needing assistance. At present, Medicaid provides the majority of paid LTSS, but has strict means-testing requirements that conflict with other policies intended to encourage savings and economic independence. For example, persons with disabilities who

would like to work more face an unacceptable choice between losing the assistance needed to survive or not working and keeping that assistance.

In addition, America does not fully deliver LTSS in the settings people want most, an inefficient use of resources. While high quality care must be assured in all settings, virtually everyone desires to be at home and in their community. Yet, Medicaid still suffers from a “bias” that places far too many in an institution when they could otherwise remain at home or in their community. Beyond, ending this bias, improving delivery also means ensuring an adequate workforce to provide these services and that family caregivers and workers alike have the supports they need to provide quality care in the community.

The principles enclosed were adopted by CCD and LCAO at the start of the Long-Term Care Commission in 2013. We are committed to working together to ensure that all Americans, regardless of age, can access high quality LTSS. We hope you will use them as a means to guide you through weighing different options to solve our long-term services and supports challenge.

Again, thank you for holding this hearing. Our organizations look forward to engaging with you on this important issue.

Sincerely,



Max Richtman
Chair, Leadership Council of Aging Organizations



Kim Musheno
Chair, Consortium for Citizens with Disabilities

Financing Principles for Long-Term Services and Supports

Our nation has too long ignored the urgent need to address in a fiscally responsible manner the emerging long-term services and supports crisis facing older adults, baby boomers, and people with disabilities of all ages. Long-term services and supports should offer consumers access to a broad array of support options, including a continuum of home and community-based supportive services, as well as residential options, as needed. Our current system forces people into institutions inappropriately, 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 financing principles for long-term services and supports are intended to provide a framework for focusing attention, generating discussion and crafting a solution to the problem in the near future. In the interim, members of the LCAO and CCD will work toward a strong Medicaid program, substantial additional resources for home and community-based services, and opportunities for individual planning.

1. **National Problem, National Solution** – Recognize that although states, communities, families, and individuals have important roles to play, financing for long-term services and supports is a national problem that requires a national solution.
2. **Universality with Limited Opt-Out** – Create a public program that allows all people, including individuals with disabilities and those near retirement, the opportunity to contribute to and prepare for the costs of long-term services and supports. Make participation as convenient as possible but give people the limited choice to opt out.
3. **Public/Private Partnership** – Provide a strong foundation of protection while providing opportunities for personal planning that include a role for private sector options.
4. **Affordability and Risk Pooling** – Provide for broad pooling of risk and appropriate low-income subsidies to make premiums affordable enough so that all people, regardless of income and health status, can participate. Ensure that a new program does not force people to impoverish themselves to qualify.
5. **Fiscal Responsibility** – Provide actuarially sound funding, such as through voluntary premiums that build reserves over time sufficient to pay for future needs in a way that is affordable to individuals and to society as a whole.

6. **Relieve Pressure on Medicaid** – Provide additional long-term services and supports funding mechanisms that will help take the pressure off of future Medicaid expenditures, while preserving the guaranteed safety net.
7. **Consumer Choice and Control** – Promote independence and dignity across the broad continuum of services and supports by ensuring beneficiaries the right to control and choose what services they receive, how and where they are delivered and who provides them.
8. **Support Family Caregivers** – Recognize and support the central role families and other informal caregivers play in planning for and providing long-term services and supports, including developing strategies to support working caregivers to maintain their financial security.
9. **Invest in Quality Care and Quality of Life** –Target additional funding to ensure sufficient training and compensation for the workforce and to strengthen oversight, enforcement, and advocacy programs that improve quality of life and quality of care in all settings.