

Long-Term Care Financing Collaborative

July 2015

Vision of a Better Future for People Needing Long-Term Services and Supports

The **Long-Term Care Financing Collaborative** developed a **consensus statement** describing the challenges with the current long-term supports and services system in the United States and laid out a set of foundational principles for designing a sustainable and affordable system of care. The Collaborative recognizes that financing and delivery of services and supports are inextricably linked. The purpose of this statement is to express our agreement on LTSS recommendations that recognize the role of families and communities in delivering services and supports.

Background

People of all ages who need help with activities of daily living want to live lives that are as independent and fully engaged as possible. The vast majority will live at home and, when they need assistance, will often turn to their families, neighbors, and other trusted members of their communities.¹

Family caregivers are the bedrock of our system for delivering personal assistance and social supports to the frail older adults and younger people with disabilities. They not only provide direct care, but also help their loved ones navigate the complex network of professional health and long-term care services. For the vast majority of care recipients, families are the first line of support. Communities, including neighbors and friends, also provide critical assistance as well as access to services and social engagement.

More than eight in ten elders and younger people with disabilities who require some level of personal assistance receive this care at home.² More than eight in ten of them do so with only the help of family and friends and without any paid assistance.³ Those family caregivers who play such a critical role often do so at great physical, financial, and emotional cost.

As a result, reforms to the nation's long-term care system must acknowledge and support the role of family caregivers and communities. At the very least, government should remove disincentives to effective family and community supports for people with chronic conditions. However, the Collaborative also believes government should actively recognize and support both family caregiving and a wide variety of grassroots community supports.

This is especially important in the face of profound changes in demographics, social and family structure, and the delivery of medical care, all of which are increasing pressure on these caregivers. Specific changes include:

- Increasing numbers of people living to advanced old age and living longer with disabilities, trends that may require more years of supports than ever before.
- Low fertility rates that result in fewer adult children to care for aging parents.
- Growing employment among women--who have traditionally served as primary caregivers.
- Profound changes in the nature of families, including high rates of divorce and those who never marry, and increasing numbers of children born to single-parent households.
- Accelerated discharges from in-patient facilities that require family members to provide more complex care.
- The growing preference for less institutional and more home-based care.

The confluence of these trends will make it difficult, if not impossible, for many families to care for their loved ones without additional support. It may, in fact, no longer be possible to rely on the "traditional family" to carry this weight alone. As a result, both professional services and communities may play a critical and much broader role in assisting people who require personal assistance. We anticipate that new models of supports and new forms of communities may develop in coming years.

At the same time, federal, state, and local governments will continue to face enormous fiscal pressures that will require them to make the most effective use of available funds.⁴

This may result in a fundamental change in the role of government at different levels—from financing and delivering services (directly or indirectly) to also recognizing and enhancing both family caregiving and local community initiatives.

We recognize that not all people with functional limitations can or would choose to live their entire lives at home. In some cases, residential care may be more appropriate or preferred as needs increase or family caregiving becomes unavailable or insufficient. However, a robust structure of family and community support can make it possible for people to remain at home for a longer period of time—a situation that can improve their well-being and quality of life and, not incidentally, save the system money.

Reforms to the nation's long-term care system must acknowledge and support the role of family caregivers and communities.

Policy Recommendations For Family Caregiving & Home- And Community-Based Services

The Collaborative supports a broad national strategy aimed at supporting family caregiving and encouraging community-based supports for those receiving care and their families. This includes significant changes in the delivery of health and long-term services and supports (LTSS) as well as social supports for older adults and younger people with disabilities. Expanding access to social care may reduce the need for medical interventions. Specific reforms for family care giving and home- and community-based services (HCBS) include:

Better Integration of LTSS and Medical Care

- Redesigning delivery systems that make it possible for people with chronic conditions to receive well-integrated care that bridges existing definitions of LTSS on one hand and medical care on the other. A new payment model should reflect person- and family-centered choices and needs.
- Encouraging payment models that result in current funding sources working together to effectively meet the needs of the individual. Such models would increase incentives for better integrated care and reduce incentives for inappropriate care.
- Supporting state governments in their efforts to further break down barriers between Medicaid services such as home health aides, and non-Medicaid services such as

housing, transportation, and information-and-referral. The federal government should make it easier for states to combine housing, health, and social services programs in ways to encourage more affordable and better coordinated community-based care.

- Revising payment and licensing systems to support the growing use of telehealth/ telemedicine, mhealth, and monitoring and assistive technologies that promote more affordable and better coordinated care.

Support for Paid Caregivers

- Changing scope of practice rules and state licensing laws to allow health care professionals and direct care workers to “work to the top of their skills.” For instance, in such a model advanced health practitioners would provide certain types of care now permitted only to physicians, Registered Nurses would take on some roles now filled by Nurse Practitioners, and home health aides would do some work currently limited to Licensed Practical Nurses or Licensed Vocational Nurses. States may want to consider additional measures for ensuring quality of care.
- Expanding competency-based training and opportunities for promotion for direct care workers. This would likely result in higher compensation for these workers. Similarly, medical and health professionals need to receive advanced training in geriatrics and the care of patients with functional and cognitive limitations or other complex care needs.

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Family Support

- Encouraging the creation of care teams that include health professionals, direct care workers, and family caregivers, with the permission of those receiving care.
- Creating incentives for the creation of plans of care that acknowledge the central role of family caregivers as a key part of care teams. Discharge and care plans should assess and address the needs of family caregivers, especially when the plan of care depends upon the family, and assess the availability of community supports.

With permission, family caregivers should have access to an individual's medical records.

- Providing family caregivers with opportunities for training and support.
- Developing, under federal legislation or administratively, a national strategy to support family caregivers similar in scope to the government's current initiative aimed at assisting those with Alzheimer Disease and other forms of dementia.

Community and Employer Reform

- Modifying local regulations that impede new forms of community, such as zoning laws that limit the number of unrelated people who may share a home; and liability and licensing rules that constrain ride-sharing.
- Leveraging existing institutions as portals to and providers of care. This is especially important in low-income communities. These institutions may include faith-based organizations, neighborhood associations, food banks, housing providers, job training sites, schools, community health centers, other community-based non-profits, and hospitals. They may also include social media and not-for-profit information services aimed at increasing caregiver knowledge about sources of services and supports.
- Encouraging employers to voluntarily create "family-friendly" flexible workplaces that include caregivers who can remain employed while doing the hard work of caregiving.

We are aware of many models that build on existing institutions. Some examples include:

- Faith-community or parish nurse programs help coordinate holistic models of care for members of their communities. **Grand-Aides** are community-based direct care workers who serve as the "eyes and ears" for medical professionals within their neighborhoods. This model can both improve medical care and create employment opportunities in low-income

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neighborhoods. In the United Kingdom, district nurses help organize care by leading teams of community nurses and social support workers.

- In the “Memphis model” (also known as the **Congregational Health Network**), hospitals work closely with churches to coordinate care for members. This model enhances care in the hospital and makes it possible for hospital-based and church-based coordinators to work together to organize post-discharge care. This often includes the use of church members to provide volunteer transportation, meals, and social supports for a discharged patient. The model also trains family caregivers.
- Volunteers from fraternal organizations, such as the Ohio Masons, provide social supports, home repairs, and routine maintenance for members who need assistance to remain at home. Denver-based **Mercy Housing** uses subsidizing housing as a platform for providing medical and social services to more than 110,000 people, including seniors and veterans with disabilities.⁵ In Vermont, the **Supports and Services at Home (SASH)** program organizes care for people living in senior housing communities. The Veterans Administration operates a **medical foster home program** where people with functional limitations live and receive assistance in the homes of trained caregivers. These living arrangements serve as an alternative to nursing home care.

These are just some examples. Different communities, often in cooperation with local institutions, will develop their own ways to help neighbors or friends assist one another. Our aim is for government to encourage development of these local models by first removing regulatory impediments and second by providing active support.

Today’s Realities Impacting Families and Communities

The need for greater public support of families and communities is grounded in four broad realities:

The Growing Importance of Home-based Care

More than eight out of every ten people receiving services and supports already live at home,⁶ and surveys show nearly everyone with care needs would like to remain in their communities.⁷ In response, the political system continues to take steps that are likely

to expand home-based care. State Medicaid programs are enlarging their home- and community-based services initiatives, and in many states, Medicaid managed care includes strong financial incentives to provide supports and services at home or in other settings rather than in nursing facilities.

Today, family caregivers are the bedrock of the home-based system. Yet, these relatives pay an enormous physical, emotional, and financial price for providing this assistance. Family members report spending more than \$5,000 out-of-pocket each year to care for loved ones.⁸ A 50-something daughter who leaves her job to care for an aging parent can expect to forego more than \$300,000 in lifetime income.⁹ Caregivers often report higher levels of depression and physical illness than non-caregivers of the same age.¹⁰

Yet, family caregivers receive little to no support. Few training programs prepare family members with the technical or emotional skills they need. The lack of skills training is especially important since family caregivers increasingly are expected to provide sophisticated medical care, such as wound care and medication management, which was once the province of highly-trained Registered Nurses.¹¹ This is compounded by families' limited access to respite care that provides an occasional (and much-needed) break from the rigors of caregiving.

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At the same time, the role of paid aides is limited due to constraints of both demand and supply. On the demand side, at an average cost of \$20/hour,¹² aides are beyond the financial reach of many families. Yet the supply of paid aides remains limited, due in part to high injury rates and low compensation. While families pay agencies about \$20/hour for aides, the front-line workers themselves often make less than \$10/hour.¹³

The Changing Nature of Families

Despite the weaknesses in today's system, we may be living at the apogee of family caregiving. In coming years, the nation will face three interconnected challenges: As

Baby Boomers age into their 70s and 80s, their care needs will increase. Boomers are likely to insist on even more service options outside of facility-based care, and the pool of people available to provide that care compared to those who will need assistance will continue to shrink dramatically.

Today, there are more than seven people in the prime caregiving ages of 45-64 for every one aged 80 or older.¹⁴ Thirty years from now, that ratio will fall to about 3 to 1.¹⁵ Yet, even this may overstate the potential pool of family caregivers given high levels of divorce, broad geographic dispersion of families, and other dramatic changes in the nature of families. Even as demand for home-based care is expected to grow, demographic trends suggest a sharp decline in the future availability of family caregivers.

For example, nearly half of women aged 75 or older live alone, and they are three times more likely to live in poverty than those living with families.¹⁶

These issues may be especially challenging in low-income communities. For instance, among women making less than \$10,000 who gave birth in 2011, nearly 70 percent were unmarried.¹⁷ Many low-income women work multiple jobs. For them, working, raising children, and caring for aging parents or relatives with disabilities is an enormous burden.

The challenges of caregiving in low-income neighborhoods are magnified by the lack of community resources to supplement their needs and provide choice.

As the population becomes increasingly diverse, we also recognize the need for care providers to understand the unique social, cultural, and language needs of care recipients. Addressing cultural competency in planning, training, and delivery of long-term care services can reduce disparities, improve access, and enhance independence and quality of life.

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The Changing Nature of Disease and Health Care

The U.S. health care system is built around treatment of acute episodes. Yet as a result of advancements in medical science, health care technology, and unprecedented increases in life expectancy, more Americans are living for decades with disabilities and chronic conditions, such as congestive heart failure and diabetes. Chronic care now accounts for more than 70 percent of all medical costs in the U.S.,¹⁸ with functional impairments being a key cost driver for those who live with chronic conditions.¹⁹

While people with long-term illness, injury, or disability do require medical assistance, these health services and their associated costs can be better contained if they receive the proper services and supports. Help managing medications, diet, and proper exercise, as well social supports such as transportation and safe housing may improve their quality of life and prevent acute episodes that are both hazardous and expensive.

Inappropriate care and poor coordination of care are especially serious problems for those moving from acute care in the medical system to custodial long-term care. These difficult and risky transitions can be prevented by better discharge planning from hospitals and skilled nursing facilities, improved training for individuals receiving care and their family caregivers, greater regulatory flexibility and better education for health care providers and aides, and improved access to primary care, including in-home primary care.

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The Value of Community-Based Programs

The federal and state governments support community-based LTSS through various programs, including through the federal Older Americans Act. These include a long-term care ombudsman, nutritional services, family caregiver support, and disease prevention and health promotion activities. At the same time, local communities are developing many innovative solutions to help provide services and fill gaps in caregiving.

In other models, friends and neighbors provide some level of assistance to one another. Some may choose creative new alternative housing arrangements such as co-housing, where people with common interests move into a community to share both paid and volunteer services. Others may stay in their own homes but join neighborhood support initiatives such as senior villages. Still others may look to faith-based or fraternal organizations, or other forms of support built on common interests.

Some of these models may be created or enhanced by health or social service providers while others may be built by non-profits or community groups. While each includes some form of communal support, the models are vastly different from one another and may appeal to different socio-economic and cultural groups.

An important policy challenge is to open the door to as many of these organizations as possible while still recognizing the need to prevent fraud or abuse. Government can help these creative new models flourish by removing regulatory impediments to innovation even as it provides technical support and perhaps start-up funding.

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Background on the Collaborative

In 2012, a group of policy experts representing a wide range of interests and ideological views created the Long-Term Care Financing Collaborative to re-energize the discussion of long-term care and build the foundation for new thinking and innovation. Convergence Center for Policy Resolution convenes the Collaborative and facilitates our efforts to build trust, identify solutions, and form alliances for action. The Collaborative's goal is to develop pragmatic, consensus-driven recommendations that empower people of all incomes to receive high quality services and supports.

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The Long-Term Care Financing Collaborative is convened by
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www.convergencepolicy.org

References

- ¹ Friedland, Robert B., Caregivers and Long-Term Care Needs in the 21st Century: Will Public Policy Meet the Challenge?, pg. 1. Georgetown University Long-Term Care Financing Project. 2004. <http://caregiverslibrary.org/Portals/0/caregivers%20and%20LTC%20needs%20and%20Public%20Policy.pdf>
- ² Id.
- ³ Id.
- ⁴ Medicaid and its Role in State/Federal Budgets & Health Reform, pgs. 4-20. The Kaiser Commission on Medicaid and the Uninsured. 2013. <https://kaiserfamilyfoundation.files.wordpress.com/2013/04/8162-03.pdf>
- ⁵ Who We Serve. Mercy Housing. 2015. <https://www.mercyhousing.org/who-we-serve>
- ⁶ See supra, n. 1.
- ⁷ Home and Community Preferences of the 45+ Population, pgs. 1-19. AARP. 2010. <http://assets.aarp.org/rgcenter/general/home-community-services-10.pdf>
- ⁸ Evercare Study of Family Caregivers – What They Spend, What they Sacrifice: Findings from a National Survey, pgs. 15-17. Evercare in Collaboration with National Alliance for Caregiving. 2007. http://www.caregiving.org/data/Evercare_NAC_CaregiverCostStudyFINAL20111907.pdf

- ⁹ The Metlife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents, pg. 2. Metlife Mature Market Institute. 2011. <http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>
- ¹⁰ 2013 Alzheimer's Disease Facts and Figures, pg. 35. Alzheimer's Association. 2013. https://www.alz.org/downloads/facts_figures_2013.pdf
- ¹¹ Feinberg, Lynn. Populations in Need of LTSS and Service Delivery Issues, pgs. 103-04. Testimony to the Commission on Long-Term Care. 2013. <http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/July-17-Official-Testimony.pdf>
- ¹² Alkema, Gretchen. Current Issues and Potential Solutions for Addressing America's Long-Term Care Financing Crisis, pg. 2. The Scan Foundation. 2013. <http://www.thescanfoundation.org/briefing-whats-state-ltc-financing-and-what-are-options-future>
- ¹³ Gleckman, Howard. The Faces of Home Care, pgs. 125-29. Health Affairs. 2010; 29(1). <http://content.healthaffairs.org/content/29/1/125.full>
- ¹⁴ Feinberg, Lynn, Ari Houser, and Donald Redfoot. The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers, pg. 1. AARP Public Policy Institute. 2013. http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf
- ¹⁵ Id.
- ¹⁶ A Profile of Older Americans: 2013, pgs. 1, 10. Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services. 2013. http://www.aoa.acl.gov/Aging_Statistics/Profile/2013/docs/2013_Profile.pdf
- ¹⁷ Kreider, Rose M, Rachel M. Shattuck. Social and Economic Characteristics of Currently Unmarried Women with a Recent Birth: 2011, pg. 5. United States Census Bureau. 2013. <http://www.census.gov/prod/2013pubs/acs-21.pdf>
- ¹⁸ Berbayer, David, Peter Esselman, Janna Friedly, Carl Granger, R. Sam Mayer. Chronic Care Education in Medical School: A Focus on Functional Health and Quality of Life, pg. 800. American Journal of Physical Medicine and Rehabilitation. 2009; 88(10). http://c.ymcdn.com/sites/www.physiatry.org/resource/resmgr/chronic_care_education_in_me.pdf
- ¹⁹ Effective Management of High-Risk Medicare Populations, pg. 3. Avalere Health LLC. 2014. <http://avalere.com/news/avalere-issues-white-paper-on-the-management-of-high-risk-medicare-populati>