STATEMENT FOR THE RECORD

SUBMITTED TO THE

Special Committee on Aging

United States Senate

on

"The Future of Long-Term Care Policy: Continuing the Conversation"

December 18, 2013

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AARP appreciates Chairman Nelson and Ranking Member Collins convening this important hearing on the future of long-term care policy, and especially on continuing the conversation after the recent work of the federal Commission on Long-Term Care.

Long-term care is really about helping people live independently and supporting family caregivers who help their loved ones do just that. This critical issue affects millions of individuals of all ages and their families every day. Whether it is a 29 year-old man with a disability who needs supports to work and remain employed, an 89-year old woman who needs services to help her live independently in her home, or a 49-year old woman who works outside the home and spends nearly 20 hours per week providing unpaid care to her mother for nearly five years – the "average" US family caregiver – all these individuals rely on or provide services and supports to enable independent living. Right now, at kitchen tables across America, millions of real families are confronting the same question: how will we care for mom or dad, or another loved one, if something happens and they can't care for themselves without assistance? And if and when the time comes, who will care for us?

About 12 million Americans need assistance to help them with regular daily activities, such as eating, bathing, dressing, and transportation. Almost half (44 percent) of these individuals are under age 65, and a little over half (56 percent) are age 65 and over. These 12 million people are projected to more than double to 27 million in 2050.[1] These individuals should receive the long-term care services they need as part of a person- and family-centered approach that is responsive, efficient, and integrated with health and other services to ensure people can access quality services in settings they choose.

Family Caregiving

Family caregivers are the backbone of long-term care in this country and they are the first line of assistance for most people who need help to live independently. In 2009, about 42 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time. They provided unpaid care valued at $450 billion that year, more than total Medicaid spending in 2009 and more than twice the total for paid services and supports, according to AARP's Public Policy Institute.[2]

As the number of individuals needing services to help them live independently will grow in the coming decades, a recently released AARP Public Policy Institute report finds that the number of family caregivers available for older Americans will drop dramatically over this same time period. From 1990 to 2010, the Baby Boom generation entered their prime caregiving years; at the end of those two decades, there were 7.2 potential caregivers aged 45-64 for every person aged 80-plus. Over the next 20 years, as the Boomers become the population that will need the most care, the number of potential caregivers drops to 4:1. Looking even further out, between 2030 and 2050, the number plummets to

[1] Commission on Long-Term Care, *Report to the Congress* 5 (September 30, 2013) *available at* *http://www.ltccommission.senate.gov/Commission%20on%20Long-Term%20Care-%20Final%20Report%209-26-13.pdf*.
[2] L. Feinberg, S. Reinhard, A. Houser & R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* 1,3 (AARP PPI, 2011), available at http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html.

2.9:1.[3] That means more people will be dependent on fewer family caregivers. We need better supports for family caregivers, a strong, stable paid workforce, and innovative solutions across sectors.

Many family caregivers take on care willingly and many find it a source of deep satisfaction and meaning. Yet family caregivers can also face physical, emotional, and financial challenges. Families often coordinate care and provide assistance with activities such as eating, bathing, toileting, meal preparation, transportation, managing finances, and household chores. A report released last year by AARP's Public Policy Institute and the United Hospital Fund also found that almost half of family caregivers perform medical/nursing tasks for care recipients, such as wound care, managing multiple medications, and helping with assistive devices for mobility.[4] Families generally do not receive training and other assistance to help them provide care. Such training and supports may also benefit the person receiving the assistance. Family caregivers should be given an assessment of their needs and then receive help based on the assessment, especially when a care or discharge plan depends on a family caregiver voluntarily providing services to an individual. Such assistance should include information, training, counseling, links to community resources, help locating services, respite care, or other supports. Family caregivers providing assistance to their loved ones at home can help delay or prevent these individuals from needing more costly care in a nursing home and help prevent unnecessary hospital readmissions.

Paying for Services

When families are not able to provide all the services that a loved one needs to live independently, individuals and their families turn to paid care. Often, they may be looking for someone to provide services in their local community or a long-distance family caregiver may be tracking down available services in her mother's community. Finding quality services and providers can be challenging. And, costs can quickly add up. The national median rate for home health aide services is over $30,000 annually based on 30 hours per week. The national median cost for an assisted living facility is over $41,000 annually, and the national median cost of a private room in a nursing home is almost $84,000.[5] These costs can be overwhelming for individuals and their families. Financing options are currently limited. Private health insurance and Medicare do not cover these services and supports, even though many people believe they do.

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[3] D. Redfoot, L. Feinberg, & A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* 3-6 (AARP PPI, 2013), available at 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.

[4] S. Reinhard, C. Levine & S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* 1 (AARP PPI and United Hospital Fund, 2012), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.

[5] D. Redfoot & W. Fox-Grage, *Medicaid: A Program of Last Resort for People Who Need Long-Term Services and Supports* 3 (AARP PPI, 2013), available at http://www.aarp.org/health/medicare-insurance/info-05-2013/medicaid-last-resort-AARP-ppi-health.html.

A small percentage of the population has private long-term care insurance to help pay for services. However, private long-term care insurance is unaffordable for many, especially since many companies have dramatically raised premiums and introduced gender rating that has increased premiums for women. Most companies offering coverage a few years ago have left the market. Those still offering policies have often increased underwriting in recent years making it harder to purchase; many people are unable to obtain it due to pre-existing conditions, such as a disability. Products that combine long-term care insurance with life insurance or other products may help some individuals, but these products are relatively new and can be complicated, confusing, and even more expensive for consumers.

Given limited financing options, general denial about the potential need for help to live independently, the more immediate needs of paying a mortgage and other monthly bills, the need to save to send children to college, and inadequate savings for retirement generally – let alone help to live independently **–** many individuals and families struggle to pay for care when disability occurs. Many individuals spend down their life savings and end up relying on Medicaid to pay for services to help them live independently in their homes and communities or pay for nursing home care. Medicaid provides an important safety net for those with low incomes or those who have exhausted their retirement savings on the high costs of health care and the help needed to live independently. Clearly, more and better financing tools are needed.

Balancing

Most people who need services and supports don't need or want to stay in expensive nursing homes. They want to live independently, and they could live in their homes if they have the right help with everyday tasks and other supports. Medicaid has an institutional bias that makes it more difficult to serve people in their homes and communities. Federal law requires Medicaid to cover institutional care, such as nursing homes, but home and community-based services (HCBS) are mostly "optional" services provided at state discretion. States provide these services, but they often have limitations, such as the number of people who can receive services, the types of services, and the amount of services. Most older Americans and persons with disabilities prefer to receive services in their homes and communities, and these services are cost effective, yet barriers to HCBS persist in the Medicaid program. On average, the Medicaid program can provide HCBS to roughly three older adults and adults with physical disabilities for the cost of serving one person in a nursing home.[6] Research shows that states that invest in HCBS, over time, slow their rate of Medicaid spending growth, compared to states that remain reliant on nursing homes. While states and the federal government have made gradual progress on

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[6] A. Houser, W. Fox-Grage, & K. Ujvari, *Across the States: Profiles of Long-Term Term Services and Supports 2012* 16 (AARP PPI, 2012), *available at* *http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf*.

increasing access to HCBS, much remains to be done, especially for older individuals who have lagged behind younger people with disabilities in receiving HCBS.[7]

Quality and Workforce

Individuals who need services and supports should receive both quality care and services that improve quality of life regardless of payer and where they are receiving services. A person- and family- centered approach to service delivery means providing quality services that meet the needs of the individual and their family caregivers, as appropriate. While there are quality providers across the array of services, the quality of services that help people live independently in their homes and communities or in nursing homes varies greatly. In addition, quality oversight is often insufficient, and quality measures in HCBS are lacking.

A vital part of providing quality services to older adults and persons with disabilities is having a strong, competent and stable workforce to provide these services. Too often, direct care workers (who provide most paid care) face difficult jobs, inadequate compensation, high turnover rates, limited opportunities for career advancement, and other challenges. Given the current and future demand for services, especially for individuals living independently in their homes and communities, and the declining number of family caregivers in the coming decades, it is important to recruit and retain a strong and stable paid workforce with better career opportunities. Direct care workers, as well as family caregivers and individuals receiving services, are critical members of interdisciplinary teams providing services to individuals.

Recent Developments

In September, a federally appointed Commission on Long-Term Care released a report with important bipartisan recommendations to help build a better system to support individuals and their family caregivers nationwide. Congress and the Administration should seriously consider these recommendations in developing legislative and administrative steps to improve options to help people live independently. Importantly, the Commission called for a national strategy to address the needs of family caregivers. The Commission also specifically recommended assessing family caregivers and their needs in the care planning process, including family caregivers in patients' health records and as members of care teams, ensuring family caregivers have access to relevant information technology and, importantly, encouraging family caregiver interventions, including respite, training, and other supportive services and volunteer support.

In addition to providing support to family caregivers, the Commission endorsed the broader ideas that people should have greater choice about care setting and that HCBS should be sufficiently robust to meet the needs of older Americans and people with disabilities who

[7] D. Rowland, Testimony before the Commission on Long-Term Care on *What Would Strengthen Medicaid Long-Term Services and Supports?* 4 (August 1, 2013), available at http://www.ltccommission.senate.gov/DRowland%20Testimony.pdf.

wish to remain in their homes and communities. However, we wish the Commission had gone farther in calling for enhancements to the social safety net.

The Commission also made some important recommendations relating to service delivery and care coordination, among others, and to help address the needs of individuals with disabilities who need services and supports to enable them to work.

While these recommendations are a good start, they are only one step in what must become an ongoing constructive national conversation that looks at the whole picture. The Commission had limited time and regrettably did not reach agreement on comprehensive financing. Solutions in these and other areas are important.

No one silver bullet will address all the challenges outlined in these comments. A continued dialogue and action among individuals, stakeholders, and the public and private sectors is essential to address these issues in our country. There are some important steps Congress could take in the short-term, such as requiring the development of a national strategy to support family caregivers.

Again, AARP thanks the Senate Special Committee on Aging for today's hearing. We encourage those on both sides of the aisle to continue engaging to help find solutions on this vital issue to millions of individuals of all ages and their families. We have an opportunity to seize the moment to raise the visibility on this issue – and to build on the Commission's bipartisan recommendations for a better system to support individuals and their family caregivers nationwide. AARP looks forward to working with Congress, the Administration, and a diverse array of stakeholders to successfully address these issues.