

Statement of Anne Tumlinson
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March 23, 2022 Hearing before the U.S. Senate Special Committee on Aging
“An Economy That Cares: The Importance of Home-Based Services”

Chairman Casey, Ranking Member Scott, and Members of the Committee, thank you for the opportunity to testify on the importance of investments in Medicaid home and community-based services.

My name is Anne Tumlinson, and I am the CEO of the research and consulting firm, ATI Advisory, which employs over 20 experts working with business and government to improve care delivery and financing for complex care populations. I am also the Founder of a grassroots community of family caregivers, called Daughterhood. Daughterhood operates local groups across the country that provide informal support and resources to family caregivers.

Home and community-based services (HCBS) are a critical part of the continuum of care for people with long-term services and supports (LTSS) needs. Whether funded by Medicaid or through private dollars, we know that these services make it possible for many individuals with high needs to remain safely in their homes, which is the preferred care setting for most individuals. A 2021 study replicating the CAPABLE program, an integrated home visit and home modifications program, found substantial improvements in function among participants who were able to remain in their own homes with targeted home care supports and modifications.¹ Home care can provide a family the key support it needs to delay or avoid a long-term institutional placement. Research shows that a person’s risk for nursing home

¹ [Sarah L. Szanton et al., “CAPABLE program improves disability in multiple randomized trials,” Journal of the American Geriatrics Society 69, no. 12: 3631-40.](#)

placement is significantly lower for each five-hour increment in personal care the person received.²

Unfortunately, our home and community-based system and its infrastructure are vastly underdeveloped to meet the needs of the growing population that will need long-term services and supports at some point in their lives.

- Even now, Medicaid spends more (54%) on institutional care than on home and community-based services for older adults and individuals with physical disabilities.³
- Of the approximate 3 million Medicare beneficiaries living in the community who need support with two or more activities of daily living, one third live below 200% of the federal poverty level but are not on Medicaid, and therefore cannot access HCBS.⁴
- Three-quarters of the direct care workforce supplying the labor for LTSS doesn't earn a living wage.⁵ More than half of home care workers are on public assistance, and more than half are paid less than \$13 per hour.⁶
- Even among individuals with resources, finding and deploying privately financed home-based services and supports is challenging. These individuals often report not knowing where to go, and not being able to find what they need.

² Sands LP, Xu H, Thomas J 3rd, et al. Volume of home- and community-based services and time to nursing-home placement. *Medicare Medicaid Res Rev.* 2012;2(3):mmrr.002.03.a03. Published 2012 Aug 6. doi:10.5600/mmrr.002.03.a03. For additional data on the value of HCBS, see ATI Advisory and Arnold Ventures compendium of research.

³ Steve Eiken et al., "Medicaid Expenditures for Long-Term Services and Supports in FY 2016." Calendar year 2016 was chosen because more recent reports do not include all states, which affects the national average.

⁴ ATI Advisory analysis of the Medicare Current Beneficiary Survey, 2019.

⁵ [LeadingAge](#), "Making Care Work Pay."

⁶ [PHI](#), "Direct Care Workers in the United States: Key Facts."

As a result, the majority of high need older adults living in the community are receiving assistance from family caregivers alone. Mounting evidence shows that family caregiving has a significant impact on the economy: 40% of family caregivers reported having to go from full-time to part-time employment to care for a loved one and almost 20% left their paid jobs altogether.⁷ To say those family caregivers are stretched thin is euphemistic. What I hear from our Daughterhood community over and over is that every single family operates like it is on its own island. There is nowhere to turn for services and supports. When we can't do it anymore, and the money runs out, often a nursing home is the only option.

The good news is that some efforts are underway to address system inadequacies. States received an infusion of federal funds in the historic American Rescue Plan Act (ARPA). This is important to respond to the added HCBS needs and costs associated with the pandemic. And it will help jumpstart HCBS capacity building. But it's just a start. And importantly, it is temporary. States tell me that they need a reliable and sustained federal commitment of resources in order to commit to long-term changes.⁸ There have been some limited private sector initiatives as well, including technology developments and health plan offerings.

But these small, incremental, or temporary solutions are not enough. It's like we are bringing an umbrella to a hurricane.

The population shift the U.S. is experiencing right now is nothing short of seismic. The number of individuals in our country who are 85 years and older will double by 2035 and triple by 2060, up to 19 million people.⁹ At the same time, the number of caregivers available to provide support

⁷ [Rosalynn Carter Institute for Caregiving, "How "Working While Caring" Impacts Our Caregivers and Our Nation's Economy."](#)

⁸ [ATI Advisory, "A Blueprint for Reforming Medicaid Long-Term Services and Supports and Creating Good Caregiving Jobs."](#)

⁹ [Census.gov, "Demographic Turning Points for the United States: Population Projections for 2020 to 2060."](#)

is declining. Much more federal investment is needed to galvanize and support states and local communities in developing the infrastructure and systems along which a variety of publicly and privately funded HCBS can travel.

There are significant consequences if we fail to make a sustained federal investment in Medicaid HCBS. Without investment, we will continue to rely heavily on nursing homes. Today they are the primary infrastructure we have, and the only guaranteed source of long-term services and supports for people with high needs. And we will also continue to over-rely on unpaid family caregivers.

And what I can tell you from my own experience as well as being part of a community of unpaid family caregivers is that families face very tough choices today. Caring for a person who needs assistance performing daily activities is work, whether it's paid or not. It requires not only the hands-on support but also the management of care needs that cross-cut long-term services and supports AND medical care. I often say that families end up being the ultimate case coordinators. Over and over, they tell me about quitting jobs to provide this care and the threat this creates to their economic security. In addition, they severely compromise their own health and well-being. They compromise relationships with their children and spouses.

As growth in the size of the very old population starts to accelerate, our families, employers, communities, and states will feel these strains in a much more pronounced way. To prepare, we must invest in HCBS. This is the number one, most impactful federal outlay we can make right now to support individuals in need and their families. Without it, I fear the current state HCBS infrastructure will collapse leading to more and more families facing financial and emotional devastation, and an even greater reliance on institutional care.