



SUPPORTING CAREGIVERS AND ACCESS TO QUALITY LONG-TERM CARE

Federal Policy Framework

BACKGROUND

Caring Across Generations was launched in July 2011 to bring together workers, older Americans, people with disabilities and their families, to reimagine the future of long-term care. Specifically, the campaign focuses on supporting increased access to quality, affordable home care for families and individuals, and ensuring quality, dignified jobs for the home care workforce. Currently, Caring Across Generations works with partners in 16 states and in coalition with more than 200 organizations nationally, including the National Council on Aging, Paraprofessional Healthcare Institute, and Bend the Arc.

As the Baby Boom generation reaches retirement at a rate of 10,000 people per day, and advances in healthcare and medicine extend our lifespans, American families need more care than ever before. At least 20 percent of our population will be over the age of 65 by the year 2030. The country is crying out for a new, holistic, affordable and accessible system of long-term services and supports (LTSS) that meets the needs of individuals wherever they are in the care continuum.

Long-term, this must involve creating a new care infrastructure at the federal level that is sustainable and dignified for all. It will also include other solutions – at the community, local, state levels – as well as private sector solutions, but existing private sector solutions have proven inadequate. We need a federal policy solution that addresses affordability, choice, quality of care and quality of care jobs, including a path to citizenship for the immigrant care workforce. In the meantime, as we move toward that long-term goal, there are many interim state and federal policy solutions that can support families, caregivers and consumers alike. Here are some of the ideas we suggest supporters and partners adopt.

INCREASED ACCESS TO CARE CHOICES

Nearly 90 percent of people desire to age and heal at home, connected to the people and places they love. Because of this, we believe that all people should have increased access to quality, dignified, and affordable care choices, particularly home and community-based services. In addition to protecting and improving Social Security and Medicare, Caring Across Generations supports:

- 1. Developing a national, holistic long-term care system that works for all.**

Medicaid and Medicare are falling short when it comes to LTSS for both workers and consumers. A new compulsory long-term care insurance program would ensure financial peace of mind and security in unexpected and unplanned situations. Additionally, a new insurance program would increase access to care, distribute risk, and include a national plan for recruiting and retaining the workforce necessary to meet anticipated future long-term care needs.



2. Expanding access to home and community-based services.

Many states are seeing increasing Medicaid expenditures for nursing home care. Despite studies that prove the cost of homecare is far less, and the overwhelming desire of individuals to stay in their homes for as long as possible, public programs still default to institutionalized care.

3. Supporting states in planning and/or pilot programs.

States need support to invest in creative, innovative solutions that address their LTSS needs and care workforce development. The federal government can serve as both a monetary and technical resource to catalyze and build upon state innovation.

SUPPORT FOR FAMILIES

Much of the foundation of LTSS in this country was based upon shorter lifespans, extended families staying close together, and nursing homes built to “protect” those who were too old to care for themselves. Today, family members are scattered across the country, and often the world. Many of the “sandwich generation” are stretched between work, caring for their family, and providing care for a loved one who is aging or has a disability. Still, 85 percent of care is provided by family caregivers. With more people desiring to age in community, the pressure is only rising to provide the necessary LTSS to enable aging with independence and dignity. Because of this, we support:

1. Increasing financial support for family caregivers.

Working families are already struggling to care for themselves. Having to manage or provide care for an aging family member on top of this are forcing some people out of work, leaving them even more financially insecure. Affordability and income loss are major issues for consumers and family caregivers. We advocate for policy that will:

- a. Provide paid family and medical leave, that includes caring for parents and grandparents.
- b. Adjust the rates and caps of earned income tax credits to make care more affordable.
- c. Provide income credits toward Social Security for individuals who reduce work hours or leave the workforce to provide care for a child or an ill, disabled, or aging family member.

2. Lifting asset requirements as a qualifier for Medicaid eligibility for long-term services and supports, and indexing asset limits to inflation.

Medicaid, the primary payer for LTSS, limits eligibility to those with few or no assets, often for short-term public assistance. These asset limits often discourage anyone considering or receiving public benefits from saving for the future. Additionally, personal savings and assets are precisely the kinds of resources that help families support themselves and prolong institutionalized care.

3. Updating the national study on caregiving youth and eliminating federal age qualifiers associated with defining caregiving.

As of 2004, there were more than 1.4 million youth caregivers in the U.S. Evenly split between boys and girls, they are defined as individuals 18 years of age or younger providing at least two hours of care a day. Youth caregivers are often in the shadows, balancing childhood, school, and the responsibility of caring for someone else. This vulnerable population has no training opportunities, benefits, or special programs. Updating national data is a necessary first step to identifying how



federal policy can support this vulnerable population. Eliminating age qualifiers associated with defining caregiving would also increase access to public services and supports.

4. Documenting and training family caregivers.

Family members provide care, often after a loved one has been discharged, with no access to medical information or training. Documenting a named family caregiver formally acknowledges their vital role as part of a care team, and providing family caregivers with training increases their confidence and supports quality and continuity of care for their loved ones.

BETTER CARE JOBS

Around 10 million adults are estimated to be in need of LTSS. As our country ages, this number will increase dramatically over the coming years. To meet this need, our nation must improve existing care jobs, create new jobs, and recruit and retain a robust care workforce. Because of this, care workers should be valued and their jobs should be high-quality jobs. Caring Across Generations supports:

1. Increasing the national wage floor for all jobs.

Homecare workers spend long hours doing laborious work to care for those we love. But care jobs--nearly 90% of which are performed by women--are often low-wage jobs. With a median annual earnings of \$13,000 a year, the average pay for a home care worker is \$9.61. In many parts of the country, that is not enough to afford rent, food, utilities, and health and childcare expenses. The people we hire to care for our families should earn enough to care for their own. We support increasing the minimum wage, with a goal of \$15.00 per hour for home care workers.

2. Improving workforce training and career mobility.

Improving training for direct-care workers is integral to ensuring the quality of LTSS. Existing federal training programs are not geared toward personal care workers (who provide non-clinical services), particularly those serving clients through public consumer-directed programs.

3. Developing a path to citizenship for undocumented caregivers.

The home care industry faces a rapidly growing labor shortage. The precarious status of many current caregivers who are undocumented threatens the well-being of consumers, families, and employers who depend on these workers. A path to citizenship for undocumented caregivers who have already provided caregiving services helps fill the worker gap and provides security for families already receiving quality care from an undocumented caregiver.

4. Creating a national initiative to incentivize and recruit family caregivers into the paid workforce.

Over 85% of long-term care is provided by family members. With the transformative experience of providing care, family caregivers are uniquely poised to understand the complexities of care. This makes them a robust pool of potential talent to help meet a growing shortage in the paid care workforce.