

Preparing for the Elder Boom

A FRAMEWORK FOR STATE SOLUTIONS



CARING ACROSS GENERATIONS
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Executive Summary

With Millennials becoming parents and Baby Boomers getting older, the need for care across all generations of our families is growing. Many people can no longer rely on just family to provide the care they need. One of the most important steps we can take - and must take - in creating a family-centered caregiving system built for the 21st century is to address, head-on, the question of how we better provide long-term services and supports (LTSS) for our aging population and people with disabilities. Supporting care at any age and every stage of life will mean that we must invest now in eldercare, childcare, and paid leave for all. This paper reflects Caring Across Generations' recommendations for the first of these critical components of a new, inclusive, interdependent vision for Universal Family Care.

Overview: The Rising Need for Home Care in America Today

Every eight seconds, a person turns 65 in America.¹ That's 10,000 people every day. The demand for long-term services and supports (LTSS) is expected to surge over the next decade. As it stands, seven out of 10 of us will need LTSS at some point in our lives due to disability or the simple process of getting older. While institutional care may be the right choice in some cases, over 90 percent² of Americans prefer to receive care in their homes and communities for as long as possible rather than in nursing homes or assisted living facilities. And yet the systems and policies we have in place fail to reflect this overwhelming desire and the changing nature of families today.

¹<http://www.census.gov/>

² <https://assets.aarp.org/rgcenter/ppi/liv-com/aging-in-place-2011-full.pdf>



With the Baby Boomer generation (our nation's largest) reaching retirement age, and medical advances allowing people to live longer than ever before, there has never been a greater opportunity or sense of urgency to reimagine how we care for one another during our latter stages of life.

Current LTSS programs, both public and private, are unable to meet the needs of our growing and rapidly aging population. Some people erroneously believe that their private insurance will cover home care, leading to large gaps in insurance coverage and care planning. Private long-term care insurance costs are getting so high that most people are not signing up for these plans. For those that do, they often find out too late that their insurance does not offer robust benefits.

Most Americans also misunderstand what Medicaid and Medicare actually covers when LTSS needs arise. Medicaid, under strict income eligibility, does offer key long-term care benefits, such as doctor's visits, nursing home care and care services at home. To be eligible for programs through Medicaid though, consumers often need to spend their assets down to poverty levels. Coverage through Medicare is notably short-term and not comprehensive, focusing mostly on short stays in nursing homes. While Medicare may cover home health care services after a medical incident, the federal program requires an individual to be homebound and in need of care to qualify and does not cover longer-term home and community-based services and supports.

Amidst inadequate long-term care insurance and misinformation around Medicaid and Medicare, the demand for LTSS is increasing and families are unable to afford the care they need. Additionally, a historical failure to professionalize the care workforce has resulted in an inadequate retention of workers to meet the rising demand for care. Many families now face the unexpected expenses of having to care for and/or support themselves or a loved one needing quality LTSS.

Designing a New Care Solution

In late 2015, Caring Across Generations convened policy experts, academics and advocacy groups representing care workers and care recipients from across the country to consider a question: "If we were building the care system we want and need reflecting the realities of families today, would we be satisfied with what we have now and work to improve it - or would we build something new?"



In answering the question, an idea emerged: a policy proposal for a statewide LTSS benefit that would take full advantage of state authority to provide universal LTSS coverage. Universal coverage would mean that any individual or family regardless of income could access the benefit, and that correspondingly, all individuals and families would share the responsibility of costs without overburdening those who cannot afford the care they need. There was resounding consensus that the benefit must work for individuals needing care and their family caregivers while providing dignified jobs with fair wages for care workers.

Participants organized into two work groups, researching either design components for a statewide insurance program or the necessary financing mechanisms to support it. The main goal for both groups was simple: expand, as broadly as possible, access to affordable home care within existing state authority. Under this charge, the work groups set forth to develop recommendations that:

- Empower individuals and families to remain in their own homes for as long as they choose;
- Supplement, support, and sustain care provided by family and friends;
- Set minimum standards for a statewide universal benefit, with a focus on the needs of individuals who often don't qualify for Medicaid and/or Medicare;
- Address affordability by considering different financing measures and shared responsibility;
- Build and support the workforce needed to meet the increasing demand for home care.

This resulting white paper:

- Outlines the gaps in coverage and lack of sufficient care resources for older Americans, people with disabilities, the family members that support them, and the care workforce;
- Proposes a bold new public statewide long-term care program that provides support to individuals and families, offers protection from the risks and costs of long-term care, and increases access to desired home and community-based services;
- Identifies opportunities that states should consider to finance a new statewide long-term care program.



The Current State of Long-Term Services and Supports

Public and private solutions are falling short of meeting the surging demand for home and community-based long-term care - and people are paying the price for it. Medicare doesn't cover most people's LTSS needs while Medicaid requires people to impoverish themselves to access support for home and community-based care. Meanwhile premiums for private long-term care insurance plans are rising exponentially while market options continue to shrink, making coverage through the private market almost entirely out of reach for most families. The result is that the vast majority of individuals and families have very limited access to any coverage solutions at all, forcing too many people to feel overwhelmed and their lives upended when LTSS needs arise.



Weaknesses of the Current System

#1: Medicare's Focus on Acute Medical Care

Medicare is a federal health insurance program administered by the Centers for Medicare and Medicaid Services (CMS), providing health benefits for millions of Americans aged 65 years and older, and for people under age 65 receiving Social Security Disability Insurance (SSDI).

In skilled nursing facilities, or nursing homes as they are more commonly known, Medicare coverage is limited to post-acute care only. At best, Medicare only covers up to 100 days of skilled nursing facility care per benefit period, during which the patient must need and receive daily skilled nursing and/or therapy. The program doesn't provide care to individuals that have ongoing personal care needs, such as an older adult who is able to function fully but needs help getting dressed or using the restroom.

Further, Medicare only covers a nursing home stay if the stay was preceded by an inpatient hospital admission of at least three consecutive days.³ This requirement is increasingly difficult to satisfy as many hospital stays are now characterized as "outpatient" observation status rather than inpatient admission, unfairly further limiting the Medicare benefit for skilled nursing facility care.

For individuals who can access home care, Medicare requires them to be "homebound," meaning s/he has a general inability to leave home without assistance, or only leaves occasionally for certain specified reasons. This is a very high bar with many people excluded, such as an individuals who who may require assistance with tasks that take a long time to accomplish but who can otherwise leave their house on their own accord.

Because of the stringent assessment process and required approval from a provider, people are unable to obtain the care they need through Medicare on a long-term basis. Further, no coverage is available for homemaker services or for personal care services, such as those that support activities of daily living like bathing, dressing, and eating, unless the person also requires nursing, speech, or ongoing occupational therapy.

³ <https://www.medicare.gov/Pubs/pdf/10153.pdf>



#2: Medicaid's Bias Toward Institutional Care

Medicaid is the nation's largest publicly-financed payer of long-term services and supports. It is administered by states within established federal standards and is financed jointly by states and the federal government.

Medicaid covers both medical care and long-term services and supports for millions of Americans of all ages below a certain income threshold. To qualify for Medicaid, participants have to meet very low income eligibility standards. In addition to income eligibility, people's assets cannot exceed set thresholds. This often means that people have to "spend down" their assets to less than \$2000 to qualify for the benefits they need. Caps to income eligibility also mean that people able to work are discouraged from doing so without disruption to services. Seniors are sometimes forced to sell their homes and avoid meaningful work to access the support they need.

Nursing home care is a mandatory service all states are required to offer while home and community-based services and supports are optional. Despite proven savings when Medicaid dollars are applied to home and community-based care, the program maintains a long-standing bias toward institutional care such as nursing homes.⁴ As the Baby Boomer generation gets older and the demand for long-term services and supports increases, states are seeing an increase in their Medicaid expenditures because many people who need care have no other affordable options except Medicaid. States have numerous options for funding Medicaid home and community-based services under the Affordable Care Act.

A rapidly aging population in need of home and community-based services without affordable options will only have Medicaid as their option, continuing to increase Medicaid expenditures at the state level. Eventually, states will have to reform their care systems in a way that infuses new money into programs to make care more affordable while expanding the services offered.

#3: The Limits of Private Long-Term Care Insurance

Private long-term care insurance has existed for over three decades. The market for this product is very small and continues to shrink as premiums rise and people find it too expensive, and providers withdraw and people find the benefits that remain available not comprehensive enough. The cost of long-term private insurance coverage is often unaffordable, especially for individuals with limited or fixed

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<http://kff.org/medicaid/fact-sheet/medicaid-long-term-services-and-supports-an-overview-of-funding-authorities/>



incomes. According to the American Association for Long Term Care Insurance 2016 Long Term Care Insurance Price Index⁵, a policy offering a basic benefit level starts at about \$960 a year, or \$80 a month. If more care is needed, the plan will need to be supplemented by savings and income. Additionally, insurance benefits are time-limited, which requires people to estimate the amount of time they will need long-term services and supports in the future.

Given these high costs and limitations, only 16 percent of those 65 and over, and who are ineligible for Medicaid and can afford a private plan, actually have long-term care insurance.⁶ Participation in private long-term care is even lower - only about 5 percent - for individuals aged 45 to 64.⁷ Because of the low purchase rate and the challenges in underwriting anticipated care needs and costs, many insurers are offering fewer and fewer plans or leaving the market altogether. Tom McInerney, president and chief executive officer at Genworth, the nation's largest seller of long-term care insurance and one of the few companies still left in the market, stated that the rising costs of LTC is the "new normal" and it is one of the nation's biggest societal issues that must be addressed.⁸

⁵ <http://www.aaltci.org/news/wp-content/uploads/2016/02/2016-Price-Index-LTC.pdf>

⁶ http://www.naic.org/documents/cipr_current_study_160519_ltc_insurance.pdf

⁷ <https://aspe.hhs.gov/basic-report/economic-impact-long-term-care-individuals>

⁸

<http://newsroom.genworth.com/2016-05-10-Genworth-2016-Annual-Cost-of-Care-Study-Costs-Continue-to-Rise-Particularly-for-Services-in-Home>



The Need for LTSS

- In 2015, 47.7 million Americans were age 65 and older. Half of those had less than \$22,887 in yearly income from all sources. In 2015, _____ received less than \$38,515 in yearly income from all sources.⁹
- Although the level of need may vary, 50% of people who reach the age of 65 will require a high level of LTSS.¹⁰ 19% of older adults will need this level of care for one year while 14% will need this level of care for five or more years.¹¹
- Nursing homes can cost almost \$7,700 a month. While cheaper than nursing home services, home care costs of more than \$3,000 a month are still a heavy toll for many families.¹² These expenses are paid for in various ways but individuals and their families pay for about 53 percent of their total LTSS expenditures out-of-pocket.¹³
- ¾ of older adults with long-term care needs live at and home.¹⁴
- The bulk of the provision of day-to-day long-term services and supports is falling on family members through a patchwork of unpaid, uncompensated care. According to AARP, family caregivers are providing upwards of \$470 billion worth of unpaid services to family members.¹⁵

⁹ <http://www.pensionrights.org/publications/statistic/income-today's-older-adults>

¹⁰ Favreault, M. M., & Dey, J. (2015). Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief. Retrieved _____ from <https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief>

¹¹ http://www.thescanfoundation.org/sites/default/files/lctf_recommendations_side-by-side_feb_2016.pdf

¹² <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

¹³ <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

¹⁴ Freedman, V. A., & Spillman, B. C. (2014). Disability and Care Needs Among Older Americans. *The Milbank Quarterly*, 92(3), 509-541.

¹⁵ AARP, _____, 2015, and PHI, _____, 2013.



Falling Through the Cracks: Caregivers and the Middle Class

Under the current system, individuals and families who are not poor enough to qualify for Medicaid but not wealthy enough to afford to pay for care out-of-pocket are especially vulnerable. Public programs are calling for families to spend down their assets and savings on one end, and private insurance benefits are increasingly out of reach on the other. This patchwork system, oscillating between impoverishment and unaffordable, inflexible benefits, leaves many individuals and families in crisis and with mounting unmet needs.

Along with the troubling income requirements, Medicaid's long-term care services and supports do little to offer supports for family caregivers. Medicaid services differ state to state, and even county by county. Very few Medicaid programs offer training or respite for the family caregiver, and even fewer programs offer income replacement to offset lost wages.

On average, family caregivers report spending more than 24 hours a week providing care, and nearly a quarter provide more than 40 hours of care per week.¹⁶ Nearly two thirds of workers between the ages of 45 and 74 are also caring for an aging spouse or parent or relative.¹⁷ More and more people, mostly women but a growing number of men, are working, caring for a child, and caring for aging parents. Annually, family caregivers contribute an estimated \$470 billion worth of unpaid labor and value to our economy.

¹⁶ AARP PPI and National Alliance for Caregiving, _____, 2015.

¹⁷ <http://www.aarp.org/content/dam/aarp/ppi/2014-10/family-caregivers-workplace-fact-sheet-aarp.pdf>



The Squeeze on Family and Professional Caregivers

- Unpaid family caregivers and home care workers are the backbone of in-home, long-term services and supports, but they face serious challenges.
- Nearly ¾ of older adults with long-term care needs living at home receive all help from unpaid family and friends.¹⁸ The demands of family caregiving can impact health and disrupt one's ability to work, leading to poor health outcomes and a lack of income and retirement security for caregivers.
- Many family caregivers have to reduce work hours or leave their job to provide care. In fact, 19% of people quit their job earlier than planned while 68% of caregivers report making work adjustments such as arriving late or early, taking time off, changing jobs, turning down a promotion, or cutting back on work hours to care for a loved one¹⁹.
- Despite increasing demand, home care workers have seen stagnant hourly wages, \$10.21 in 2005 to \$10.11 in 2015.²⁰ This, plus minimal, if any, benefits, and challenging scheduling and working conditions, leads to alarming turnover rates that are costing the industry nearly \$6 billion annually.²¹
- Over 50 percent of home health care workers rely on public assistance, such as food stamps, Medicaid or cash assistance.²²

¹⁸ Freedman, V. A., & Spillman, B. C. (2014). Disability and Care Needs Among Older Americans. *The Milbank Quarterly*, 92(3), 509-541.

¹⁹

http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf

²⁰ <http://phinational.org/home-care-workers-key-facts>

²¹ PHI, _____, February 2015.

²² Ibid.



The ratio of family caregivers to older adults is also on a sharp decline. In 2010, the ratio was more than seven potential caregivers to every one person in the high-risk, 80-plus years age group. In 15 years, that ratio will shrink to be four to one, and by 2050, it is expected to be only three to one.²³ The lack of systemic support and training for family caregivers further adds to the burden they are already bearing.

Some progress is starting to assist and support family caregivers. For example, 33 states including DC have passed the CARE Act, which tracks family caregivers, informs them of status changes of their loved ones, and provides them in-home trainings of any medically related tasks they have to perform. **But as the availability of family caregivers declines, we must rely even more on the home care workforce** Progress on the affordability front for families to access this additional care is sorely limited, while serious systemic challenges stand in the way of caring, skilled workers choosing to stay in the profession.

Home care workers provide 70 to 80 percent of all paid, direct care. Aging at home would be impossible for millions of older adults without the combined work of family and paid caregivers.²⁴ The workforce, however, suffers especially under both Medicaid and Medicare when inadequate funding and reimbursements and the lack of wage pass-throughs undermine the quality of their jobs.

Making home care jobs quality jobs will be necessary to retain and recruit the workforce needed to allow people to remain at home. Creating a \$15 an hour wage floor and ensuring workers benefits, regular hours, good working conditions, and opportunities for advancement could attract the more than 600,000 home care workers needed by 2024.²⁵ This workforce is needed to meet the growing demand for home and community-based care, as well as to support family caregivers.

In states with an organized workforce, unionized care workers have fought for and won higher standards, including wages and benefits. Along with traditional worker organizing, Caring Across Generations and partners such as the National Domestic Workers Alliance and SEIU's Fight for \$15 movement have pushed for policies that improve labor protections, increase home care funding and raise wages.²⁶

Improving the quality of these jobs has also improved the continuity of care. For example, when San Francisco enacted a living wage requirement for home care workers, worker turnover dropped by 57 percent.²⁷ To forge a long-term services

²³ AARP Public Policy Institute, _____, 2013.

²⁴ Ibid.

²⁵ National Employment Law Project (NELP), _____, 2015 and PHI, _____, February 2015.

²⁶ NELP, _____, 2015.

²⁷ Howes, Candace, _____, Industrial Relations Journal, 2005.



and supports system that meets the needs of all Americans, we must create wage and labor standards that ensure there is a strong, adequately sized workforce available to meet the growing demand for care.

The Rising Cost of Care

Annually 8.3 million people receive support from five primary types of long-term care providers: home health agencies, nursing homes, hospices, residential care communities, and adult day service centers.²⁸ In envisioning a more effective system that meets the needs of seniors, people with disabilities, their families, care workers, and our communities, we must take into consideration the enormous current costs of our care system. This includes the costs of care paid by families, insurers, and the public sector:

- Home care can cost \$46,332 a year while nursing home care can cost \$92,378²⁹.
- These expenses are paid for in various ways, but individuals and their families pay for about 53 percent of their total LTSS expenditures out-of-pocket.³⁰
- Medicare spending grew 5.5% to \$618.7 billion in 2014, while Medicaid spending grew 11.0% to \$495.8 billion.³¹
- Between 2002 and 2012, private-pay prices for a private or semiprivate room in a nursing home grew by an average of 4.0% and 4.5%, respectively, per year.
- By comparison, growth in the average wage of a home health aide—a proxy for the price of community-based care—grew by less than 2 percent per year.³²

²⁸ http://www.cdc.gov/nchs/data/nsltcp/long_term_care_services_2013.pdf

²⁹ <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

³⁰ Ibid.

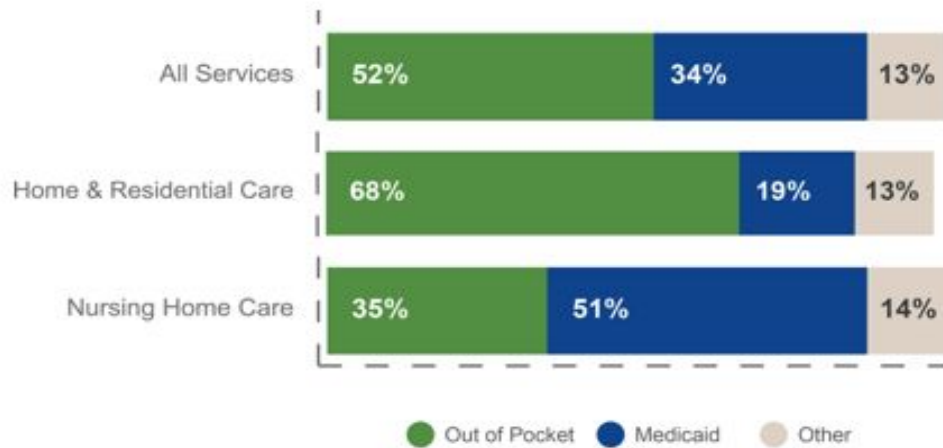
³¹

<https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/nationalhealthexpenddata/nhe-fact-sheet.html>

³² <https://www.cbo.gov/sites/default/files/113th-congress-2013-2014/reports/44363-LTC.pdf>



Medicaid & Out of Pocket Cover Most Lifetime Average LTC Spending



The costs of care, and the costs of a system filled with gaps and inequity, do not stop with direct costs:

- According to AARP, family caregivers are providing upwards of \$470 billion worth of unpaid services to family members.³³
- Often missing from the policy discussion around LTSS are the lost wages of caregivers due to caregiving responsibilities, including the long-term impact on their future Social Security benefits due to depressed income.
- In addition, businesses lose an estimated \$33.6 billion nationally each year due to family caregivers reduced paid working hours and household spending in order to support the long-term care needs of their loved ones.³⁴

As we develop a new system of care that addresses needs more systemically, more equitably, and with less strain on families, we must start by acknowledging the full costs of the current system and the inadequate outcomes it is yielding. The current system is falling woefully short of creating peace of mind and a better life for all stakeholders - individuals, families, and the workforce. We have to consider new ways to finance a 21st century system of care under principles that ensure protections for all of these stakeholders, and which can remain relevant and sustainable as more people live longer.

³³

<http://www.aarp.org/about-aarp/press-center/info-07-2015/family-caregivers-provide-470-billion-in-unpaid-care-aarp-study.html>

³⁴ <https://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>



Our Recommendation: A New Universal, State-Based LTSS Benefit

As the nation's population ages, it is clear that the current landscape of splintered long-term care coverage will leave many families at risk. At the federal level, significant reforms to improve access to affordable long-term care have largely stalled. Foundational programs like the Programs for All-Inclusive Care for the Elderly (PACE) and the lifespan respite care program remain underfunded. The Community Living Assistance Services and Supports (CLASS) Act would have established a public long-term care insurance option as a provision through the Affordable Care Act, but the provision was repealed in 2013. Meanwhile states continue to be on the frontlines of dealing with their populations' growing LTSS needs.

The good news is states do not have to stand by idly. Within their full legal authority, states can provide the solutions people need and implement models the federal government can learn from.

Caring Across Generations recommends the creation of a state-level, public long-term services and supports benefit accessible to all who need it as a proactive way to improve access to affordable long-term care. This new benefit must be accessible to all individuals and families, regardless of income, and be administered by the state government. A new program that meets a set of minimum requirements would protect individuals and families from the risk and cost of long-term care while increasing access to desired home and community-based services. Innovation and actions to establish programs at the state level could also yield invaluable learnings and build momentum for an eventual federal solution. The key issues to be considered in the design and implementation of such a state-level benefit are:

- Potential impact
- Benefits floor
- Program structure



Potential Impact: Addressing Need and Affordability

States are on the frontlines of dealing with their population's long-term care needs. With the estimated cost of home and community-based services averaging \$46,332, families need a safety net and support to afford the care they need.³⁵

The table on the next page shows the number of uninsured individuals between the ages of 50 and 64 in select states where Caring Across has had an active on-the-ground presence through its network of field partners, with the exception of Florida³⁶. While we know that this population's need for long-term care is significantly less than those in older age brackets, this is the very population that we rely on to be family caregivers³⁷. The table also shows the number of people 65 years and older who would likely benefit from increased access to affordable long-term care. These numbers combined begin to paint the picture of those who need increased support in order to access affordable care.

³⁵ <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

³⁶ Florida was added because of its significant aging population.

³⁷ <https://www.caregiver.org/caregiver-statistics-demographics>



CARING ACROSS GENERATIONS
PREPARING FOR THE ELDER BOOM: A FRAMEWORK FOR STATE SOLUTIONS

State	Annual Cost of Care ³⁸		Average Household Income ³⁹	Total adult population over age 50 ⁴⁰	Number of people 50-64 with NO insurance ⁴¹	Number of people 65+ likely to need care ⁴²	Households containing at least 1 person over 60 ⁴³
	a. Homecare	b. Nursing Home Care					
NY	a. \$52,624 b. \$135,963		\$58,005	6,931,795	506,137	80,562	2,615,000
WA	a. \$56,834 b. \$107,675		\$67,243	2,450,889	151,469	425,598	844,000
ME	a. \$54,340 b. \$108,223		\$50,756	564,557	30,016	198,137	208,000
OR	a. \$52,624 b. \$107,310		\$60,834	1,468,497	110,362	27,611	535,000
MN	a. \$59,488 b. \$97,032		\$68,730	1,928,994	73,370	171,839	656,000
IL	a. \$50,336 b. \$74,825		\$60,413	4,376,488	316,958	86,345	1,596,000
MO	a. \$43,472 b. \$63,171		\$59,196	2,191,297	138,157	104,083	807,000
CO	a. \$54,912 b. \$97,546		\$66,596	1,762,695	117,341	317,633	576,000
MI	a. \$48,048 b. \$98,185		\$54,203	3,676,969	228,935	171,047	3,872,510
UT	a. \$48,048 b. \$76,650		\$66,258	746,199	42,716	73,940	877,690
NC	c. \$41,184 d. \$89,425		\$50,797	3,486,076	264,142	34,504	3,745,160
FL	e. \$45,188 f. \$100,375		\$48,825	8,034,792	734,263	116,161	7,420,810

³⁸ <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

³⁹ <https://www.census.gov/>

⁴⁰ <https://www.census.gov/>

⁴¹

http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/Health-Insurance-Coverage-for-50-64-year-olds-insight-AARP-ppi-health.pdf

⁴² Average life expectancy is 79. We know that 70% of people over the age of 65 will need an average of 3 years of care. Of the 14 years of expected life between 65 and 79 years of age, 3 years of care is about 21%. We took 70% of the total population of those over 65 years old and multiplied that number by 21% to get the average annual population that would utilize the program.

⁴³ <https://suburbanstats.org> (We rounded down for a more conservative number.)



Many families are living in multiple-generational households with an aging loved one who likely needs care. Providing additional support through a statewide program goes beyond helping individuals; it impacts entire households who are managing complex care dynamics.

Costs to consumers and family caregivers are ballooning, making care increasingly unaffordable for many individuals and their families. Rising costs also drive further costs to system stakeholders in the public and private sectors, and to the economy overall. Institutional care is sometimes the only option but a quiltwork of informal and formal home care is much cheaper for many families as a way of meeting the desire of their loved one to age and heal at home.

While cheaper than nursing home services, home care costs are still a heavy toll for many families.⁴⁴ In a 2007 report, caregivers reported spending an average of \$5,531 annually. This average saw long-distance caregivers spending \$8,728, co-resident caregivers spending \$5,885, and those who cared for someone nearby spending \$4,570. Others spent upwards of \$10,000 out-of-pocket⁴⁵.

This does not take into account the growing number of multiple-generation households who are likely paying for both childcare (averages close to \$10,000 per year⁴⁶) and care for a loved one such as an aging or sick spouse or parent. The cost of wages and even combined household income is not increasing at the same rate as the rising costs of care. Additionally, the cost to employers in lost productivity and additional resources need to supplement or replace family caregivers leaving the workforce is over \$33 billion annually⁴⁷.

⁴⁴ <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

⁴⁵ National Alliance for Caregiving & Evercare, 2007

⁴⁶ <https://www.newamerica.org/in-depth/care-report/introduction/>

⁴⁷

http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf



Benefits Floor

All benefits must be sufficient in amount, duration, and scope to achieve the best outcomes and supports for individuals and their families.

- **A statewide universal program should be accessible to all state residents regardless of income.** Income should only be considered if there is a need to set benefit levels and if the state-level program being considered requires everyone to share in some of the cost. In these situations, cost-sharing measures should be developed in a way that exempts all individuals under the federal poverty level and considers cost protections for middle-income individuals.
- **A taskforce of diverse stakeholder table of experts, service providers, consumers, workers, family caregivers, and policymakers should be created and engaged in establishing a new benefit program.** This task-force ensures that the voices of all impacted are a critical part of developing a program that works for everyone. Responsibilities could include establishing minimum benefit and setting minimum standards for providers and services. Wherever possible, existing grassroots coalition tables should be utilized as a starting place.
- Because Medicaid will be the primary payer, where applicable, **states could consider sliding-scale levels of benefits based on income and already existing access to other programs.** This benefit should be available to all regardless of their current access to public programs. Any program that requires broad cost sharing should cap out-of-pocket contributions for low and middle-income individuals and families.
- **In individual situations where Medicaid is not the primary payer, Caring Across Generations recommends a benefit of no less than \$2,200 a month,** equivalent to the top range of home and community-based allowance offered through Medicaid's assessment of costs of care, unless there is clear evidence that the cost of needed care is less. States should make incremental annual increases that take inflation into account without compromising benefits and the solvency of the program.
- **There should be no lifetime caps.** People should be able to get support for the care they need when they need for the needed length of time.



- **Anyone needing care for more than one activity of daily living (ADLs), or instrumental activities of daily living (IADLs), or a minimum of two hours of care a day should be eligible.** Eligible individuals must have contributed to the program for a period of time to be determined by the state based on solvency and sustainability of the program.
- To truly meet the needs of individuals and families, **a new program must offer eligible individuals the option of a flexible cash benefit or the option of paying directly for services.** Benefits cannot be taxable and cannot be claimed as income.
- **A new program must offer the option of consumer-directed care model or agency-based care.** In consumer-directed care, individuals are more hands-on and have more flexibility, choice, and responsibility in their care, including the choice to hire, train, and fire a worker of their choice. In agency-based care, all of those responsibilities fall on a home care agency.
- **A new state program must establish consumer protections.** Caring Across Generations recommends that the program include a matching dollar-for-dollar protection of assets from Medicaid for the amount contributed to the program if a state program requires individuals to contribute. This would mean that the amount of money that an individual contributes to this new benefit program would be protected from the spend-down requirement if an individual ever has to access Medicaid. Additionally, the program administrator must offer program applicants a list of recommended providers and services based on those who meet minimum standards.
- **Costs and benefits must take into account the imperative to pay the care workforce a living wage.** In fact, providers must adhere to workforce standards set by stakeholders in order to receive payments from this program.
- **Every state should include a workforce development plan that addresses the recruitment and retention of the home care workforce.** These requirements should address training, wages, and benefits and other ways to improve the quality of homecare jobs. Without improving job quality, this workforce will continue to experience high turnover and insufficient numbers of needed workers.

The development of a statewide long-term care benefits program should also consider the existing disparities of access to care among a state's population. Those disparities will raise many intersectional issues including unemployment, poverty,



rural access to care, workforce development, and other challenges specific to the most underserved populations. Intentionality in addressing inequity and health care disparities will ensure the most comprehensive approach to developing a benefit program.

Benefit Interaction With Other Public Programs

This new benefit should have no effect on eligibility for Medicaid, Medicare, Social Security, Disability or any other public benefits. Benefits under a new program will be used to supplement other public benefits. States should consider multiple benefit levels based on other program eligibility and benefits. This benefit should be structured to fill the gaps for those experiencing unmet needs in spite of access to public assistance programs and for those who make too much to qualify for public programs but yet are burdened with the out-of-pocket costs of care. States should not require benefits under this program to be claimed as income or to be taxable.

Program Structure

Caring Across Generations recommends one of two⁴⁸ structures for this new benefit program.

1. States can establish an interest yielding long-term care benefits fund. Under this recommendation, all revenue would be placed in this fund to finance the program; or
2. States can establish this program as a new eligibility group within the state Medicaid system where participants at higher incomes qualify for benefits. In addition to what states contribute, states can take full advantage of the federal matching funds offered to state Medicaid programs, plus the infusion of added funds from participant contribution.

⁴⁸ Some states may already have an existing program that if strengthened, expanded, and funded with a dedicated revenue stream could be the appropriate vehicle for a statewide universal program.



Financing Recommendations for a New State-Based LTSS Benefit

In developing a new statewide benefit for long-term services and supports, the private and public sectors must play a role in increasing access, mitigating costs and spreading risk. The startling reality that quality care is out of reach for so many individuals and families requires a new approach to supporting access to care and financing care in a way that relieves some burden on working families. Our nation needs to invest significant revenue into a new care infrastructure - one that not only works for individuals, families, workers, and state governments, but one that is paid for, affordable, and sustainable.

States need a dedicated revenue source while participants need cost-sharing protections to ensure their contribution does not become too expensive for them to access care. Every state is different in the levers they can pull to produce revenue. What may be a suitable option in New York may not be a suitable option in Maine. While we cannot prescribe a uniform financing mechanism to finance a new program, we can recommend a framework of principles that will lead to financing that is not harmful to consumers, families and workers.



Caring Across Generations makes the following recommendations as principles for financing a statewide LTSS benefit:

- Paying for care must be a shared responsibility that includes government financing options;
- Developing new revenue must be done fairly without shifting an unequal amount of costs to families who already cannot afford care;
- New revenue must be progressive, i.e. not burdening people in lower income brackets more than in higher ones;
- Controlling costs must not come at the expense of needed services, quality of care, or the workforce;
- Costs must consider the individuals who need care and their informal caregiving network and must have cost-sharing policies to ensure affordable health services;
- Program design must take into account the imperative to pay the care workforce a living wage;
- Benefits obtained must not compromise other public benefits and should not be counted as income;
- Any new program must be sustainable.

The issue of financing the care infrastructure we need has been elusive at the national level. However, states are poised not only to offer a comprehensive and meaningful benefit, but to explore options that offer fully financing a sustainable expansion to affordable long-term care. There are a number of mechanisms from which to raise revenue for a public LTC benefit that states should consider.

1. Progressive Taxation

The most basic tenet of progressive taxation calls for those who are most well off to pay a greater share than others. A tax that imposes an equal tax rate regardless of relative income or wealth or imposes a higher rate on the poor is considered regressive. To fund programs of social uplift, progressive taxation is more equitable as it asks those most able to pay to help support those least able to pay. It is also a more popular option, according to polling aggregated by Americans for Tax Fairness.

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<http://www.americansfortaxfairness.org/files/5.22.15-ATF-Polling-Questions-on-Tax-Fairness-Issues-UPDATED-V2.pdf>



Progressive taxes tend to tax income, while regressive taxes tend to tax consumption. Progressive taxes include personal income taxes as well as corporate income taxes, estate taxes, inheritance taxes, and capital gains taxes. Regressive taxes include sales taxes, including sales taxes imposed at the business level, like property taxes and payroll taxes. So-called “sin taxes” like taxes on cigarettes, alcohol, soda, and the lottery are all regressive as they impose a higher marginal tax on the poor than the wealthy. There are a few exceptions to this rule, which we discuss below.

States impose a combination of these taxes to generate revenue for their state budget and no two states are identical in how they go about doing it. Each forgoes some and leans heavily on others, but one way or another, they all generate revenue.

2. Taxing Estates and Inheritances

The federal estate tax is a hundred-year-old levy on the wealthiest households in society. Sometimes referred to as the “Paris Hilton Tax,” it is a check on the intergenerational concentration of wealth and is designed to both generate revenue as well as break up wealth dynasties.

The three important characteristics when considering an estate tax are the rate(s), the exemption levels, and the propensity for loopholes. The rate is the nominal rate of the tax, which is currently a flat 40 percent at the federal level and about 16 to 20 percent for states. The exemption is the amount of money an estate can hold before being taxed. At the federal level the exemption is about \$5.5 million for an individual or \$11 million for a married couple, while at the state level, exemptions range from \$675,000 up to the equivalent of the federal level.⁵⁰ Loopholes in the tax code, including creating complex trusts, can mitigate the impact of the estate tax.

States have historically benefitted tremendously from the federal estate tax as a result of a state estate tax credit, which distributed a significant portion of estate tax revenue directly to states. Unfortunately, this credit was eliminated by the Bush tax cuts passed in 2001 and phased out over four years through 2005. Since that time, many states have lost their estate tax. According to a new report from Elizabeth McNichol at the Center on Budget and Policy Priorities, only 18 states plus the District of Columbia now have a tax on estates or inheritances. Her report,

⁵⁰ <http://taxfoundation.org/blog/does-your-state-have-estate-or-inheritance-tax-0>



, provides significant background on the estate tax that is worth reading when considering a new tax initiative.⁵¹

Table 1 shows the potential for increasing revenue in target states, adapted from McNichol’s report. Also bear in mind that for states with existing estate taxes, adjustments can be made to exemption levels or rates to increase revenue. Studies show that differences in tax levels among states have little to no effect on whether and where people move. As such, considering the revenue will support services that make a state an attractive place to do business and live, it will help, not harm, a state’s economy.⁵²

Table 1. How Much Revenue Would Reinstating an Estate Tax Raise?⁵³
 Estimated Annual Collections (millions)

State	\$1 million exemption	\$3.5 million exemption	\$5.45 million exemption
CO	110	70	60
ME	Has tax	Has tax	Has tax
MA	Has tax	Has tax	Has tax
MI	240	140	130
MN	Has tax	Has tax	Has tax
MO	20	10	10
NY	Has tax	Has tax	Has tax
NC	170	100	100
OH	320	190	180
UT	40	20	20
WA	Has tax	Has tax	Has tax

⁵¹

http://www.cbpp.org/research/state-budget-and-tax/state-estate-taxes-a-key-tool-for-broad-prosperity?utm_source=CBPP+Email+Updates&utm_campaign=ca353b6f2a-5_11_16_StateEstateTaxPaper_General5_11_2016&utm_medium=email&utm_term=0_ee3f6da374-ca353b6f2a-43383205

⁵² <http://www.cbpp.org/sites/default/files/atoms/files/5-11-16sfp.pdf>

⁵³ <http://www.cbpp.org/research/state-budget-and-tax/state-estate-taxes-a-key-tool-for-broad-prosperity>



3. Carried Interest Loophole

Another potential that does not require raising tax rates is closing the carried interest loophole. The carried interest loophole enables hedge fund managers and private equity firms to claim their income as capital gains and thus be taxed at a significantly lower rate.

While carried interest has been the subject of much debate at the federal level, it has not yet generated significant interest from states. The HedgeClippers issued a report on the topic titled, “Closing Wall Street’s Lucrative Loophole: How States Can Raise Billions by Taxing Carried Interest.”⁵⁴ Their graphic below shows the impact carried interest can have in a handful of states.



Source: <http://hedgeclippers.org/wp-content/uploads/2016/03/0306-Carried-Interest.pdf>

⁵⁴ <http://hedgeclippers.org/wp-content/uploads/2016/03/0306-Carried-Interest.pdf>



4. Luxury Consumption and Real Estate Taxation

While most consumption taxes are regressive, there are progressive consumption taxes that are aimed at the profligate consumption of the wealthy. For example, the State of New Jersey has a “Luxury and Fuel Inefficient Vehicle Surcharge” that taxes new vehicles priced over \$45,000 with low mileage.⁵⁵ States could levy consumption taxes on private jet use, luxury goods such as jewelry and electronics over a certain price, or yachts and large scale recreational boats. Real estate taxes could also be structured to have graduated rates for assessments over several million dollars.

5. Reallocating Civil Money Penalty

Civil money penalty is a fine which penalizes a violating entity for misconduct and/or illegal and unethical actions. The fee is often preset by the state and, at times, is equal to the profit made by the misconduct. In many states, civil money penalties are assessed on nursing homes, hospitals, and various businesses and industries. Civil money penalties collected by the state can be reallocated to programs aimed at improving access to affordable care options. For example, civil money penalties gathered from nursing home facilities in violation of state laws can be applied to a new statewide benefit to increase access to affordable home and community-based services.

6. Other Revenue Considerations

Other options exist for raising revenue beyond the aforementioned. Changing income tax rates, corporate tax rates, or state capital gains taxes all have potential. However, focus on taxing estates and on loopholes that only benefit the wealthy are perhaps uncharted territory and could be a useful financing option for a similarly new idea like universal long-term care.

Additionally, each state will have its own idiosyncrasies regarding increasing revenue. Colorado is subject to the Taxpayer Bill of Rights (TABOR) that puts

⁵⁵ <http://www.nj.gov/treasury/revenue/njbgs/luxvehs.shtml>



numerous onerous restrictions on increasing taxes, notably that it must be done at the ballot, in an odd-numbered year.⁵⁶

State constitutions play a serious role as well. Massachusetts has a constitutionally mandated flat income tax, which makes raising a progressive income tax impossible without a constitutional amendment. The last attempt to increase progressive income tax occurred in 1994 and it will be on the ballot in 2018 and polls very high.⁵⁷ Every state considering the implementation of a new statewide universal long-term services and supports benefit should conduct a review of existing tax loopholes. A review like this could reveal opportunities to general needed program revenue.

⁵⁶ <http://www.bellpolicy.org/basic/colorados-tabor>

⁵⁷ <http://www.cltg.org/cltg/clt2015/15-09-03.htm>



Where State Reform Meets Private and Federal Reform

Curbing costs of long-term services and supports while increasing access to the more affordable option of home and community-based services will be critical in how states address their care needs moving forward. Any public universal solution should also include some new reforms to the private insurance marketplace to provide competitive alternatives. Some states have considered catastrophic coverage or front-end coverage options. Caring Across Generations believes that the risk pool at the state level is not large enough to make this program affordable for consumers or sustainable for state governments.

Lastly, we must address the role of Medicaid. We know Medicaid is the primary payer of long-term services and supports. While states are concerned about the growing budget expense of Medicaid, Medicaid offers flexibility under state authority to increase coverage to long-term services and supports and home and community-based services. Some states, through program waivers, have conducted small experiments and created initiatives to address some of the core issues surrounding access to affordable long-term care. These experiments have garnered lots of lessons, data, and information for states and the federal government to learn from.

States should continue to explore Medicaid flexibility as a way to cover more people. The Medicaid buy-in program identified in our recommendations is a robust way of building on an existing program to address current state long-term care services and supports needs, including the desire for home-based care, while protecting participants from spending down into poverty. Additionally, states must take on the full expansion of Medicaid afforded to them under the Affordable Care Act.



The Role of Federal Government

To ensure that all Americans have access to the care they need, the federal government must play an instrumental role in shaping the care model and participate in its financing. The federal government should provide clear and strong leadership in addressing the looming crisis our nation faces with long-term care. The federal government serves as a policymaker, regulator, financier, purchaser, provider, researcher, administrator, standard-bearer and negotiator of health care.

The federal government has made attempts in the past to reform the nation's long-term care system. The most recent example, noted earlier, is the Community Living Assistance Services and Supports Act, or CLASS Act. CLASS was a provision in the Affordable Care Act aimed at addressing the growing need for long-term care. CLASS would have created a voluntary and public long-term care option for employees and included a five-year vesting period for a lifetime benefit. Any working adult needing assistance with two or more ADLs would be eligible for a cash benefit of up to \$75 a day. The benefit would be subject to increase with future costs of long-term care. Students and people with low-income would have discounted premiums. Participants would have paid a monthly premium through a payroll deduction.

Despite the estimated \$2 billion savings to Medicaid spending, the CLASS Act was repealed in January 2013. A major lesson learned from analyses of the CLASS Act proposal was that any successful program must be compulsory as a way to spread risk and share costs. Currently, there are many piecemeal initiatives to address various degrees of the challenges people are facing with long-term care.

The challenges of cost, quality, access, and adequate workforce stability will ultimately require federal intervention. For truly sustainable and inclusive long-term care, we will need a federal response that is committed to strengthening existing safety nets, building on what states have learned and will learn, and thinking in new and innovative ways. Regardless of state progress, federal intervention to set minimum standards of care, increase quality and affordability, address service and payment delivery, while recruiting, retaining, and improving the conditions of the care workforce is necessary. However, in the absence of the federal government taking action, change seems most feasible at the state level in a timeframe needed to alleviate the burden of affordable care on individuals and their families.



Conclusion

The current tapestry of care is diverse and complex. Families often are responsible for caring not only for young children, but also for aging parents. Young adults are finishing school, planning for careers, and looking at the promise of their future with little acknowledgement of their future need for long-term care, or the likelihood of the care they may have to provide for their own aging parents. Many adults do not or cannot prioritize saving, let alone invest in long-term care insurance when faced with other competing family financial priorities. These complexities combined with our nation's changing demographics will only continue to put increased pressure on our existing system and safety nets, while people currently in need don't have access to necessary care.

The current system is placing especially heavy burdens on middle class families who do not qualify for Medicaid. Public financing for care is inadequate and heavily biased toward institutional care, precluding the majority of Americans' desire to live, age, and heal at home and in their community for as long as possible. Not only do the demographic changes place increased pressure on the system, people currently in need do not have uniform access to the care they need. And the expectation that families should shoulder the sole burden of cost is unreasonable, unfair, and a serious threat to our economy's strength and future growth.

Recent cuts to Medicaid reimbursements, often brought on by budgetary pressures, are a reminder of the uncertainty and fragility of means-tested programs. The need for costly long-term care is a life risk for everyone, with increased chances of encountering the need for care as we enjoy longer lives. While 65 is the age to access Medicare, Medicare does not meet the full scope of needs and presents challenges in accessing home and community-based services and supports. Additionally, a robust skilled workforce is necessary to meet the growing demand.

While a federal solution is most desirable, states have the opportunity now to develop comprehensive solutions to address their state's long-term care needs. Caring Across Generations encourages states to take immediate action in leading a stakeholder process to thoughtfully identify the needs and priorities of its populations' long-term care needs. States should lead statewide research that includes an economic and feasibility study focusing on our outlined recommendations to expand access to affordable care. States must explore the design, financing, and administration of LTSS benefits that will not compromise a state's constitutional obligations. States should use their authority, with our



recommendations as a guide, and move promptly with the necessary stakeholders, including state agency experts, to advance the necessary legislation and implement plans to have an immediate impact on people's lives. States must also design a benefits program that offers sustainable financing without harming or further burdening the very people intended to benefit from the program.

Long-term care planning and coverage would mean families don't have to struggle when a need for care arises. States have the opportunity and the authority to get ahead of a looming crisis. Investing in a sustainable caregiving infrastructure for all generations of our families is a historic opportunity - and supporting how we care for our aging population will be a critical component of this. By investing in care, we can make sure we do not drive more families into poverty. And we can make it more possible for all of us to live well and be there for the people we love.



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