

heavy hearts



The piecemeal long-term services & supports financing system, its impacts on Washington families, & the road to a sustainable future



June 2016

One Caregiver's Story

There are an estimated 850,000 Washingtonians who are doing their best to provide care to an aging loved one. They are the backbone of Washington's long-term services and supports system. It is a precariously-financed system that is unsustainable for seniors, their families, and Washington State.

Like so many other women in the "Sandwich Generation" Carrie Lange of Kent, Washington is the backbone of her family: mother, wife, and daughter. Carrie was employed as an insurance agent, but in 2015 after her mother Jocelyn's bouts with falls and memory loss led to multiple hospital stays, Carrie added full-time adult caregiver to her duties. Jocelyn moved from Indiana to Washington and now Carrie shares her home with her husband, two teens, and her mom.

Jocelyn and her husband are both retired school teachers with pensions and Social Security; it was enough for the couple to live on, but not at all close to what they'd need to cover paid long-term services and supports for Jocelyn. When Jocelyn was diagnosed with Alzheimer's in 2015, her children dedicated part of their future inheritance from their parents into a separate account for any possible long-term services and supports expenses that Jocelyn might incur, but given the high cost of care the account only has enough funds to cover 3-4 months of paid care. Carrie and her family have also spent thousands of dollars of their own money to cover miscellaneous care expenses as well as her mother's co-pays for an adult day health program that allows Carrie to take a handful of hours off each week.

Carrie loves her mother and wouldn't want Jocelyn's golden years spent anywhere else, but it hasn't been easy. At first, Carrie tried to continue working at her job while also providing full-time care to Jocelyn. However, she found that with the new caregiving workload "everything, including my job, was suffering." The toll on Carrie was especially difficult, "It felt like I had been dropped in hell. It was just too much." After seven months of trying to be a full-time insurance agent and full-time caregiver, she chose to leave her job to focus on her mother's health. The job she left provided her with a strong middle-class salary, but she felt that the family would be all right given her husband's salary and benefits as a graphic designer at Boeing. Unfortunately, Carrie's husband was laid off earlier this year and they are now making hard decisions about how they will cover expenses and health needs through this period of unemployment.

Carrie and her family are faced with tough times, but they remain hopeful as her husband's job search continues. She'd like to see a day when there are more affordable long-term services and supports options to help families like hers keep loved ones at home and provide the care they need without having to leave paid employment and deplete generations of hard-earned savings.

Carrie & her mother Jocelyn



- Long-term services and supports (also known as long-term care) helps older adults maintain or improve their daily life by assisting with tasks like bathing, toileting, getting dressed, fixing meals, and maintaining health and well-being.
- Contrary to popular belief, long-term services and supports is not covered by Medicare or other traditional health insurance plans, and the private long-term services and supports insurance plans that do exist are unaffordable for most individuals.
- Seventy percent of those 65 and older will need long-term services and supports within their lifetime.
- The most recent national estimates show that for those over 65 who need long-term services and supports, the lifetime costs average about \$260,000, while seniors' median retirement savings stands at just \$148,000.
- In Washington, more than 850,000 unpaid family caregivers provide care valued in 2015 at \$11 billion annually.
- Family caregivers who leave the workforce to provide unpaid long-term services and supports lose, on average, a total of \$300,000 in income and benefits.
- Demographic shifts mean that fewer potential family caregivers will be available in the future. Today there are around 7 potential caregivers for each senior, but by 2030 that ratio will drop by 43% to just 4 to 1.
- Given the decline in unpaid care, families and the State could be responsible for an additional \$6.3 billion in long-term services and supports costs by 2030.
- The State has hired Milliman to produce an actuarial report on long-term services and supports financing in Washington including analysis of two potential solutions for future long-term services and supports costs: a public trust similar to Social Security and a public-private option where the State would work with insurers to help revitalize the private market. The report will be released to the legislature in December 2016.

Long-Term Services & Supports: *a system dependent upon family sacrifice*

What is Long-Term Services and Supports?

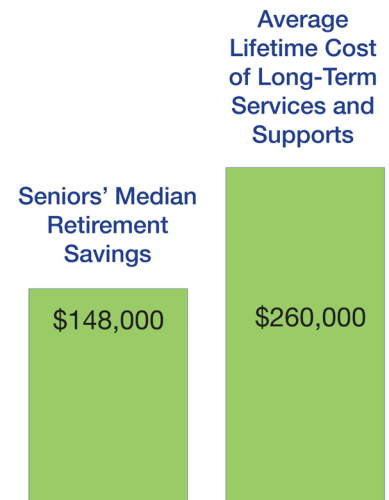
Long-term services and supports (also known as long-term care) helps older adults maintain or improve their daily life by assisting with tasks like bathing, toileting, getting dressed, fixing meals, and maintaining health and well-being. Long-term services and supports happens in many different locations: in a senior's home, skilled nursing facilities, assisted living facilities, adult family homes, senior centers, adult day health programs, retirement communities, and hospitals. Seventy percent of those 65 and older will need long-term services and supports within their lifetime, with an average care need of one to two years.ⁱ There are over 1 million seniors in Washington today, and more than 90% of them are uninsured for long-term services and supports.ⁱⁱ

Long-term services and supports is much more expensive than people realize. For instance, the typical annual cost for in-home care in Washington State is \$56,000 while average nursing home care costs are \$96,000 per-year.ⁱⁱⁱ The most recent national estimates show that for those over 65 who end up needing long-term services and supports, the lifetime costs will average about \$260,000, while seniors' median retirement savings stands at just \$148,000.^{iv,v}

How Do Seniors in Washington Receive Long-Term Services and Supports?

Washington has one of the nation's highest rated long-term services and supports systems – if you can access it. The problem is not the system itself, but the precarious financing model and its dependence on unpaid family caregiving.^{vi} Today's de facto long-term services and supports system is heavily reliant upon family sacrifice and out of pocket spending until or unless a senior is poor enough to qualify for Medicaid.

Contrary to popular belief, long-term services and supports is not covered by Medicare or other traditional health insurance plans, and the private long-term services and supports insurance plans that do exist are unaffordable for most individuals. Thus a majority of seniors rely on unpaid family caregivers when possible and spend down their entire life savings on formal services until they have less than \$2,000 to their name - the point at which they are impoverished enough to qualify for Medicaid long-term services and supports.



Private Insurance is not a Viable Option for Most Seniors

The cost of private long-term services and supports insurance is prohibitively expensive for all but the most prosperous among us. The price tag is high because unlike other insurance markets with broad-based participation, like health or auto insurance, only those who are very likely to use the benefits – older adults – choose to purchase a plan. According to

the National Association of Insurance Commissioners, long-term services and supports insurance is affordable for only 21% of seniors aged 60-79.^{vii} Furthermore, plans can reject applicants based on their health, making the market inaccessible even to those who can afford the premiums: about 14% of applicants aged 50-59 are denied coverage due to their medical history, while the rejection rate increases to 45% for those aged 70-79.^{viii}

The high price tag and medical underwriting have led to a lack of demand, which in turn has led to an exodus of insurance companies from the market. In 2002 there were 102 companies selling a significant number of policies nationally, but as of 2013 that number has declined to just 12 companies remaining in the United States.^{ix}

The Hidden Impacts of Our Long-Term Services & Supports System: *families struggling to meet the need*

Unpaid Family Caregiving: The Backbone of Long-Term Services & Supports

The overwhelming majority of long-term services and supports in Washington is provided by an estimated 850,000 unpaid family caregivers – 12% of the State’s total population. Most family caregivers are women in their forties and fifties who are holding paid employment in addition to their caregiving responsibilities, and while the average caregiver provides around 20 hours of care per week, one-fourth provide more than 40 hours of weekly care.^{x,xi} One survey done by Gallup in 2011 found that about 20% of all female and 16% of all male workers in the U.S. are also working as adult family caregivers.^{xii}

Families Bear the Financial and Physical Tolls of Long-Term Services & Supports

Caregiving creates financial challenges for the family, including providing direct financial support for the disabled loved one, lost paid employment, reduced general savings, lost retirement savings, and health care coverage, and other associated benefits of full-time employment.^{xiii} Almost 40% of family caregivers report moderate to high degrees of financial strain resulting from providing long-term services and supports to a loved one. An estimated \$300,000 is lost in income and benefits for the average family member who leaves the workforce to provide long-term services and supports.^{xiv,xv} In addition, a caregiver’s health is often affected when providing long-term services and supports. More than half of caregivers feel overwhelmed by the amount of care their loved one requires, and they are more likely to report being in fair to poor health.^{xvi,xvii} Caregivers consistently show higher levels of depression and report having chronic conditions (including heart disease, cancer, diabetes, and arthritis) at nearly twice the rate of non-caregivers.^{xviii, xvix, xx}

Seniors Are Losing Financial Independence & Slipping into Poverty

Ultimately more than half of all long-term services and supports expenses are paid for out-of-pocket through personal savings, and when confronted with the high costs seniors can see a lifetime of hard-earned savings dwindle until they meet the government’s definition of poor.^{xxi} The average 65 year old needing long-term services and supports will face about \$260,000 in

expenses - while the average senior has just under \$150,000 in savings.^{xxii, xxiii} Many will go through the process of “spending down” what savings and assets they do have until they have less than \$2,000 in savings; only then can they qualify for Medicaid long-term services and supports coverage.

Medicaid Long-Term Services and Supports is Highly Efficient, but is Still a Major Budget Driver for the State

Washington is fortunate to have a top quality and highly efficient Medicaid long-term services and supports system, with 90% of its budget going to direct services for more than 62,000 Washingtonians. Washington is in fact a national leader in using less costly and client-preferred home and community-based care whenever possible.^{xxiv} Yet as efficient as the program is, long-term services and supports already makes up around 6% (\$1.7 billion) of the State’s entire budget and a third of the Department of Social and Health Services’ budget.^{xxv}

An Unsustainable System for the Future

Currently



By 2030



\$6.3 BILLION MORE BY 2030

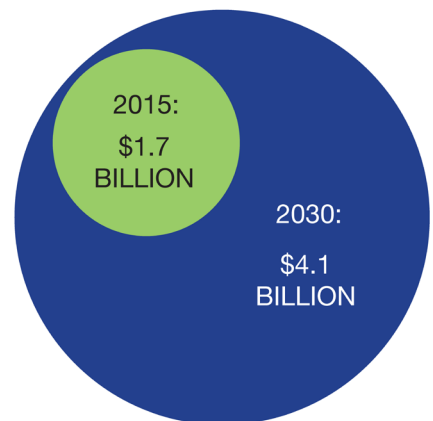
in formal care paid for by families & Medicaid

The Age Wave and Demographic Shifts will Result in Unprecedented Demand for Paid Services

Nationally, unpaid family caregivers are providing \$470 billion of unpaid care per year – nearly equal to the annual sales of Walmart, the world’s largest corporation.^{xxvi} Here in Washington, more than 850,000 unpaid family caregivers provide care valued at more than \$11 billion per year – care that would otherwise be paid for through family savings or by the Medicaid long-term services and supports program.^{xxvii}

Unfortunately, today’s system, built upon the cornerstone of unpaid family caregivers, is not sustainable into the future. Given the unprecedented size of the aging Baby Boomer Generation coupled with the fact that they married less often and had fewer children than their forbearers, by 2030 Washington’s senior population will grow by 70% while the number of younger potential family caregivers is in steep decline. Nationally there is an average of 7 potential caregivers – those in their primary caregiving years (ages 45-64) – for each senior but by 2030 this ratio will drop by 43% to just 4 to 1.^{xxviii, xxix} Because of the declining number of unpaid family caregivers,

Long-Term Services & Supports Costs to State Budget



the State's Medicaid system and Washington's families could end up paying for an additional \$6.3 billion in long-term care services and supports by 2030.^{xxx}

The demographic changes ahead mean that even as families continue to take responsibility for their elders as best as they can, there will be a significant increase in the need for formal, paid long-term services and supports services.

Costs to the State Budget by 2030

Washington's Department of Social and Health Services projects that as this demographic shift plays out, long-term services and supports costs to the state budget will balloon from \$1.7 billion in 2015 to \$4.1 billion in 2030.^{xxxii} As the Medicaid long-term services and supports program continues to overtake a significant portion of the state budget, it will displace spending on other critical investments such as K-12 and higher education.

The Path Forward

This year the State hired Milliman, one of the nation's largest and most prestigious actuarial firms, to produce a report on long-term services and supports financing in Washington. Milliman will be analyzing two potential solutions that would help families and the State plan for future long-term services and supports costs: first, a public trust similar to Social Security or unemployment insurance, which is open to and paid for by all workers via a payroll deduction; and second, a public-private option where the State would work with insurers to help revitalize the private market so that it is accessible and affordable to more seniors. The report, with recommendations, will be released to the legislature in December 2016.

Civic leaders in Washington must be proactive in finding and implementing sustainable solutions for families like Carrie Lange's before it's too late. Our state can have a system that is accessible and affordable - one that allows families to take personal responsibility for care needs without impoverishing themselves and garnishing their financial future - but only if our leaders act before it's too late.

Washingtonians for a Responsible Future is a broad-based coalition of aging and disability advocates, businesses, long-term services and supports providers, labor, consumer rights organizations, and families working to start the important conversation around unpaid family caregiving and financing a sustainable long-term services and supports system into the future.

Member organizations include:

AARP of Washington, Adult Family Home Council of Washington State, Alzheimer's Association - Washington State Chapter, Asian Pacific Islander Coalition Washington, Caring Across Generations, ElderCare Alliance, Equal Rights Washington, First Choice In-Home Care, Latino Community Fund, LeadingAge Washington, LGBTQ Allyship, Keiro Northwest (formerly Nikkei Concerns), Puget Sound Advocates for Retirement Action, Service Employees International Union 775, Washington Association of Area Agencies on Aging, Washington Health Care Association, Washington State Senior Citizens' Lobby, and the Washington State Long-Term Care Ombudsman.

Endnotes

- ⁱ Favreault, M. (2016). *Long-Term Services and Supports for Older Americans: Risks and Financing*. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb-rev.pdf>
- ⁱⁱ Office of Financial Management. (2015). *State of Washington Forecast of the State Population*.
- ⁱⁱⁱ Genworth Financial. (2016). *Genworth 2016 Cost of Care Survey*.
- ^{iv} Favreault, M. (2016). *Long-Term Services and Supports for Older Americans: Risks and Financing*. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb-rev.pdf>
- ^v Government Accountability Office. (2015). *Most Households Approaching Retirement have Low Savings* (No. GAO-15-419). Washington, D.C. Retrieved from <http://www.gao.gov/assets/680/670153.pdf>
- ^{vi} AARP. (2014). *Washington: 2014 State Long-Term Services and Supports Scorecard Results*. Washington, D.C.: AARP. Retrieved from <http://www.longtermscorecard.org/~media/Microsite/State%20Fact%20Sheets/Washington%20Fact%20Sheet.pdf>
- ^{vii} Wiener, J. M., & O'Keeffe, J. (2011). Long-Term Care Reform Options in Hawaii.
- ^{viii} Frank, R. G. (2012). Long-term care financing in the United States: Sources and institutions. *Applied Economic Perspectives and Policy*, 34(2), 333-345
- ^{ix} Cohen, M. A. (2013, June). *The Current State of the Private Long-Term Care Insurance Industry*. Presented at the The Long-Term Care Commission.
- ^x Reactor, B. (2013, September 25). Inventory of Resources; presented to the Joint Legislative/Executive Committee on Aging and Disability.
- ^{xi} AARP Public Policy Institute and the National Alliance for Caregiving. (2015). *Caregiving in the U.S.*
- ^{xii} Gallup Inc. (2011). More Than One in Six American Workers Also Act as Caregivers. Gallup.com. Retrieved from <http://www.gallup.com/poll/148640/One-Six-American-Workers-Act-Caregivers.aspx>
- ^{xiii} Reinhard, S., & et. al. (2015). Valuing the Invaluable: 2015 Update. AARP Public Policy Institute.
- ^{xiv} AARP Public Policy Institute and the National Alliance for Caregiving. (2015). *Caregiving in the U.S.*
- ^{xv} MetLife Mature Market Institute. (2011). *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents*.
- ^{xvi} American Psychological Association. (2012). *Stress in America: Our Health at Risk*
- ^{xvii} AARP Public Policy Institute and the National Alliance for Caregiving. (2015). *Caregiving in the U.S.*
- ^{xviii} Schulz, R., O'Brien, A.T., Bookwals, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35: 771-791.
- ^{xix} Pinquart, M. & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250-267.
- ^{xx} Ho, A., Collins, S., Davis, K. & Doty, M. (2005). *A Look at Working-Age Caregivers Roles, Health Concerns, and Need for Support* (Issue Brief). New York, NY: The Commonwealth Fund.
- ^{xxi} Favreault, M. (2016). *Long-Term Services and Supports for Older Americans: Risks and Financing*. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb-rev.pdf>
- ^{xxii} Favreault, M., Gleckman, H., & Johnson, R. (2015). Financing Long-Term Services and Supports: Options Reflect Trade-Offs For Older Americans and Federal Spending. *Health Affairs*, 34(12).
- ^{xxiii} Government Accountability Office. (2015). *Most Households Approaching Retirement have Low Savings* (No. GAO-15-419). Washington, D.C. Retrieved from <http://www.gao.gov/assets/680/670153.pdf>
- ^{xxiv} Kettel, J. (2013, September). *Presentation to the Joint Legislative Executive Committee for Planning on Aging and Disabilities Issues*.
- ^{xxv} Ibid.
- ^{xxvi} Reinhard, S., & et. al. (2015). *Valuing the Invaluable: 2015 Update*. AARP Public Policy Institute.
- ^{xxvii} AARP. (2012). *Across the States, Profiles of Long Term Services and Supports*. Inflation-adjusted for 2016 dollars.
- ^{xxviii} Office of Financial Management. (2015). *State of Washington Forecast of the State Population*.
- ^{xxix} Reinhard, S., & et. al. (2015). *Valuing the Invaluable: 2015 Update*. AARP Public Policy Institute.
- ^{xxx} Used 2013 estimates of unpaid caregiving value of \$10.7 billion. Using an assumed 2% inflation found an estimated value of unpaid family caregiving in 2030 dollars of \$14.65 billion. Forty-three percent of this is \$6.3 billion in 2030 dollars.
- ^{xxxI} Kettel, J. (2013, September). *Presentation to the Joint Legislative Executive Committee for Planning on Aging and Disabilities Issues*.