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The Challenge of Financing Long-Term Care

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THE CHALLENGE OF FINANCING LONG-TERM CARE

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Despite the continued political battle surrounding the Affordable Care Act, even critics recognize that insurance is essential to assure access to health care and protection against financial catastrophe associated with its costs. Although insurance is similarly essential to assuring access and financial protection for long-term care—the need for personal help with basic daily tasks like bathing, eating, or toileting—insurance protection is lacking. Private health insurance doesn't cover long-term care, and few Americans have private long-term care insurance, which typically costs a lot, offers limited value, and is subject to premium increases that can cause purchasers to lose coverage they have paid into for years. On the public side, Medicare—which older people and some younger people with disabilities rely on for health insurance—does not cover long-term care. The federal-state Medicaid program does serve as a valuable last resort for people who need long-term care, but its protections (especially for care at home) vary considerably from state to state and become available only when people are, or have become, impoverished taking care of themselves.

As a result, families bear enormous responsibility for caregiving at substantial physical and economic cost; overall access to long-term care falls short of demonstrable need; and individuals and families who need care are at risk for its potentially catastrophic costs. As the population ages, the inadequacy and inequity of current long-term care financing mechanisms will only increase. Enactment of an effective insurance system, with public protection at its core, is essential to protect Americans against the unpredictable, catastrophic risk of needing expensive, extensive long-term care.

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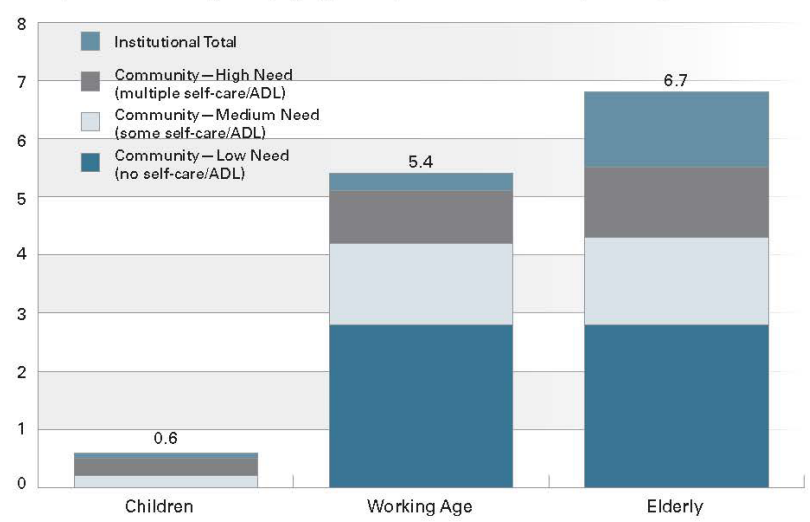
I. THE NEED FOR LONG-TERM CARE IS A RISK, NOT A CERTAINTY

Although the risk of needing long-term care rises at older ages, people of all ages are at risk—and even at older ages, whether and the extent to which a person may need long-term care varies widely among individuals. Among people under the age of sixty-five, less than two percent have long-term care needs, but they constitute over five million of the roughly twelve million people who need long-term care.

PEOPLE OF ALL AGES FACE THE RISK OF NEEDING LONG-TERM CARE[1]

People (in millions) with long-term care needs, 2012

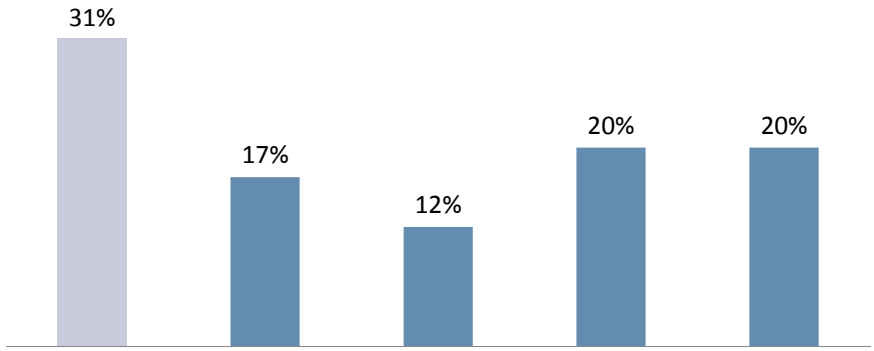


Among people now turning age sixty-five, an estimated three in ten will not need long-term care during the rest of their lives, while two in ten will need five or more years of long-term care.

1. *See generally* COMM'N ON LONG-TERM CARE, REPORT TO THE CONGRESS 3 (Sept. 30, 2013) (statement of H. Stephen Kaye).

EVEN AMONG PEOPLE AGED 65 AND OVER, THE NEED FOR LONG-TERM CARE IS A RISK, NOT A CERTAINTY—YEARS OF CARE NEED VARY CONSIDERABLY[2]

Percent of people now age 65, by estimated years of needing care after age 65



Years needing long-term care after age 65

The bulk of long-term care today is provided not by public programs, but by families.[3] Most people who need long-term care (over eighty percent of people with long-term care needs living at home) rely solely on family and friends to provide it and do not receive paid services.[4] For many people, that may be as it should be—families doing what families do. But the health and economic costs of caregiving can be substantial.[5] And families cannot always provide the full amount, intensity, or type of care that is needed. Accordingly, spending on long-term care varies enormously. Though just over forty percent of people

2. Peter Kemper et al., *Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?*, 42 INQUIRY 335, 342 (2005/2006).

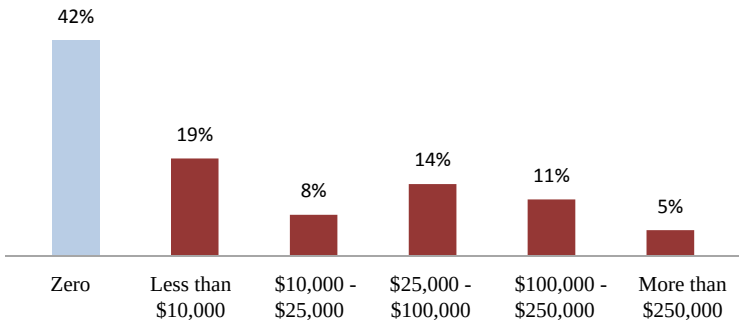
3. JUDY FEDER & HARRIET KOMISAR, THE IMPORTANT OF FEDERAL FINANCING TO THE LONG-TERM CARE SAFETY NET 2 (SCAN Found. ed., 2012), *available at* http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf. *See also* H. Stephen Kaye et al., *Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?*, 29 HEALTH AFF. 11, 12-20 (2010).

4. Kaye et al., *supra* note 3, at 15.

5. *See* LYNN FEINBERG ET AL., AARP PUB. POL'Y INST., VALUING THE INVALUABLE 2011 UPDATE: THE GROWING CONTRIBUTION AND COSTS OF FAMILY CAREGIVING 1 (2011), *available at* http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf (analyzing the economic costs of long-term care); *see also* SUSAN REINHARD, ET AL., AARP & UNITED HOSP. FUND, HOME ALONE: FAMILY CAREGIVERS PROVIDING COMPLEX CARE 28-29 (2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregiversproviding-complex-chronic-care-rev-AARP-ppi-health.pdf (analyzing the social impact on family members engaged in long-term care to other family members).

now turning age sixty-five are predicted to incur no care costs at all, expenses for the costliest five percent are estimated in the hundreds of thousands of dollars.

SPENDING VARIES EVEN MORE[6]



Note: Expenditures are calculated as the discounted present value, in 2005 dollars, of future spending.

II. THE COST OF LONG-TERM CARE CAN EXCEED THE RESOURCES OF PEOPLE WHO NEED IT

When paid care is necessary, its costs can far exceed most families' resources. In 2012, personal assistance at home averaged twenty-one dollars per hour, or almost $22,000 annually for twenty hours per week of assistance, and adult daycare center services cost an average of seventy dollars per day, or about $18,000 on an annual basis for five days of services per week.[7] Assisted living services averaged $42,600 for a basic package of services.[8] For people who need the extensive assistance provided by nursing homes, the average annual cost was $81,000 for a semi-private room, but varied widely among markets and exceeded $100,000 a year in many of the country's most expensive areas.[9]

6. *See* Kemper et al., *supra* note 2, at 335-50 (noting that expenditures are calculated as the discounted present value, in 2005 dollars, of future spending).

7. METLIFE MATURE MARKET INST., MARKET SURVEY OF LONG-TERM CARE COSTS: THE 2012 METLIFE MARKET SURVEY OF NURSING HOME, ASSISTED LIVING, ADULT DAY SERVICES AND HOME CARE COSTS 5 (2012), *available at* https://www.metlife.com/mmi/research/2012-market-survey-long-term-carecosts.html#keyfindings.

8. *Id.* at 4-5.

9. *Id.* at 4, 18-25.

EXTENSIVE LONG-TERM CARE IS A CATASTROPHIC EXPENSE[10]

Type of Service	Average Price in 2012
Nursing Home	$81,030 annually, semi-private room $90,520 annually, private room
Assisted Living	$42,600 annually for basic package
Home Care	$21 per hour 20 hours per week = $21,840 annually
Adult Day Services	$70 per day 5 days per week = $18,200 annually

The mismatch between the costs of these services and the resources of the people who need them is dramatic. Focusing on the older people who are most at risk of needing long-term care, fewer than one-third of people age sixty-five and over have incomes equal to or greater than four times the federal poverty level[11]—at about $44,000 for an individual age sixty-five or older or $56,000 for an older couple in 2013.[12] Most people's incomes are clearly well below what is necessary to pay for institutional or intensive home care.

Although, in theory, savings can help fill the gap between income and service costs, in practice, savings are inadequate to the task. For people of working age who need long-term care, their disability often comes well before they have a chance to accumulate savings that might help pay for long-term care costs. Most older people also lack assets sufficient to finance extensive care needs. In 2013, half the population over age sixty-five living in the community had savings of less than $73,000—insufficient to cover the average cost of a year in the nursing home.[13]

III. INSURANCE FAILS TO PROTECT AGAINST THE UNPREDICTABLE RISK OF NEEDING LONG-TERM CARE

Given the unpredictability and catastrophic nature of extensive long-term care needs, heavy reliance on savings to finance them is never likely to work. Insurance is the best way to protect against the risk of unpredictable,

10. *Id.*

11. ZACHARY LEVINSON ET AL., KAISER FAMILY FOUND., A STATE-BY-STATE SNAPSHOT OF POVERTY AMONG SENIORS 4 (2013), *available at* http://kff.org/medicare/issue-brief/a-state-by-state-snapshot-of-poverty-among-seniors.

12. *Poverty Thresholds*, U.S. CENSUS BUREAU (2013), https://www.census.gov/hhes/www/poverty/data/threshld/.

13. GRETCHEN JACOBSON ET AL., KAISER FAMILY FOUND., INCOME AND ASSETS OF MEDICARE BENEFICIARIES, 2013-2030, at 3 (2014), *available at* http://kaiserfamilyfoundation.files.wordpress.com/2014/01/8540-income-and-assets-of-medicare-beneficiaries-2013-e28093-20301.pdf.

potentially catastrophic expenses. But private insurance for long-term care has never really gotten off the ground and—in recent years—several insurance companies have given up on trying to market a successful product.[14] Only about seven million people are estimated to currently hold any type of private long-term care insurance,[15] and most purchasers have relatively high incomes. Unfortunately, many people in their fifties and early sixties are accumulating insufficient resources to cover basic living expenses in retirement, let alone to finance potential long-term care needs. In addition, available long-term care insurance policies offer limited and uncertain benefits—raising questions about the wisdom of purchase. Policies limit benefits in dollar terms in order to keep premiums affordable, but therefore can leave policyholders with insufficient protection when they most need care; and policies have often lacked the premium stability that can assure purchasers of their ability to continue to pay in year after year, in order to receive benefits if and when the need arises.

IV. MEDICAID PAYS FOR MOST LONG-TERM CARE BUT ITS PROTECTIONS ARE LIMITED AND VARIABLE

It is not surprising, then, that people turn to Medicaid when they need long-term care. To qualify for Medicaid protection, individuals must have low income and savings to begin with, or exhaust the resources they have in purchasing medical and long-term care. Given how high service costs can be, the opportunity to qualify for Medicaid when the costs exceed an individual's income and savings is essential to assure that people have access to care. But Medicaid limits the availability of care at home, where most people prefer to stay, and recipients of Medicaid benefits in nursing homes are required to spend all of their income on their nursing home care (subject to limits for people with spouses at home), except for a small "personal needs allowance" of thirty to sixty dollars in most states.[16]

14. For a recent assessment of the long-term care insurance market, its limitations and suggestions to improve it, *see* RICHARD FRANK ET AL., THE SCAN FOUND., MAKING PROGRESS: EXPANDING RISK PROTECTION FOR LONG-TERM SERVICES AND SUPPORTS THROUGH PRIVATE LONG-TERM CARE INSURANCE 3, 7 (Mar. 2013), *available at* http://www.thescanfoundation.org/sites/thescanfoundation.org/files/tsf_ltc-financing_private-options_frank_3-20-13.pdf.

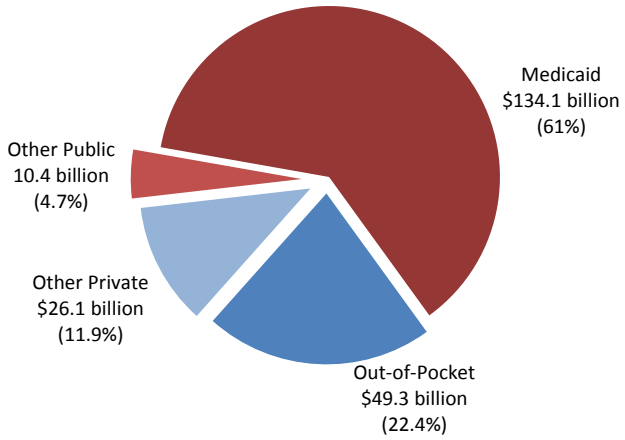
15. *Id.*

16. LINA WALKER & JEAN ACCIUS, ACCESS TO LONG-TERM SERVICES AND SUPPORTS: A 50-STATE SURVEY OF MEDICAID FINANCIAL ELIGIBILITY STANDARDS 12 (Sept. 2010), *available at* http://assets.aarp.org/rgcenter/ppi/ltc/i44-access-ltss_revised.pdf.

MEDICAID FINANCES THE LONG-TERM CARE SAFETY NET[17]

National expenditures for long-term care, by source

2012 Total = $219.9 billion



Some argue that people "transfer" their assets in order to qualify for Medicaid rather than exhaust their assets before they qualify, allowing even well-to-do people to qualify for Medicaid benefits. But evidence shows the following realities: (1) few older adults have the income or wealth that would warrant such transfer; (2) people in poor health are more likely to conserve than to exhaust assets; (3) for the elderly population as a whole, transfers that occur are typically modest (less than $2,000); and (4) transfers associated with establishing eligibility are not significant contributors to Medicaid costs.[18]

Despite Medicaid's importance, its protections vary considerably from state to state and, most, if not all, states fall short of meeting people's needs. Variation takes multiple forms. The first variation is in the breadth or narrowness of its eligibility requirements and the share of people in need of care each state's program serves. The states with the most extensive coverage are estimated to reach about two-thirds of low-income adults with long-term care needs—about three times the share in the states with the least extensive programs. Half the states reach only about a third of this population.[19]

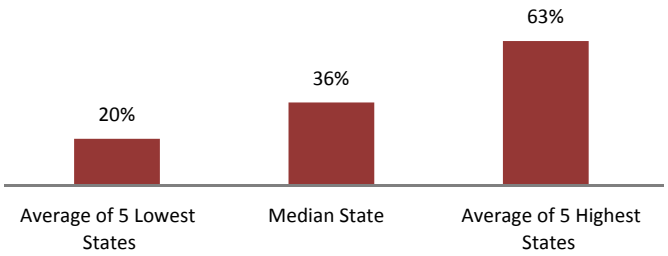
17. CAROL V. O'SHAUGHNESSY, THE BASICS: NATIONAL SPENDING FOR LONG-TERM SERVICES AND SUPPORTS (LTSS), 2012 at 3 (Mar. 27, 2014), *available at* http://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf.

18. FEDER & KOMISAR, *supra* note 3, at 5.

19. *Id.* at 6

MEDICAID PARTICIPATION VARIES ACROSS STATES[20]

Percent of low-income adults needing long-term care with Medicaid support, 2007



Note: Estimated in each state as the ratio of the approximate number of people receiving Medicaid long-term services and supports to adults age 21 or older who reside in a nursing home or who reside in the community with income at or below 250% of the federal poverty level and have difficulty with bathing or dressing.

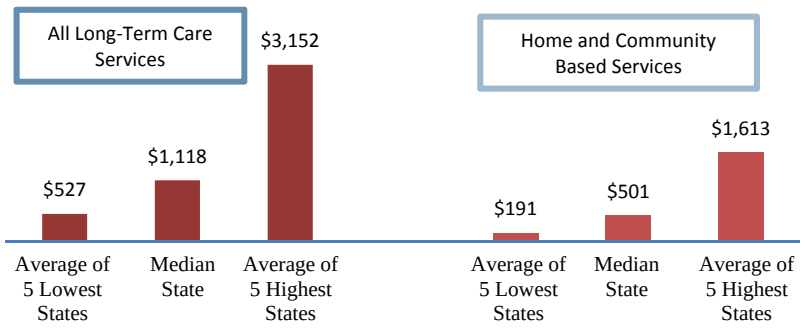
Even greater variation among state programs is apparent when comparing states' Medicaid long-term care spending per low-income state resident. Medicaid long-term care spending per low-income state resident in the highest spending states (averaging $3,000 in federal fiscal year 2009 in the five highest states) is about six times the amount of the lowest spending states (averaging $500 in the five lowest states). The range is still larger—from about $1,600 to about $200, or eight to one—for Medicaid's non-institutional long-term care services for people in the community, the setting where most people with long-term care needs reside.[21] For older people and people with physical disabilities, nursing homes and other institutional services continue to dominate spending in most states, with substantial variation across the nation.

20. *Id.* (citing Susan Reinhard et al., *Raising Expectations: A State Scorecard on Long-Term Care Services and Supports for Older Adults, Adults with Physical Disabilities, and Family Caregivers*, AARP PUB. POLICY INST. 95 (Sept. 2011), *available at* http://assets.aarp.org/rgcenter/ppi/ltc/ltss_scorecard.pdf).

21. *Id.* at 6; Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports: 2011 Update*, THOMSON REUTERS (October 31, 2011); U.S. CENSUS BUREAU, POV46: POVERTY STATUS BY STATE: 2010 (2011) [hereinafter POVERTY STATUS BY STATE]. *See* FEDER & KOMISAR, *supra* note 3 (construing POVERTY STATUS BY STATE, *supra* note 21, and Eiken et al., *supra* note 21, for state expenditures in federal fiscal year 2009) (also construing POVERTY STATUS BY STATE, *supra* note 21, for number of state residents with income below 200% federal poverty level in 2010).

MEDICAID SPENDING VARIES ACROSS STATES[22]

Medicaid long-term care spending per state resident with income below 200% of poverty level, 2009



This variation in the availability of home and community-based care services across states, particularly for older people and people with physical disabilities, has enormous consequences in terms of access to adequate care. Unlike most Medicaid services, which the law requires be made available to all people eligible, home and community-based care services are subject to enrollment caps. Most states have limits on enrollment and establish waiting lists for care at home. Most people who have long-term care needs are, in fact, at home—and depend primarily on family for the services they need. But surveys have shown that many people living at home are receiving insufficient care and, as a result, are at a heightened risk of negative consequences—like falling, soiling themselves, or going without bathing or eating. Analysis indicates that the prevalence of unmet needs for long-term care, though significant across the country, is lower in states with greater availability of services at home.

22. FEDER & KOMISAR, *supra* note 3, at 6 (construing Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports: 2011 Update*, THOMSON REUTERS (October 31, 2011) for Medicaid expenditures in federal fiscal year 2009; also construing POVERTY STATUS BY STATE, *supra* note 21, for number of state residents with income below 200% of the federal poverty level in 2010).

MEDICAID SUPPORT FOR CARE AT HOME VARIES ACROSS STATES[23]

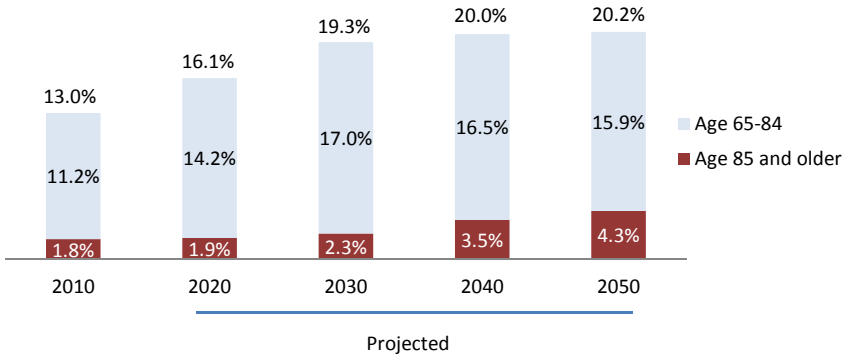
Percent of Medicaid long-term care spending on non-institutional services, 2009 for older adults and people with physical disabilities

	Percent of Spending that is for Non-Institutional Services
Lowest state	4%
Average of 5 lowest states	11%
Median state	28%
Average of 5 highest states	63%
Highest state	79%

The current inadequacy and inequity in Medicaid is only likely to grow with the aging of the population. The percentage of the population age eighty-five and older is expected to increase by more than one-quarter by 2030 (from 1.8% in 2010 to 2.3% in 2030) and to more than double by 2050 (to 4.3%).

THE U.S. POPULATION IS AGING[24]

Percentage of the population that is age 65 and older, 2010 to 2050



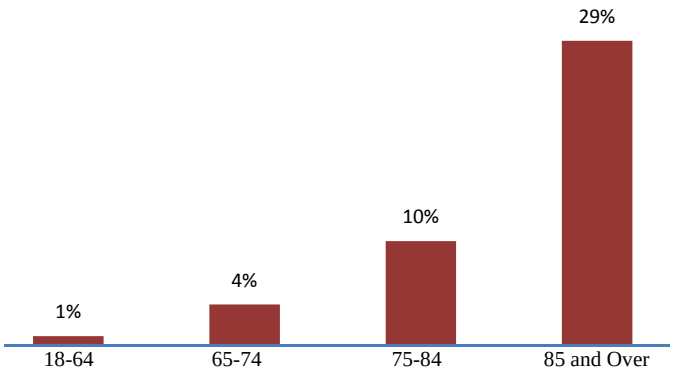
23. FEDER & KOMISAR, *supra* note 3, at 6 (construing Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports: 2011 Update*, THOMSON REUTERS (October 31, 2011). Amounts are for federal fiscal year 2009.

24. CARRIE A. WERNER, U.S. CENSUS BUREAU, C2010BR-09, THE OLDER POPULATION: 2010 at 2 (2011); GRAYSON K. VINCENT & VICTORIA A. VELKOFF, U.S. CENSUS BUREAU, P25-1138, THE OLDER POPULATION IN THE UNITED STATES: 2010 TO 2050, at 10 (2008).

It is among this population that the need for long-term care is most substantial. Nearly three in ten people age eighty-five years or older have moderate to severe long-term care needs—three times the proportion among seventy-five to eighty-four year-olds.

THE RISK OF NEEDING LONG-TERM CARE INCREASES WITH AGE[25]

Percentage of people in each age group who have moderate to severe long-term care needs, 2005



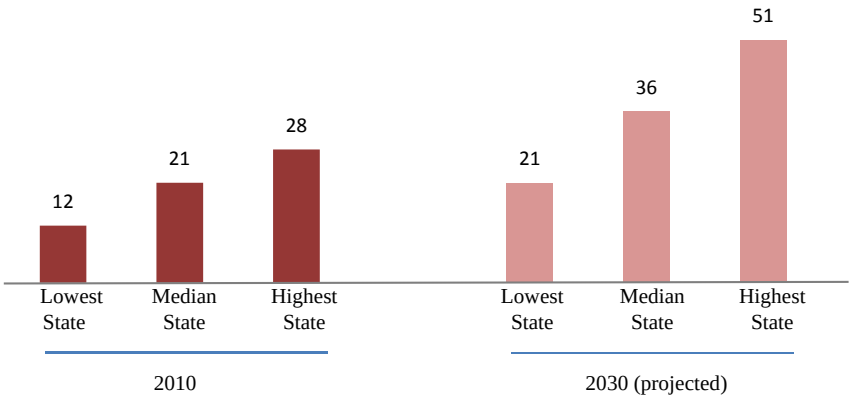
Note: Based on community residents needing assistance with activities of daily living and nursing home residents.

Although the population is aging in every state, the effects—and the burdens—of an aging population will be larger in some states than others. It is uncertain whether any state has the capacity to deal with the needs of an aging population.

25. FEDER & KOMISAR, *supra* note 3 (citing *Needing Help With Activities Of Daily Living, Ages 18+: US, 1997-2012*, CTRS. FOR DISEASE CONTROL & PREVENTION, http://205.207.175.93/HDI/TableViewer/tableView.aspx?ReportId=134 (last visited Sept. 22, 2014); *Number Of Nursing Home Residents By Assistance With Activities Of Daily Living (ADLs) And By Age, Sex, And Race: United States, 2004—Con.*, CTRS FOR DISEASE CONTROL & PREVENTION (June 2008), http://www.cdc.gov/nchs/data/nnhsd/Estimates/nnhs/Estimates_FunctionalStatus_Tables.pdf#Table14).

THE RATE OF AGING VARIES ACROSS STATES[26]

Range among states in the number of people age 65 and older per 100 people ages 18-64



What is certain is that the greater the imbalance between the older population and the working-age population, the greater the challenge states will face in sustaining, let alone improving, the adequacy of long-term care services.

V. AN EFFECTIVE LONG-TERM CARE INSURANCE MUST HAVE A PUBLIC CORE

The absence of effective insurance against the risk of needing long-term care is a market and policy failure. The need for extensive, expensive long-term care is precisely the kind of catastrophic, unpredictable risk for which we typically rely on insurance to spread costs. If, as is often claimed, people should "prepare" to manage this risk, they must have a reliable insurance mechanism to which they can contribute. Experience indicates that public social insurance must be the core of that mechanism; private insurance can play a complementary role, but even its proponents estimate that building future policy around a private market will, at best, leave eight in ten Americans uninsured.[27]

When enacted, the Affordable Care Act included a modest version of a public insurance core. The Community Living Assistance Services and

26. FEDER & KOMISAR, *supra* note 3, at 6 (citing LINDSAY M. HOWDEN & JULIE A. MEYER, U.S. CENSUS BUREAU, C2010BR-03, AGE AND SEX COMPOSITION: 2010, at 7 (2010); U.S. CENSUS BUREAU, FILE 2. INTERIM STATE PROJECTIONS OF POPULATION FOR FIVE-YEAR AGE GROUPS AND SELECTED AGE GROUPS BY SEX: JULY 1, 2004 TO 2030 (2005).

27. FRANK ET AL., *supra* note 14, at 2.

Supports Act (CLASS) was designed to provide a limited daily cash benefit to people with functional impairments who make at least five years of payments beginning during their working years (and continue to pay premiums thereafter).[28] But CLASS relied on voluntary participation and was required to be fully premium-financed—conditions the Administration found impossible to satisfy without modifications in the law. The Administration therefore suspended implementation and Congress formally repealed CLASS in 2013.[29]

VI. THE REAL LONG-TERM CARE FINANCING CHALLENGE WILL BE MUSTERING POLITICAL WILL

As baby boomers become caregivers and then care recipients, they may well press policymakers to return to the financing issue—creating an opportunity to enact effective public insurance. Clearly, establishing a new social insurance program will pose an enormous political challenge, especially since its effectiveness will depend on broad financial participation and enhancement of currently inadequate investment in long-term care services. To mitigate that challenge, public benefits could be limited, rather than comprehensive, and could emphasize, or even facilitate, people's planning for future long-term care needs. For example, benefits could be designed to vary with an individual's lifetime income—including a waiting period that would be shorter for people with lower incomes, longer for people with higher incomes. With a clear income-related benefit schedule, people could know well in advance the likely risk or "hole" they should plan to fill (or the protection they might want to supplement) from personal resources or private insurance, should they become impaired. This type of public structure would not replace personal responsibility or eliminate a role for private insurance; rather its establishment of a core public benefit would make personal responsibilities more manageable and private insurance more workable.[30]

Support—both political and financial—for public long-term care insurance will require a fundamental change in attitudes toward long-term care. Policymakers and the public must recognize that the need for long-term care is the kind of unpredictable, catastrophic risk that individuals and families cannot be left to bear on their own; that access to affordable long-term care services

28. Community Living Assistance And Supports (CLASS) Act, Pub. L. No. 111-148, § 8001, 124 Stat. 828 (repealed 2013).

29. *See* Letter from Kathleen Sebelius, Sec'y, U.S. Dep't of Health & Human Servs., to Congress (Oct. 14, 2011) (stating there was no viable path forward for CLASS implementation); *see also* American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642, 126 Stat. 2313, 2358 (repealing the CLASS Act).

30. The author developed this proposal as a member of the Congressional Long-Term Care Commission. *See* LONG-TERM CARE COMM'N, A COMPREHENSIVE APPROACH TO LONG-TERM SERVICES AND SUPPORTS 1 (2013).

must be a social, not just personal, responsibility. Until that happens, policy will continue to fail people, young and old, now and in the future, who need long-term care.