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# The Reverberating Risk of Long-Term Care

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The Fiftieth Anniversary of Medicare and Medicaid offers an opportunity to reflect on how American social policy has conceived of the problem of long-term care. In this essay, I argue that current policies adopt too narrow a conception of long-term care risk, by focusing on the effect of serious illness and disability on people who need care and not on the friends and family who often provide it. I propose a more complete view of long-term care risk that acknowledges how illness and disability reverberates through communities, posing insecurity for people beyond those in need of care.

Social insurance programs aim to create greater security for American families.[1] But programs for long-term care have had mixed results. The most recent attempt at reform, which Ted Kennedy ushered through as a part of the Patient Protection and Affordable Care Act (PPACA),[2] was the Community Living Assistance Services and Supports (CLASS) Act.[3] Participation was optional,

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1. Social insurance is a term typically used to refer to government programs that spread risk—for example, Medicare or Social Security—and is what I mean when I use the term "social insurance" herein. *See generally* MICHAEL A GRAETZ & JERRY L. MASHAW, TRUE SECURITY: RETHINKING AMERICAN SOCIAL INSURANCE (1999); THEODORE R. MARMOR ET AL., SOCIAL INSURANCE: AMERICA'S NEGLECTED HERITAGE AND CONTESTED FUTURE (2014). Because these programs are also redistributive, some argue that they are more like tax and transfer programs than "real" (meaning private) insurance. This view, however, fails to recognize that all insurance, whether private or public, redistributes resources from low-risk to high-risk people and from the lucky to the unlucky. That is the purpose of insurance. Pricing can attempt to diminish such redistribution by charging risk-rated premiums or to enhance it by charging community-rated prices. Redistribution of risk to any extent is a defining and critical feature of all insurance. *See* James Kwak, "*Social Insurance," Risk Spreading and Redistribution*, *in* RESEARCH HANDBOOK ON THE LAW AND ECONOMICS OF INSURANCE (Daniel Schwarcz & Peter Siegelman, eds., forthcoming 2015).

2. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), *amended by* Health Care and Education Reconciliation Act (HCERA) of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010).

3. Patient Protection and Affordable Care Act § 8002(a).

which made it actuarially unsound and led to its repeal.[4] Medicaid, which is currently the primary government program to finance long-term care, has fallen short for people who need long-term services or supports—the care recipients.[5]

Even more troublesome is the fact that long-term care policy, especially with Medicaid's recent evolution toward home-based care, has intensified a second type of insecurity for Americans. This insecurity affects people who are responsible for the long-term care of a loved one.[6] Such responsibility results in staggering costs—both monetary and nonmonetary. The latter include health and emotional harms as well lost opportunities that are more difficult to measure but nonetheless significant. In a longer forthcoming article, I explore these costs in greater detail and make the case for why we should consider these stochastic harms a collective problem—a social risk—that threatens Americans' wellbeing and needs to be addressed. I call this threat "next-friend risk."[7]

Current long-term care social policy ensures heavy reliance on family and friends. Of course, people have long relied on family for care.[8] Yet throughout the early twentieth century, local and federal governments began to experiment with systems of long-term care that had the potential to lessen reliance on families.[9]

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4. The American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642, 126 Stat. 2313, 2358 (2013).

5. This widely-acknowledged shortcoming is what led to the aforementioned CLASS Act and the creation of a Commission on Long-Term Care by President Barack Obama and the United States Senate after the CLASS Act was repealed. The Commission's Report outlines problems with the current system and recommended solutions. LONG-TERM CARE COMM'N, REPORT TO THE CONGRESS (2013). The Commission did not, however, reach consensus, leading to a second set of recommendations from one-third of the commissioners looking for more comprehensive social insurance solutions. LONG-TERM CARE COMM'N, A COMPREHENSIVE APPROACH TO LONG-TERM SERVICES AND SUPPORTS (2013).

6. Some people respond to this responsibility by paying for care, but most have no choice but to provide it because they cannot afford to pay for any or all of the necessary care. Two-thirds of informal caregivers are women. NAT'L ALLIANCE FOR CAREGIVING IN COLLABORATION WITH AARP, CAREGIVING IN THE U.S. 4 (2009).

7. I borrow the phrase "next friend" from a legal term for a person who in litigation represents someone with a disability who is otherwise unable to represent himself. Although not a legal guardian, the next friend protects the interests of an incompetent person. I use this term to recognize that those responsible for another's long-term care are sometimes family and sometimes friends. I also use it instead of "informal caregiver" to imply the possibility that in an ideal world a next friend might choose to pay for care, rather than to provide it herself.

8. *See* HENDRIK HARTOG, SOMEDAY ALL THIS WILL BE YOURS: A HISTORY OF INHERITANCE AND OLD AGE (2012).

9. At the beginning of the twentieth century, most long-term care needs were met by family, though some poor and mentally ill people were cared for in almshouses. By the mid-twentieth century, state institutions for long-term care were built, relying on local and state funding to pay for care. Subsequently, long-term care shifted to private nursing homes when federal programs began reimbursing some care provided in these private facilities, but not when provided in public state institutions. *See* David B. Smith & Zhanlian Feng, *The Accumulated Challenges of Long-Term Care*,

Medicaid emerged as the primary payer for long-term care, largely displacing other efforts.[10] It is worth noting that Medicare only funds long-term care "tangentially,"[11] despite the common misconception that it pays for long-term care for older Americans.[12]

Thus, over the past half century, Medicaid has transformed long-term care financing. Because Medicaid is means-tested, all but the poorest Americans have no social insurance for long-term care, with the exception of a small number with private insurance.[13] In turn, most Americans who need long-term care either "spend down" until they qualify for Medicaid or, more often, rely on family and friends to help.

Even those who are eligible for Medicaid are increasingly likely to rely on friends and family. Medicaid initially favored the provision of long-term care in licensed nursing homes or similar institutional settings, often referred to as Medicaid's "institutional bias."[14] Care in such institutions is a mandatory benefit—one that states must cover to receive federal matching funds.[15] In contrast, in-home personal care (e.g., bathing, dressing, feeding, doing light housework, shopping for groceries, etc.)[16] and "home and community-based services" are optional benefits.[17] States receive matching funds if they offer these benefits but they are not required to offer them. For some time, states mostly paid for care in institutional settings.[18] But over the past few decades, Medicaid's bias toward institutional care has yielded an increased reliance on home and community-based services, which in most cases just means long-term care at home. Incentives in the

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29 HEALTH AFF. 29 (2010); Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History*, 26 GA. ST. U. L. REV. 937 (2010); *see also* EILEEN BORIS & JENNIFER KLEIN, CARING FOR AMERICA: HOME HEALTH WORKERS IN THE SHADOW OF THE WELFARE STATE (2012).

10. *Medicaid and Long-Term Care Services and Supports: A Primer*, KAISER FAM. FOUND. 1 (2012), http://kaiserfamilyfoundation.files.wordpress.com/2014/07/8617-medicaid-and-long-term-services-and-supports_a-primer.pdf.

11. Judith Feder et al., *Long-Term Care in the United States: An Overview*, 19 HEALTH AFF. 40, 44 (2000).

12. *Id.* Medicare pays for post-acute care in hospital settings and to a very limited degree in home settings. *Id.*

13. KATHLEEN UJVARI, AARP PUB. POL'Y INST., LONG-TERM CARE INSURANCE: 2012 UPDATE 1 (2012) (reporting that 7-9 million Americans hold private insurance policies).

14. Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 61 (2004).

15. JULIE STONE, CONG. RESEARCH SERV., R40718, LONG-TERM CARE (LTC): FINANCING OVERVIEW AND ISSUES FOR CONGRESS 7 (2010). They must also fund home health care for people who would otherwise be eligible for nursing facility services. 42 U.S.C. § 1396(a)(10)(D) (2012).

16. 42 U.S.C. §1396d(a)(24) (2012).

17. 42 U.S.C. §1396d(a)(22) (2012).

18. Bagenstos, *supra* note 14, at 61.

Deficit Reduction Act of 2005 and PPACA in 2010 to move people from institutional care to home care amplified this trend.[19]

The move toward long-term care at home offers considerable promise. People with illness and disability can stay in their homes and live as independently as possible. The stories of lives transformed when people are moved from nursing homes into home care are undeniable successes.[20] Some believe that home-based care also saves states money, although the evidence is mixed on this front.[21]

On the other hand, Medicaid's evolving approach cements reliance on family and friends of people who need care in several ways. First, programs tend to be underfunded and many have long waiting lists for services.[22] Some advocates of home-based care support it because of its potential as a cost-effective alternative to institutional care, and are generally resistant to increased public expenditures for these programs. Second, without the economies of scale that enabled twenty-four-hour care in nursing homes, it is difficult for states to finance the wraparound care that people might need in a home setting. Finally, as noted above, the provision of non-medical care, such as bathing or getting dressed, is an optional Medicaid benefit; that is, states might choose not to cover this care at all, even as they shift toward home-based care.[23] Family and friends often step in to fill these gaps.

But family and friends can no longer bear such burdens without risking their own financial stability, emotional stability, health, and general wellbeing. The world has changed in ways that make de facto reliance on families and friends increasingly untenable. Care needs are becoming more intensive. Demand for long-term care has increased as medicine saves people who previously would not have survived. In 2010, the life expectancy at birth for an American was nearly 79 years,[24] ten years longer than it was in the mid-twentieth century and twenty years longer than at the beginning of the century.[25] Heroic trauma care and miracle drugs

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19. Terence Ng et al., *Medicaid Home and Community-Based Services Programs: 2010 Data Update*, KAISER FAM. FOUND. (Mar. 27, 2014), http://kff.org/medicaid/report/medicaid-home-and-community-based-service-programs.

20. Watson, *supra* note 9, at 937-38.

21. *See e.g.*, Andrea Wysocki et al., *Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care*, AGENCY FOR HEALTHCARE RES. AND QUALITY (2012), http://www.effectivehealthcare.ahrq.gov/ehc/products/369/1277/CER81_Long-Term-Care_FinalReport_20121023.pdf.

22. Ng et al., *supra* note 19, at 3.

23. *Medicaid Benefits*, MEDICAID.GOV (Oct. 29, 2014), http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Medicaid-Benefits.html.

24. Sherry L. Murphy et al., *National Vital Statistics Reports: Deaths: Preliminary Data for 2010*, CTRS. FOR DISEASE CONTROL & PREVENTION 51 (2012), http://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_04.pdf.

25. Elizabeth Arias, *National Vital Statistics Reports: United States Life Tables 52-53*, CTRS. FOR DISEASE CONTROL & PREVENTION (2007),

are preserving and extending lives of people with serious injuries.[26] And the "old old," defined as those over 80 years old, is growing as a percentage of the population.[27] More Americans suffer from chronic disease than ever before, and the proportion of Americans with chronic conditions is projected to continue to rise.[28]

At the same time, families are less able to address the needs of the chronically ill. The number of single-parent families and two wage-earner households has increased significantly over the past several decades, leaving little cushion for unanticipated caregiving needs.[29] Families have dispersed geographically.[30] Moreover, the ratio of people needing care to those who might provide it is increasingly disproportionate, as people live longer and have fewer kids.[31]

As a result, the average informal caregiver for a parent who reduces working hours or leaves the workforce faces monetary losses—foregone income, pensions, benefits, and retirement savings, including Social Security—of as much as $200,000 to $300,000.[32] Considering that the median household net worth in the

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http://www.cdc.gov/nchs/data/nvsr/nvsr59/nvsr59_09.pdf.

26. *See* Andrew I. Batavia et al., *Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disabilities*, 16 J. HEALTH POL. POL'Y & L. 523, 523 (1991) (citing studies about the changing nature of disability).

27. Arias, *supra* note 25, at 44 (of those born in 1900, only 13,529 lived to 80. The number will more than double for those born in the mid-1900s and will double again for those born in the early 21st century). *But see* DONALD L. REDFOOT & ARI HOUSER, AARP PUB. POLICY INST., MORE OLDER PEOPLE WITH DISABILITIES LIVING IN THE COMMUNITY: TRENDS FROM THE NATIONAL LONG-TERM CARE SURVEY, 1984-2004 2 (2010) (suggesting that decreasing disability rates have offset this aging to some degree, so even with a 17% increase in the older population, rates of disability increased only 1.4% between 1989 and 2004).

28. *See* Gerard Anderson & Jane Horvath, *The Growing Burden of Chronic Disease in America,* 119 PUB. HEALTH REP. 263, 267 (2004) (reporting 125 million Americans or 45% of the population with one or more chronic conditions in 2000 and that prevalence is projected to increase over the next 30 years). For example, the proportion of informal caregivers reporting to care for someone with Alzheimer's Disease or dementia rose from 6% to 12% from 2004 to 2009. NAT'L ALLIANCE FOR CAREGIVING IN COLLABORATION WITH AARP, *supra note* 6, at 41.

29. U.S. CENSUS BUREAU, STATISTICAL ABSTRACT OF THE U.S. 840 tbl.1337 (2012); Howard N. Fullerton, Jr., *Labor Force Participation: 75 Years of Change, 1950-98 and 1998-2025*, MONTHLY LAB. REV. 4 tbl.1 (1999)..

30. Ping Ren, *Lifetime Mobility in the United States: 2010*, U.S. CENSUS BUREAU (2011), http://www.census.gov/prod/2011pubs/acsbr10-07.pdf.

31. *See, e.g.*, WILLIAM O'HARE, ANNIE E. CASEY FOUND., THE CHANGING CHILD POPULATION OF THE UNITED STATES: ANALYSIS OF DATA FROM THE 2010 CENSUS 4 (2011) (reporting a decrease in the percentage of the population under age 18 from 40% in 1900 to 24% in 2010, as a result of fewer children per family and increased longevity); Emily Brandon, *65-and-Older Population Soars*, U.S. NEWS & WORLD REP., (Jan. 9, 2012, 9:15 AM), http://money.usnews.com/money/retirement/articles/2012/01/09/65-and-older-population-soars (reporting that the proportion of Americans 65 and older has grown from 4.1% in 1900 to 13% in 2012)..

32. METLIFE MATURE MKT. INST., THE METLIFE STUDY OF CAREGIVING COSTS TO WORKING

U.S. was just under $70,000 in 2011,[33] losses at this level are devastating for all but the wealthiest households. More than one-third of people caring for aging parents leave the workforce or reduce working hours, and women are more likely than men both to become caregivers and to leave the workforce altogether.[34] Informal caregivers also face significant non-economic costs, including health and psychosocial consequences.[35] For example, research shows that 40% to 70% of people caring for older adults have symptoms of depression and 25% to 50% meet the diagnostic criteria for major depression, far outpacing the rates in the general population.[36] And people providing long-term care for another undoubtedly miss out on the ability to engage in other relationships or opportunities that bring meaning to their lives. These are, in effect, the invisible copayment of a long-term care policy.

These costs threaten Americans' financial, emotional, and physical wellbeing as seriously as any of the other phenomena that have motivated the creation of social insurance programs, including unemployment, outliving one's savings, and medical spending in retirement. As we think of the next era of reform efforts, we should consider these costs collectively as posing a social risk—not as a private problem. This perspective illuminates that next-friend risk could be mitigated through better long-term care social insurance and suggests at least four implications for the development of future policy:

**1. The Scale of the Problem.** Current policy hides costs borne by next friends. By one estimate, the total costs of informal caregiving in the United States in 2009,

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CAREGIVERS: DOUBLE JEOPARDY FOR BABY BOOMERS CARING FOR THEIR PARENTS 15 (2011) [hereinafter METLIFE DOUBLE JEOPARDY] (estimating total loss, including wage, Social Security, and pensions, of $283,716 for men and $324,044 for women among Baby Boomers caring for their parents who leave the workforce for any period of time). Some studies estimates are even higher. METLIFE MATURE MARKET INSTITUTE, THE METLIFE JUGGLING ACT STUDY: BALANCING CAREGIVING WITH WORK AND THE COSTS INVOLVED 5-6 (1999) [hereinafter METLIFE JUGGLING ACT] (reporting average wage loss of $566,443, Social Security loss of $25,494, and pension loss of $67,202; median reported wage loss is $243,761).

33. *Wealth and Asset Ownership,* U.S. CENSUS BUREAU, http://www.census.gov/people/wealth (last visited Nov. 9, 2014) (follow link to *Net Worth and Asset Ownership of Households: 2011*).

34. METLIFE DOUBLE JEOPARDY, *supra* note 32, at 10.

35. *See* METLIFE JUGGLING ACT, *supra* note 32, at 5-6; NAT'L ALLIANCE FOR CAREGIVING IN COLLABORATION WITH AARP, *supra* note 6, at 47 (2009); ROSALYNN CARTER INST. FOR CAREGIVING, AVERTING THE CAREGIVING CRISIS: WHY WE MUST ACT NOW 12-13 (2010)..

36. Steven H. Zarit, *Assessment of Family Caregivers: A Research Perspective, in* 2 CAREGIVER ASSESSMENT: VOICES AND VIEWS FROM THE FIELD: REPORT FROM A NATIONAL CONSENSUS DEVELOPMENT CONFERENCE 12, 14 (2006) (summarizing studies on informal caregiving and depression). The rates of major depression in the general population are under 7%. *Major Depression Among Adults*, NAT'L INST. OF MENTAL HEALTH (Dec. 7, 2014), http://www.nimh.nih.gov/health/statistics/prevalence/major-depression-among-adults.shtml.

if hours were compensated at average care work wages, was $450 billion.[37] Accounting for this invisible copayment would require funding at double or triple its current levels. Such funding is admittedly unlikely, but this sum could anchor policymakers on a number that more realistically reflects the scale of long-term care demand.

**2. Insurance.** Most of us *could* end up responsible for the long-term care for another, even if not all of us *will*. This widespread stochastic harm—plus the failure of private long-term care insurance markets—makes social insurance an apt tool to mitigate the impact of this risk. More so, the inability of nearly all Americans to manage next-friend risk well privately implies that a universal social insurance program approach like Medicare or Social Security is a better fit than a means-tested program like Medicaid. Tactically, social insurance policy more sensitive to next-friend risk could be integrated into existing programs or could be created as part of a new, freestanding program.[38] Politically, seeing the problem from the next-friend perspective could make it more relatable for voters and policymakers, many of whom might worry about the possibility themselves. This relate-ability might in turn generate support both for increased funding and improved policies.

**3. Flexibility.** With or without additional funding, long-term care policies could be designed more flexibly to better mitigate next-friend risk. When someone becomes responsible for another, she can provide the care herself, pay for care, or do some combination of these two. If insurance were designed so that a next friend could toggle more freely between these choices, she could use benefits to minimize her own long-term harm, however she might define it. Current policies do not recognize the need for this toggle. As a result, responses to next-friend risk are often biased, most often incentivizing a next friend to provide the care herself. A realistic goal would be to aim to reduce such biases in current policies.

One way to curtail these biases is to create flexible funding, such as a voucher program in which benefits may be used to pay either a next friend or a professional care provider. Some programs, including the In-Home Supportive Services (IHSS) Program in California and the long-term care voucher system in Germany, are designed with such a toggle. While promising, these programs reveal how the details of policy design can limit choice, even with a toggle in place.[39] For example, in the IHSS program, household income calculations used to determine program eligibility include wages a cohabiting family caregiver earns outside the home, but

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37. LYNN FEINBERG ET. AL., AARP PUB. POLICY INST., VALUING THE INVALUABLE: 2011 UPDATE, THE GROWING CONTRIBUTIONS AND COSTS OF FAMILY CAREGIVING 2 (2011).

38. These ideas are explored further in my forthcoming article.

39. *See* Joshua M. Wiener & Alison E. Cuellar, *Public and Private Responsibilities: Home- and Community-Based Services in the United Kingdom and Germany*, 11 J. AGING & HEALTH 417 (1999).

do not account for IHSS benefits paid to the family member.[40] This means the IHSS benefits paid to a wife to care for her husband would not disqualify the husband from receiving benefits, but wages from the wife's work in a job outside the home likely would. This rule creates a strong incentive for her to provide care directly, even if doing so threatens her long-term security. Admittedly, even well-designed vouchers would be layered on underlying social norms and institutions that have long compelled women to take on caregiving, even at high personal costs.[41] Nevertheless, long-term care policies could be designed so that they do not reinforce, and perhaps counterbalance, this gendered bias.

Another way to create flexibility is to invest in better community-based infrastructure for long-term care. This might take the form of a small-scale group home or a day care for care recipients, allowing a next friend to go to work and still have time with the care recipient in the evening and on weekends. The next friend would better be able to balance her career with caregiving, minimizing impact on her earnings and the long-term harm to her own wellbeing. In the absence of appealing options for paid care, next friends have little real choice. Such models exist in experimental form, but should be expanded and replicated to help mitigate next-friend risk.[42]

**4. Tradeoffs.** Finally, taking next-friend risk seriously forces the (admittedly uncomfortable) question of whether social policy should more intentionally balance the needs of care recipients and next friends, even if it results in a solution that is suboptimal for the care recipient in some cases. For example, if an elderly widower has a stroke, the primary goal of *current* long-term care law and policy is to ensure that he has adequate care supports in the least restrictive setting appropriate.[43] If his daughter moves him into her home, as Medicaid policies

40. 20 C.F.R. § 416.1161(a)(16). Under this same rule, "in-kind support and maintenance" is not deemed income either.

41. Tomes of scholarship document how social, religious, moral, cultural, and other influences inscribe caregiving of all kinds as a personal and gendered obligation. A couple of illustrative examples from different disciplines include BORIS & KLEIN, *supra* note 10; MARTHA FINEMAN, THE AUTONOMY MYTH: A THEORY OF DEPENDENCY (2005); HARTOG, *supra* note 8; JOAN WILLIAMS, UNBENDING GENDER (2001). *See also* Vicki Schultz, *Life's Work*, 100 COLUM. L. REV. 1881, 1899-1919 (2000) (describing different feminists schools of thought on caregiving).

42. For example, On Lok Lifeways provides a mix of at-home, group care, and residential care to meet an individual's need. On Lok was developed to help the Asian American community in San Francisco and formed the basis for a larger Medicaid demonstration program, the Program for All-Inclusive Care for the Elderly. The Green House Project is another emerging model with small group homes across the country that are designed so that residents get nursing-home style care but still feel at home. COMM. ON THE FUTURE HEALTH CARE WORKFORCE FOR OLDER AMERICANS BD. ON HEALTH CARE SERVS., INST. OF MED., RETOOLING FOR AN AGING AMERICA: BUILDING THE HEALTH CARE WORKFORCE 81-85 (2008).

43. Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999) (holding that institutionalization, when avoidable, can be a form of discrimination under the Americans with Disabilities Act of 1990).

increasingly encourage, the widower's needs could be fully met at the lowest possible public cost. But his daughter may have to reduce working hours or leave a secure job with benefits, threatening her family's long-term finances and, possibly, her own health and wellbeing. Such results, where each generation sacrifices its security for the last one, are simply not sustainable.

Long-term care is an elusive problem, both because of its high cost and because these costs can be hidden as they are passed on to next friends. Seeing the problem of long-term care from the perspective of next friends reveals its full complexity. Serious illness and disability have reverberating effects. They create insecurity not only for the afflicted individual, but also for his or her family and friends. The next era of social insurance policy for long-term care must grapple with the reverberations of long-term care risk to create meaningful security for Americans.