Reimagining the Risk of Long-Term Care

*Allison K. Hoffman**

Abstract:

U.S. law and policy on long-term care fail to address the insecurity American families face due to prolonged illness and disability—a problem that grows more serious as the population ages and rates of disability rise. This Article argues that, even worse, we have focused on only part of the problem. It illuminates two ways that prolonged disability or illness can create insecurity. The first arises from the risk of becoming disabled or sick and needing long-term care, which could be called "care-recipient" risk. The second arises out of the risk of becoming responsible for someone else's care, which I call "next-friend" risk. The law and social welfare policy has focused on the first, but this Article argues that the second equally threatens the wellbeing of American families. While attempting to mitigate care-recipient risk, in fact, the law has steadily expanded next-friend risk, by reinforcing a structure of long-term care that relies heavily on informal caregiving. Millions of informal caregivers face financial and nonmonetary harms that deeply threaten their own long-term security. These harms are disproportionately experienced by people who are already vulnerable—women, minorities, and the poor. Scholars and policymakers have catalogued and critiqued these costs but treat them as an unfortunate byproduct of an inevitable system of informal care.

This Article argues that if we, instead, understand becoming responsible for the care of another as a social risk—just as we see the chance that a person will need long-term care as a risk—it could fundamentally shift the way we approach

* Thank you to my excellent edit team at YJHPLE and to Alex Boni-Saenz, Sam Bray, Ann Carlson, Scott Cummings, Ingrid Eagly, Jill Horwitz, Robert Hughes, Sung-Hui Kim, Dani Kaiserman, Russell Korobkin, Gillian Lester, Timothy Malloy, Jon Michaels, Eric Miller, Jennifer Mnookin, Steve Munzer, Jason Oh, Jessica Roberts, Vicki Schultz, Dan Schwarcz, Joanna Schwartz, Seana Shiffrin, Kathy Stone, Rebecca Stone, Seth Weisbord, Noah Zatz, and Eriz Zolt and the participants at Harvard Law School's Petrie-Flom Center Workshop, the Southern California Junior Faculty Scholarship Workshop, the Emerging Family Law Scholars and Teachers Workshop, and faculty workshops at UCLA, Berkeley, Boston University, Irvine, Loyola, Penn, and Southwestern Law Schools for valuable comments on various drafts of this project. For research assistance, I am grateful to Scott Chandler, Erynn Embree, Billy Herbert, Kenneth Kennedy, Doug Merkel, Eli Tomar and especially research librarian extraordinaire Lynn McClelland. This article is dedicated to Elliot, whom I hope will never feel obligated to care for his parents, and to some of the most admirable next friends I know—Bonnie and Les, Michael and Muffy, Lizzie, Brent, Zannah, and Lilly, and Larry and Dianne.

long-term care policy. In risk-theory terms, this Article proposes we reimagine the risk of long-term care.

TABLE OF CONTENTS

TABLE OF CONTENTS **149**

INTRODUCTION **151**

I. THE EVOLUTION OF LONG-TERM CARE LAW AND POLICY FROM THE CARE-RECIPIENT PERSPECTIVE **157**

A. THE FAILURE OF PRIVATE INSURANCE FOR LONG-TERM CARE 158

B. THE EVOLUTION AND LIMITS OF SOCIAL INSURANCE FOR LONG-TERM CARE 159

1. THE EMERGENCE OF SOCIAL POLICY ON LONG-TERM CARE 161

2. MEDICAID AND THE MODERN ERA OF SOCIAL INSURANCE 162

3. MEDICAID'S RECENT SHIFT: CARE RETURNS HOME 165

C. THE RESULTING STRUCTURE OF LONG-TERM CARE 168

II. REIMAGINING LONG-TERM CARE RISK FROM THE NEXT-FRIEND PERSPECTIVE **171**

A. LONG-TERM CARE AS A PRIVATE OBLIGATION 174

1. SOCIAL NORMS AND LONG-TERM CARE 175

2. THE NUMBERS ON INFORMAL CAREGIVING 180

B. OBLIGATION IN A CHANGING WORLD 182

C. THE COST OF PRIVATE OBLIGATION: THE INVISIBLE COPAYMENT 184

D. REIMAGINING PRIVATE OBLIGATION AS SOCIAL RISK 188

E. THE IMPLICATIONS OF IMAGINING NEXT-FRIEND RISK 192

III. SOCIAL INSURANCE FOR NEXT-FRIEND RISK **195**

A. THE CASE FOR SOCIAL INSURANCE FOR NEXT-FRIEND RISK 195

B. PRINCIPLES TO GUIDE THE DESIGN OF SOCIAL INSURANCE FOR NEXT-FRIEND RISK 198

C. POLICYMAKING AND DYNAMIC EFFECTS 201

D. CONSIDERATIONS FOR WHAT COUNTS AS NEXT-FRIEND RISK 204

1. WHO BEARS NEXT-FRIEND RISK? 205

2. DISTINGUISHING RISK FROM ROUTINE 210

3. DOES FINANCIAL STATUS QUO MATTER? 211
E. OBJECTIONS TO INSURING NEXT-FRIEND RISK 214
IV. A BRIEF SKETCH OF POLICY OPTIONS 219
A. ENVISIONING NEXT-FRIEND SOCIAL INSURANCE 219
1. THE BASIC CONCEPT 219
2. MODELS FOR NEXT-FRIEND SOCIAL INSURANCE 223
B. INCREMENTAL REFORMS 225
1. FILLING IN MEDICAID'S GAPS 226
2. EXPANDING AND DESIGNING POLICY TOGGLES IN MEDICAID CONSUMER-DIRECTED CARE PROGRAMS 226
3. INVESTMENTS IN INFRASTRUCTURE 228
4. RESHAPING THE SOCIAL AND INSTITUTIONAL BASELINE 230
CONCLUSION 231

INTRODUCTION

Americans' need for long-term care poses a daunting public policy challenge.[1] The actual demand for care has grown as the rates of disability increase, as modern medicine saves people who previously would not have survived, and as the number of "old old" Americans grows.[2] An underlying panic about the impending long-term care crisis bubbles up regularly in the news.[3] Private efforts to address it have fallen short. Even the social insurance program for long-term care that Ted Kennedy ushered through as part of the Patient Protection and Affordable Care Act (ACA),[4] called the CLASS Act,[5] collapsed.[6] Congress then tasked a Long-Term Care Commission to generate a new solution, and the Commission failed to reach consensus.[7] Long-term care policy is in limbo.

---

1 Long-term care—sometimes called "long-term services and supports"— refers to assistance for someone with chronic illness or disability who faces physical or cognitive limitations. The law defines this care in terms of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include personal care, such as bathing, dressing, getting in and out of bed, mobility, eating, and toileting. IADLs include more complex functions, including managing finances, managing medication, and shopping. INST. OF MED., THE FUTURE OF DISABILITY IN AMERICA 50 (2007) [hereinafter IOM, FUTURE OF DISABILITY]. This Article's discussion of long-term care refers to assistance with ADLs and IADLs, not to home health care or medical care (although, as discussed herein, the lines blur at times).

2 *See* Section II.B for discussion of other factors that have increased the need for long-term care. "Old old" generally refers to people over 80 years old.

3 *See, e.g.*, Jason Kane, *6 Tips for Averting America's Looming Long-Term Care Crisis*, PBS NEWSHOUR (Nov. 6, 2013); Bob Kerrey, *Long-Term Solutions... ...for Long-Term Care*, CHI. TRIBUNE (Nov. 21, 2008), http://articles.chicagotribune.com/2008-11-21/news/0811200685_1_quality-long-term-care-providers-health-care; Penelope Wang, *The Retirement Crisis Nobody Talks About: Long Term Care,* TIME (June 20, 2014), http://time.com/money/2901647/the-retirement-crisis-nobody-talks-about-long-term-care; John F. Wasik, *Long-Term Care Insurance Can Baffle, With Complex Policies and Costs,* N.Y. TIMES (Dec. 19, 2015), http://www.nytimes.com/2015/12/19/your-money/long-term-care-insurance-can-baffle-with-complex-policies-and-costs.html.

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

5 Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, § 8002(a) 124 Stat. 119, 828-41 (creating Title XXXII of the Public Health and Safety Act).

6 The Obama Administration put the program on hold and Congress repealed it because they said it was actuarially unsound. American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642, 126 Stat. 2313, 2358 (2013).

7 *Examining the Finance and Delivery of Long-Term Care in the US: Hearing Before Subcomm. On Health of the H. Comm. on Energy & Commerce*, 114th Cong. (2016) (testimony of Alice M. Rivlin, Co-Chair, Long-Term Care Initiative, Bi-Partisan Policy Center).

Policymakers and scholars who have wrestled with social policy for long-term care primarily consider the problem from the perspective of the ten million Americans who need such care—in other words from the perspective of care-recipient risk. Yet the need for long-term care undermines the security of American families in reverberating ways.

This Article argues that the full insecurity of long-term care becomes clear only when we look at the problem also from the perspective of the family and friends who are responsible for providing this care. These informal caregivers are experiencing what this Article proposes we think of as "next-friend" risk.[8]

The early to mid-twentieth century marked a period of decreased reliance on family for long-term care, as social insurance infrastructure developed. Local, state, and federal governments funded care in public institutions and private nursing homes. Yet, late twentieth century law and policy, especially with the creation and evolution of Medicaid, turned the tide back toward older traditions of family caregiving and has resulted in a legal structure that institutionalizes and intensifies caregiving burdens for American families.

Medicaid has become the locus of social insurance for long-term care, financing sixty percent of all paid long-term care.[9] Because Medicaid eligibility is means-tested, Americans must have almost no income or assets to qualify.[10] That, plus the fact that few people have any private insurance coverage for long-term care, means that most Americans have only two choices: "spend down" their savings to become poor enough to qualify for Medicaid or, more often, rely on family and friends.

Yet, even the people eligible for Medicaid increasingly rely on friends and family for significant amounts of care. Over the past few decades, Medicaid funding for long-term care has shifted from having a bias for care in

---

8 I borrow the phrase "next friend" from the legal term for a person in litigation who represents someone with a disability who is otherwise unable to represent himself. In the context of long-term care, although not necessarily a legal guardian, the next friend protects the interests of another, by providing care directly or arranging it. I use this term instead of "informal caregiver" or "family caregiver" to emphasize that the next friend might not provide care personally (instead helping to outsource it) and is sometimes, although less frequently, a non-relative.

9 Carol V. O'Shaughnessy, *National Spending for Long-Term Services and Supports (LTSS), 2012*, NAT'L HEALTH POL'Y FORUM 3 (2014), https://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf (excluding Medicare post-acute care). Medicaid, while it might have once been arguably an entitlement program, has over time increasingly resembled a social insurance program, spreading health spending risk across a growing population of beneficiaries, especially when considering long-term care since the program is universal for anyone who depletes assets to qualify, as discussed *infra* note 70.

10 *See infra* note 70 (describing Medicaid's eligibility rules).

institutions to a bias for care in homes. Now, one-half of Medicaid long-term care spending pays for home-based care.[11]

The conventional wisdom is that this trend is wholly positive.[12] It has decreased reliance on poor-quality institutional care, and it enables many people with serious illness or disability to live at home as independently as possible. On the other hand, Medicaid's evolving approach amplifies burdens for beneficiaries' family and friends.

Medicaid programs for home-based care are underfunded and have long waiting lists and gaps. These programs often limit personal care services and the other non-medical aspects of caregiving that have long been neglected in social welfare programs. Family and friends fill these gaps—gaps that were not as acute in the era of institutional care. At the end of the twentieth century, the law has thus re-inscribed long-term care as a private obligation.

Yet long-term care as a private obligation is increasingly untenable. The actual care needs of people with chronic illness and disability are becoming more intensive.[13] At the same time, families and friends are less able to address these needs. The breadwinner family structure, where the husband earned wages and the wife took care of the home and family, has eroded. Single-parent families and two wage-earner households are the new normal, leaving little cushion to absorb caregiving.[14] Families have dispersed geographically.[15] And the ratio of people needing care to those who can provide it is increasing as people live longer and have fewer kids.[16]

As a result of increased obligations combined with the changing shape of families, informal caregivers, who are disproportionately women, face

---

11 Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013: Home and Community-Based Services Were a Majority of LTSS Spending*, CTRS. FOR MEDICARE & MEDICAID SERVS. 3 (2015), https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf (documenting that home and community-based services accounted for 51.3% of total Medicaid spending on long-term services and supports in 2013).

12 *See, e.g.*, Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History*, 26 GA. ST. U. L. REV. 937, 937-38, 967-68 (2010) (describing this trend and the benefits of increased home-based care).

13 *See* note 185 *infra* and accompanying text.

14 *See* U.S. CENSUS BUREAU, STATISTICAL ABSTRACT OF THE U.S.: 2012, 840 tbl. 1337 (2012) (documenting the rise in single-parent households); Howard N. Fullerton, Jr., *Labor Force Participation: 75 Years of Change, 1950-98 and 1998-2025*, 1999 MONTHLY LAB. REV. 3, 4 tbl. 1 (documenting the past and projected increasing participation of women in the U.S. labor force).

15 *See* Ping Ren, *U.S. Census Bureau, Lifetime Mobility in the United States: 2010*, U.S. CENSUS BUREAU 1, 3 (2011) ("The U.S. population is characterized by high mobility.").

16 *See* Emily Brandon, *65-and-Older Population Soars*, U.S. NEWS (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).

staggering burdens.[17] By one estimate, the financial losses alone—including forgone income, pensions, benefits, and retirement savings—sustained by the average informal caregiver who leaves the workforce to care for a parent are $300,000.[18] These monetary losses are just the beginning. Many informal caregivers experience permanent harm to their health, relationships, and general wellbeing.[19]

What if instead of designating these costs as a private obligation, we considered them as a collective problem—the manifestation of a social risk? While caregiving might have been excluded from the American vision of social insurance at its nascence, when it was perceived as not posing a threat to the security of the breadwinner family, long-term care is clearly a serious threat to the security of American families now and should be recognized as such.

This Article offers a new possibility: considering the burdens of caregiving, at least with respect to long-term care, as a serious social risk—one equal to the risk of needing long-term care. This perspective could offer insights for two areas of legal scholarship. First, a considerable body of health, elder, and disability law and policy scholarship addresses long-term care as a social insurance problem, but it assumes the primary insurable risk is care-recipient risk.[20] Implicit in this work is, in most cases, the inevitability of continued, substantial reliance on informal caregiving—a position this Article questions. In contrast, a rich body of feminist legal scholarship demands greater state support for caregiving, mostly with regard to childcare but to some extent also long-term care, based on ideas that caregiving is a public responsibility or a public good.[21] Seeing the burdens next friends face as a social risk provides another justification for enhanced state support, and, even more importantly, reframing the costs caregivers face in the language of risk justifies social insurance to address these costs.[22]

---

17 *See infra* Section II.C.

18 METLIFE MATURE MARKET INST., THE METLIFE STUDY OF CAREGIVING COSTS TO WORKING CAREGIVERS: DOUBLE JEOPARDY FOR BABY BOOMERS CARING FOR THEIR PARENTS 15 (2011) [hereinafter METLIFE, DOUBLE JEOPARDY], https://www.metlife.com/assets/cao/mmi/publications/studies/2011/Caregiving-Costs-to-Working-Caregivers.pdf. Another recent study models the median opportunity costs of two years of caregiving for a sick mother to be $164,726. Meghan M. Skira, *Dynamic Wage and Employment Effects of Elder Parent Care*, 56 INT'L ECON. REV. 63, 82 (2015). Since the average duration of caregiving is twice as long, *see infra* note 182 and accompanying text, the average caregiver would face opportunity costs twice this amount.

19 METLIFE, *supra* note 18, at 15.

20 *See infra* notes 122-123 and accompanying text.

21 *See infra* notes 125-126.

22 Anne Alstott's "life-planning insurance" is a form of social insurance for parents of children with disabilities. ANNE ALSTOTT, NO EXIT 117-37 (2004). She justifies her proposal

The language of risk is powerful. How a society understands risk strongly shapes perceptions of the proper role of the state.[23] Every creation or expansion of social insurance in the United States required reimagining something that had previously been thought of as a private cost or obligation instead as a social risk—a threat to American families' security—in order to motivate a collective solution.[24]

The costs and obligations next friends shoulder look very similar to other insurable risks. Responsibility for the long-term care of another is unplanned and often unavoidable. The level of harm is stochastic and unmanageable for almost all Americans in the worst-case scenario involving years of intensive care. This responsibility threatens Americans' financial, emotional, and physical wellbeing as much as other phenomena that have motivated government response, including work injuries, unemployment, outliving one's savings, and medical spending in retirement.[25] Taking next-friend risk seriously has at least four major implications for long-term care policies.

---

based on public responsibility owed to these parents in return for their heightened caregiving obligation. This Article could support a similar intervention but based on a different rationale—the existence of a widely shared social risk. This rationale suggests the need for a social insurance solution available to any friend or family member who takes on the responsibility of another's long-term care, not just to parents.

23 The language of risk is increasingly used to evoke an individual's responsibility to reduce risk though responsible choices, but historically it described problems that warranted a collective solution. *See, e.g.*, JACOB HACKER, THE GREAT RISK SHIFT (2006) (describing what he calls the "personal responsibility crusade" and how it has created insecurity for American families by undermining social insurance policies); Tom Baker & Jonathan Simon, *Embracing Risk*, *in* EMBRACING RISK (Tom Baker & Jonathan Simon eds., 2002) (describing both an increased recognition of social problems in terms of risk and a reactionary trend against spreading risk); Martha McCluskey, *Rhetoric of Risk and Redistribution of Social Insurance*, *in* EMBRACING RISK, *supra*, at 146 (describing a shift in the United States from concern with the risk faced by workers to that faced by employers and big business); Jonathan Simon, *Risk and Reflexivity: What Socio-Legal Studies Add to the Study of Risk and the Law,* 57 ALA. L. REV. 119 (2005) (describing the evolution of the risks that most concern Americans and changing beliefs on how best to manage risk).

24 Examples of scholarship that describe how an understanding of risk has motivated state action to ameliorate it include MICHELE LANDIS DAUBER, THE SYMPATHETIC STATE: DISASTER RELIEF AND THE ORIGINS OF THE AMERICAN WELFARE STATE (2013); 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); DAVID A. MOSS, WHEN ALL ELSE FAILS: GOVERNMENT AS THE ULTIMATE RISK MANAGER (2002); JOHN FABIAN WITT, THE ACCIDENTAL REPUBLIC: CRIPPLED WORKINGMEN, DESTITUTE WIDOWS, AND THE REMAKING OF AMERICAN LAW (2004); Baker & Simon, *supra* note 23; François Ewald, *The Return of Descartes's Malicious Demon: An Outline of a Philosophy of Precaution* (Stephen Utz trans.), *in* EMBRACING RISK, *supra* note 23, at 278-81; and Michele L. Landis, *Fate, Responsibility, and 'Natural' Disaster Relief: Narrating the American Welfare State,* 33 L. & SOC'Y REV. 257, 271 (1999).

25 These programs are addressed by a mix of mandatory private insurance and social insurance, but they share in common that social policy requires risk to be shared collectively,

First, it redefines the scale of the problem of long-term care. Current policy hides costs borne by next friends, in ways described in Part I below. In 2013, by one conservative estimate, informal caregivers provided $470 billion worth of long-term care services to adults, if time spent caregiving were valued at market caregiver wages.[26] Accounting for replacement costs for just these hours—only a part of the problem—would require additional funding of triple Medicaid's current spending on long-term care. Even if this level of additional funding is unlikely, considering these costs as part of the problem could at least anchor policymakers on a higher number and a more complete view of the costs of long-term care, as discussed in Part II.

Second, understanding these costs as a manifestation of next-friend risk implies that social insurance might be the best tool to address the problem.[27] Part III makes the case for better social insurance protections against next-friend risk and considers conceptually what it would require to create such protections. This Part examines where next-friend risk begins and ends and for whom.

Third, whether with additional funding or not, policies could be designed to better mitigate next-friend risk, as discussed in Part IV. There are two ways that a next friend could, in theory, respond to another's need for care: provide it personally or pay for care. If she could toggle more freely between these two choices—provide or pay—she could determine how to use benefits simultaneously to minimize her own harm and to meet the needs of the person who needs long-term care. Current policy is focused so narrowly on care-

---

rather than borne privately.

26 Susan C. Reinhard et al., *Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain*, AARP PUB. POL'Y INST. 3 (2015). Note that this estimate, based on eleven surveys of family caregivers, only accounts for care recipients age 18 and older and uses an hourly wage of $12.51. Other estimates are higher and lower. One study estimates opportunity costs of $412 billion for informal elder caregivers under the age of 65 ($522 billion if also including those over age 65). Amalavoyal V. Chari et al., *The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey*, 50 HEALTH SERVS. RES. 871, 877 (2015). The same study estimates replacement costs ranging from $221 to 642 billion, depending on whether skilled or unskilled labor is used ($7.25 per hour for the former estimate and $21 per hour for the latter). *Id.*

27 "Social insurance" is used to refer to government programs that spread risk, such as Medicare or Social Security. *See* MARMOR ET AL., *supra* note 24. Because social insurance also intentionally redistributes resources, some argue that it is actually a tax-and-transfer program and not like "real" (meaning private) insurance. *See* James Kwak, "*Social Insurance,*" *Risk Spreading, and Redistribution*, *in* RESEARCH HANDBOOK ON THE ECONOMICS OF INSURANCE LAW 127 (Daniel Schwarcz & Peter Siegelman eds., 2015). This view, however, fails to recognize that all insurance, private and public, is redistributive from low-risk to high-risk people and from the lucky to the unlucky. Pricing can attempt to limit this redistribution or to counterbalance regressivity that ensues, but regardless of the extent, redistribution is a defining feature of all insurance.

recipient risk that it does not even see the need for this toggle and often prevents it.

Fourth, recognizing next-friend risk forces the admittedly uncomfortable question of whether social policy must better balance the needs of care recipients and next friends.

It is not easy to conceive of a solution to the long-term care problem when seen from both the care-recipient and next-friend perspectives, because of its sheer magnitude and complexity. But turning a blind eye to the costs borne by next friends by hiding these costs in homes across the country is not a sustainable solution. Any social insurance policy for long-term care—whether comprehensive or not—must at least grapple with the reverberating ways that long-term care needs undermine Americans' security; otherwise, policies will, in the process of creating security for some, bolster social structures that undermine security for others.

I. THE EVOLUTION OF LONG-TERM CARE LAW AND POLICY FROM THE CARE-RECIPIENT PERSPECTIVE

The existence of insurance for long-term care is a relatively recent phenomenon. Before the twentieth century, long-term care was the responsibility of family or community.[28] This notion of familial responsibility, however, has been an ambivalent one in the United States since at least the mid-nineteenth century, when a "society defined by mobility and free labor" weakened presumptions of family obligation.[29] As a result, other forms of providing and paying for long-term care slowly began to emerge.

Long-term care insurance—both private and social—has had mixed results. Private long-term care insurance has largely failed and, experts agree, would be challenging to revive.[30] Social insurance has evolved and expanded but is still piecemeal and partial.[31] Despite limited reach, both private and social long-term care insurance work, in theory, to cushion the harms people suffer when they face chronic illness or physical or mental disability. In other words, both aim to mitigate care-recipient risk. Policies can pay for variable amounts of help with personal care, such as bathing, dressing, getting in and out of bed, eating, and using the toilet—collectively referred to as the

28 *See* David Barton Smith & Zhanlian Feng, *The Accumulated Challenges of Long-Term Care*, 29 HEALTH AFF. 29, 29 (2010).

29 HENDRICK HARTOG, SOMEDAY ALL THIS WILL BE YOURS: A HISTORY OF INHERITANCE AND OLD AGE 29 (2012).

30 *See* Jeffrey R. Brown & Amy Finkelstein, *Insuring Long-Term Care in the U.S.*, 25 J. ECON. PERSP. 119, 129-31 (2011).

31 *See generally* EILEEN BORIS & JENNIFER KLEIN, CARING FOR AMERICA: HOME HEALTH WORKERS IN THE SHADOW OF THE WELFARE STATE (2012) (describing the evolution of the government's role in paying for caregiving).

Activities of Daily Living (ADLs)—and also with more complex functions, such as managing finances, household chores, medication, and shopping—collectively, Instrumental Activities of Daily Living (IADLs).[32]

This Part describes the emergence of long-term care insurance and how, in the end, Medicaid became the primary locus of public long-term care funding. It illustrates how the development of Medicaid policy from the care-recipient perspective has provided greater security for some people with disabilities and illness, but, at the same time, has increased and cemented reliance on friends and family to meet care-recipients' long-term care needs.

A. The Failure of Private Insurance for Long-Term Care

Private insurance struggles under classic conditions of market failure.[33] Only seven to nine million Americans in 2010 held private long-term care insurance policies.[34] Experts attribute the low penetration rate of private long-term care insurance to both perception and prices. Research shows that people undervalue the purchase of long-term care insurance due to poor information or cognitive biases that cause them to underestimate their future long-term care needs.[35] This undervaluation is compounded by the high price of policies, caused in part by pervasive adverse selection (i.e., people who buy policies are more likely to use them).[36]

Even without such problems, many people would still forgo private coverage. For low- and middle-income people, who might become eligible for Medicaid, its existence as a safety net crowds out private coverage.[37] For

---

32 IOM, FUTURE OF DISABILITY, *supra* note 1, at 50. I discuss below in Section II.E. why mitigating care-recipient risk does not necessarily mean simultaneously mitigating risk for next friends, based on both the comprehensiveness and the particular design of long-term care insurance.

33 *See* Brown & Finkelstein, *supra* note 30, at 129.

34 *See* Kathleen Ujvari, *Long-Term Care Insurance: 2012 Update*, AARP PUB. POL'Y INST. 1 (2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/ltc-insurance-2012-update-AARP-ppi-ltc.pdf.

35 *See* Brown & Finkelstein, *supra* note 30, at 131; Jeffrey R. Brown, et al., *Long-Term Care Insurance Demand Limited by Beliefs About Needs, Concerns About Insurers, and Care Available from Family*, 31 HEALTH AFF. 1294, 1300 (2012).

36 *See* Brown & Finkelstein, *supra* note 30, at 126-28; Mark J. Browne, *Adverse Selection in the Long-Term Care Insurance Market*, *in* INSURANCE: THEORETICAL ANALYSIS AND POLICY IMPLICATIONS 97 (Pierre-André Chiappori & Christian Gollier eds., 2006); Emily Oster et al., *Genetic Adverse Selection: Evidence from Long-Term Care Insurance and Huntington Disease,* 94 J. PUB. ECON. 1041 (2010) (showing selection among people with Huntington Disease into long-term care insurance markets).

37 *See* Jeffrey R. Brown & Amy Finkelstein, *The Interaction of Public and Private Insurance: Medicaid and the Long-Term Care Insurance Market*, 98 AM. ECON. REV. 1083,

those unlikely to qualify for Medicaid, the decision not to buy long-term care insurance might be a way for aging parents to ensure family members will care for them personally, in their homes, rather than use policy benefits to put them in a nursing home.[38] Since private insurance generally does not pay for family care, having private insurance is less appealing to people who prefer that a family member or close friend provide care.[39]

Because of these problems, the current private market is unraveling. Premium rates are unstable and for some policies the benefits are not guaranteed or inflation protected.[40] Even in the best case, benefits are typically insufficient to pay for all necessary care, especially for someone who wants to receive care at home.[41] One expert notes that "the prospective insured must have access to a dependable network of family, friends, and others to supplement the [paid] home care provider if she expects to use the policy's benefits for home care."[42]

In light of these challenges, many major insurers are terminating their business in long-term care.[43] Several attempts to revive the market, through tax incentives and programs that offer people who purchase private policies Medicaid eligibility with greater asset protection, have had little effect.[44] There may be ways to reverse this trend,[45] but to the extent the private insurance market continues to struggle, social insurance offers the only viable option for long-term care insurance for most Americans.

B. The Evolution and Limits of Social Insurance for Long-Term Care

Long-term care has not fit easily into the particular American vision of social insurance either and, as a result, social insurance policies to address long-term care needs have been incremental and incomplete. President Theodore Roosevelt described the goal of social insurance as protection

---

1092-93 (2008).

38 Mark V. Pauly, *The Rational Nonpurchase of Long-Term-Care Insurance*, 98 J. POL. ECON. 153, 163 (1990).

39 Corina Mommaerts, Long-Term Care Insurance and the Family (Nov. 11, 2015) (unpublished manuscript) (draft on file with author) (showing that informal care by family members weakens demand for long-term care insurance).

40 Insurers are prohibited from raising rates for individual policyholders, but they can and have raised rates for an entire class of policies, doubling or even tripling premiums and causing policyholders to drop coverage. *See* Richard L. Kaplan, *Retirement Planning's Greatest Gap: Funding Long-Term Care*, 11 LEWIS & CLARK L. REV. 407, 440 (2007).

41 *Id.* at 432.

42 *Id.*

43 *Id.* at 442.

44 *Id.* at 443-48. Because any assets in excess of insurance benefits must be depleted and the home equity limits still apply, this program really only targets those just above Medicaid thresholds. *Id.*

45 *See* Brown & Finkelstein, *supra* note 30; Brown & Finkelstein, *supra* note 37.

against the "hazzards [sic] of sickness, accident, invalidism, involuntary unemployment and old age."[46] These hazards shared the common feature of threatening the family wage due to a breadwinner's inability to work.[47] The role of social insurance, in turn, was to replace lost wages. Long term-care was not seen as a threat to the family wage. Non-medical caregiving was perceived as being absorbed seamlessly into a breadwinner household structure by the non-wage-earning wife.[48] Even medical care was relatively inexpensive and often ineffective at the time when social insurance first emerged.[49] As a hybrid of medical care and caregiving, long-term care was a low priority for early social policy efforts.

Over time, however, social policies took up long-term care, and Medicaid eventually emerged as the locus for long-term care social insurance policy. To be clear, a variety of other government programs address other needs of people with chronic illness or disability by, for example, replacing a portion (albeit small) of lost wages through disability insurance[50] or paying for medical needs through medical insurance. These programs, while critically important for people with disabilities and chronic illness, do not address or account for their long-term care needs—the assistance that they require on a daily basis.

This Section describes Medicaid's emergence and evolution, how it has attempted to address the needs of care recipients, and, in the process, how it has reaffirmed and intensified obligations for their friends and family.

---

46 Theodore Roosevelt, Address Before the Convention of the National Progressive Party in Chicago, Illinois (Aug. 6, 1912) (transcript at http://www.ssa.gov/history/trspeech.html).

47 GRAETZ & MASHAW, *supra* note 24, at 212. In the breadwinner family structure, the husband earned the wages and the wife cared for the household and family. *See, e.g.*, ALICE KESSLER-HARRIS, IN PURSUIT OF EQUITY: WOMEN, MEN AND THE QUEST FOR ECONOMIC CITIZENSHIP IN TWENTIETH CENTURY AMERICA (2001).

48 BORIS & KLEIN, *supra* note 31; *see also* 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'Y & L. 523, 527 (1991) (describing traditional reliance on a system of "informal support" provided by family members and close friends); Katherine C. Pearson, *Filial Support Laws in the Modern Era: Domestic and International Comparison of Enforcement Practices for Laws Requiring Adult Children To Support Indigent Parents*, 20 ELDER L.J. 269, 272 (2012)(describing how filial support laws support this notion of family caregiving). One early exception was the creation of public institutions for the care of the "feebleminded" in the early 1900s. E. FULLER TORREY, AMERICAN PSYCHOSIS: HOW THE FEDERAL GOVERNMENT DESTROYED THE MENTAL ILLNESS SYSTEM 4 (2013).

49 *See* PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE 383, 388 (1982).

50 Disability benefits, including Social Security Disability, Supplemental Security Income, and Workers Compensation, together replace only 25% of lost income and are insufficient to pay for long-term care needs. *See* GRAETZ & MASHAW, *supra* note 24, at 84.

1. The Emergence of Social Policy on Long-Term Care

In the early 1900s, long-term care was "the last holdover of the Elizabethan poor-law approach."[51] The only public welfare for long-term care was provided in poorhouses, which "amounted to incarceration for destitution."[52] Most people remained reliant on family care.[53]

But over the course of the twentieth century, publicly funded support for long-term care grew. Early efforts at the state and local levels funded the creation of public hospitals, state mental asylums, and schools for the blind and the deaf.[54] After the Great Depression, the federal government entered into the fold with cash and in-kind assistance programs to support people with disabilities. Federal efforts began in earnest with the Social Security Act of 1935, which included the Old-Age Assistance program (for poor elderly), Aid to the Blind, and Aid to Dependent Children, which were all programs of cash assistance.[55]

These programs ushered in a private nursing home industry. The federal matching funds for institutional care could not be used for "an inmate of a public institution," including state mental asylums and almshouses.[56] The availability of this restricted funding spurred the growth of new private institutions that could accept the funds.[57]

Even as nursing home care expanded, home-based care continued with the support of various local, state, and federal efforts including the Works Progress Administration's "Housekeeping Services."[58] These programs funded everything from nursing care to personal care and even housework and childcare, in some cases, for ill or disabled mothers.[59] The mid-century rise of private medical insurance, however, began to undermine these home-based care programs. Insurance required services that were medical in nature to be performed by licensed providers, which relocated the medical aspects of caregiving from homes to hospitals. The other care-intensive aspects were carved out of medical insurance and left to underfunded state welfare programs.[60]

---

51 Smith & Feng, *supra* note 28, at 27.

52 *Id.*; *see* Watson, *supra* note 12, at 940.

53 Even for family members in institutions, women were responsible for taking care of clothing, bedding, and other necessities. BORIS & KLEIN, *supra* note 31, at 20.

54 *See* Watson, *supra* note 12, at 941.

55 *Id.* at 941-47; Smith & Feng, *supra* note 28, at 31.

56 Watson, *supra* note 12, at 942; *see* Smith and Feng, *supra* note 28, at 31. The federal mental health legislation in the 1940s similarly prohibited federal funds to be spent on people living in state mental health hospitals. TORREY, *supra* note 48, at 26.

57 Watson, *supra* note 12, at 944.

58 BORIS & KLEIN, *supra* note 31, at 22.

59 *Id.* at 30.

60 *Id.* at 65.

Modeled on this medicalized framework, the 1960 amendments to the Social Security Act, including the Kerr-Mills Act, were the precursor to Medicaid and the beginning of more substantial public funding for long-term care.[61] These amendments expanded eligibility for benefits to the "medically needy"—people who were living above state public assistance levels but spending a large share of their income on medical care—and defined medical assistance to include long-term care.[62] With an expanded population of eligible beneficiaries and a continued bias toward funding long-term care in private, licensed institutions, the Kerr-Mills Act increased the number of private nursing homes tenfold and laid the conceptual and structural foundation for Medicaid.[63]

2. *Medicaid and the Modern Era of Social Insurance*

The establishment of Medicare for the elderly and Medicaid for the "deserving poor" in 1965 meant increasing social-insurance coverage of long-term care within the medicalized model.[64] Although neither program was specifically focused on long-term care, Medicaid became the default social insurance program responsible for it.

Despite the common misconception otherwise, Medicare funds long-term care at best "tangentially," such as post-acute care after hospitalization, but it does not pay for support with activities of daily living in home settings.[65] In fact, Medicare was intentionally *not* tailored to the needs of *chronically ill* elderly because the drafters envisioned it would eventually expand into a universal program for all Americans.[66] Long-term nursing care was excluded

---

61 Watson, *supra* note 12, at 946-48. The Kerr-Mills Act was officially titled the Medical Assistance for the Aged. Social Security Amendments of 1960, Pub. L. No. 86-778, §§ 601-04, 74 Stat. 924, 987-92.

62 Watson, *supra* note 12, at 948-50.

63 *See id.* at 950-51.

64 Some would refer to Medicaid as a welfare program because it is means-tested, but because it spreads the risk of medical costs among a large portion of the population, it can also be thought of as a form of social insurance. *See supra* note 25.

65 Judith Feder et al., *Long-Term Care in the United States: An Overview*, 19 HEALTH AFF. 40, 44 (2000). Medicare pays for "post-acute" care, including 90 days of hospital care and a portion of another 100 days of care in a skilled nursing facility or nursing home following hospitalization. 42 U.S.C. § 1395x(i) (2012) (requiring hospitalization for at least three days and transfer to the skilled-nursing facility within thirty days). Medicare also has a home-health benefit that includes nursing care and rehabilitative services, such as speech or physical therapy. 42 U.S.C. § 1395x(m) (covering skilled nursing care or rehabilitative services under a plan established by a doctor and reviewed every 60 days). Nursing care is limited to less than 8 hours per day and 28 hours per week and must be provided by or under the supervision of a registered professional nurse. *Id.*

66 *See* MARMOR ET AL., *supra* note 24, at 232-33.

from Medicare altogether because it was deemed more custodial than medical.[67] One study found that even in cases with Medicare reimbursing home health care, family caregivers still provided three-quarters of needed care, including in half of cases, performing skilled nursing care, such as monitoring blood pressure and symptoms, and providing counseling or physical or speech therapy.[68] In effect, Medicare is not intended to and does not insure long-term care.

In contrast, Medicaid now finances over sixty percent of all paid long-term care services.[69] It is a cooperative program between the federal government and the states. Federal regulations dictate eligibility and benefits parameters for the state-run Medicaid programs and have shaped the face of long-term care provision in the United States.

Several aspects of Medicaid's design have been particularly significant. First, even though Medicaid is now the primary financier for paid long-term care, it is available to only the poorest Americans with significant medical need *and* low income and assets.[70] Covering this population served as a release valve. By addressing the needs of the most vulnerable people, Medicaid alleviated the urgency for a more comprehensive long-term care solution. Most Americans, somewhere in the middle of poor enough to qualify for Medicaid and wealthy enough to afford a private long-term care policy,

---

67 Watson, *supra* note 12, at 956.

68 Carole Levine et al., *"This Case is Closed": Family Caregivers and the Termination of Home Health Care Services for Stroke Patients*, 84 MILBANK Q. 305, 315-16 (2006).

69 O'Shaughnessy, *supra* note 9, at 3 (excluding Medicare post-acute care). Individuals finance 22% out of pocket and private insurance finances 12%. *Id.* Other public programs, including the Department of Veterans Affairs or Department of Housing and Urban Development funding for supportive services and housing for elderly or disabled residents of HUD-assisted housing, only financed $10 billion in long-term care in 2012. JULIE STONE, CONG. RESEARCH SERV., R40718, LONG-TERM CARE (LTC): FINANCING OVERVIEW AND ISSUES FOR CONGRESS 11-13 (2009). The Older Americans Act (OAA) includes in-kind assistance for people living at home; its biggest, called "meals on wheels," provides meals to older people in home settings. Wendy Fox-Grage & Kathleen Ujvari, *The Older Americans Act*, AARP PUB. POL'Y INST. 2 (2014) (reporting that meals on wheels served approximately 2.5 million people in 2011). The total OAA budget was only $1.88 billion in fiscal year 2014. *Id.* at 3.

70 In most states an individual's Medicaid eligibility is tied to eligibility for the Supplemental Security Income (SSI) program, which provides means-tested cash assistance for disabled, blind, or aged individuals. States may extend eligibility to others with higher incomes up to 300% of the federal poverty level. *See* JULIE STONE, CONG. RESEARCH SERV., RL33593, MEDICAID COVERAGE FOR LONG-TERM CARE: ELIGIBILITY, ASSET TRANSFERS, AND ESTATE RECOVERY 4-5 (2008). Some qualify, even if above these income thresholds, by showing high medical bills that effectively deplete or "spend down" their income to eligibility levels. *Id.* at 4. Beneficiaries must also meet low assets standards, which is in most states under $2000 for an individual and under $3000 for a couple, excluding some assets, such as a car and some value of a residence. *Id.* at 6-7.

turn to family and friends to fill in the gap (so long as they are fortunate enough to have someone to whom to turn).[71]

Second, in the model of the Kerr-Mills Act, Medicaid adopted a medicalized approach.[72] It initially had an "institutional bias" favoring the provision of long-term care in licensed nursing homes.[73] Care in nursing homes and other licensed institutions was designated a mandatory Medicaid benefit—one that states must cover to receive federal matching funds.[74] In contrast, personal care in home settings (e.g., bathing, dressing, eating, light housework, grocery shopping, etc.) was designated as an optional benefit—states could receive matching funds for this type of care but did not need to cover it.[75] These rules had two implications. First, Medicaid's benefit structure created incentives for more long-term care in nursing homes. Second, as Medicaid's institutional bias receded in favor of home-based care, as described below, states' programs did not cover all of the services people might need at home, since many were optional benefits.

Finally, because of statutory rules that limited the use of federal matching funds for care in public institutions, Medicaid furthered the dismantling of state public institutions for long-term care and the proliferation of private nursing homes to take their place.[76] Medicaid made nursing homes a federally funded alternative for people with developmental delays and psychological illness, as well as an option for care for aging parents.[77] Spending on nursing homes increased exponentially after the passage of Medicaid, from $46 million in 1960 to $3.5 billion by 1967.[78] Medicaid thus significantly reshaped the institutional structure of long-term care.

Medicaid laid the foundation for a system of long-term care where only the poorest Americans were socially insured and where private nursing homes

---

71 Long-term care is not included in the typical private health insurance plan. Medigap plans might pay for assistance with ADLs but only in some plans and with a low dollar limit. Kaplan, *supra* note 40, at 421.

72 *See* Smith & Feng, *supra* note 28, at 31.

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

74 *See* STONE, *supra* note 69, at 7. States must also fund home health care for people who would otherwise be eligible for nursing facility services. 42 U.S.C. § 1396a(a)(10)(D) (2012). Medicaid also adopted the Kerr-Mills eligibility category of medically needy. *Id.* § 1396a(a)(10)(C). Since many medically needy spend down on long-term care, this policy increased the numbers beneficiaries in need of nursing home care. *See* Watson, *supra* note 12, at 955-56.

75 42 U.S.C. § 1396d(a)(24), 1396d(a)(22).

76 It prohibited payment for care in Institutions for Mental Diseases, which created incentives for states to move people from state-funded mental asylums to private nursing homes that were eligible for federally Medicaid matching funds. *See* TORREY, *supra* note 48, at 73.

77 Watson, *supra* note 12, at 953.

78 *Id.* at 952.

became the locus of care. It helped to dismantle public institutions but offered, for a period of time, an institutional alternative that continued to provide options for long-term care outside of the home. This institutional bias took the pressure off family caregivers and reduced their obligation, at least temporarily.

3. Medicaid's Recent Shift: Care Returns Home

Over the past few decades, however, Medicaid's institutional bias has receded, replaced by policies that aim to increase the autonomy of people with disabilities by helping them remain at home but, in turn, increase obligations for informal caregivers. Medicaid's evolving policies, have resituated the home as the locus of long-term care. This "rebalancing" has resulted in home- and community-based care increasing from eighteen percent of Medicaid's long-term care spending in 1995 to just over fifty percent in 2013.[79] More than three-quarters of people receiving long-term care assistance now live in home or community settings, which, in nearly all cases, means in their home or in the home of a family member.[80]

Medicaid's shift to home-based long-term care has been largely motivated by care recipients' preferences to remain at home, which is why I describe it as policymaking from the care-recipient perspective. Early calls for home-based care came from the "independent living movement," an effort in the 1970s initiated by several working-age people with disabilities in Berkeley, to remain and live independently in their communities.[81] Scandals regarding the deplorable conditions in private nursing homes and public institutions, coupled with concern over the growing costs of long-term care in these institutions, fanned the flames of the movement.[82] Efforts were driven by the beliefs that outcomes are better and care is less expensive in home settings, but both of these beliefs are at best weakly substantiated empirically.[83]

---

79 Eiken et al., *supra* note 11, at 7 fig.1.

80 NAT'L ALLIANCE FOR CAREGIVING & AARP, INC., CAREGIVING IN THE U.S.: 2009, at 8 (2009) [hereinafter NAT'L ALLIANCE, CAREGIVING], http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf ("Half of caregivers say their loved one lives in his or her own home (51%), while 29% live together with their care recipient. Only 4% of caregivers say that their care recipient lives in a nursing home and the same percentage say their recipient's home is an assisted living facility."); STONE 2008, *supra* note 70, at 3.

81 Batavia et al., *supra* note 48, at 528-29.

82 *See* Smith & Feng, *supra* note 28, at 32.

83 *See* Avalere Health, *Medicaid-Financed Home and Community-Based Services Research: A Synthesis*, AM. HEALTH CARE ASS'N 5 (2007), https://www.ahcancal.org/research_data/funding/documents/hcbs_research_synthesis.pdf (reporting that home- and community-based services are not cost-effective for state budgets);

Deinstitutionalization litigation in the 1980s and 1990s challenged the conditions in and reliance on institutional care.[84] This litigation was supported by two very different groups: on the one hand, civil libertarians who wanted to end care in settings perceived to be "oppressive, dehumanizing, and antitherapeutic," and, on the other, fiscal conservatives, who saw care at home as a way to cut spending.[85] They both aimed to unsettle institutions notorious for poor conditions and expensive care.

This litigation played out successfully in two waves. The first challenged the standards of treatment in public institutions on substantive due process grounds, relying on the assumption—one that proved true—that court orders requiring higher standards would make it too expensive for states to run these institutions.[86] The second wave relied on the then-recently passed Americans with Disabilities Act of 1990 (ADA) and its mandate to administer services "in the most integrated setting appropriate."[87] The ADA enabled litigants, for the first time, to challenge conditions in publically-funded private institutions, including the private nursing home industry that Medicaid grew.[88] In 1999, the U.S. Supreme Court in *Olmstead v. L.C.* ex rel. *Zimring* held that institutionalization, when avoidable, can be a form of discrimination against people with disabilities.[89] States were required to make "reasonable modifications" to their Medicaid programs in response to *Olmstead*.[90]

ANDREA WYSOCKI ET AL., LONG-TERM CARE FOR OLDER ADULTS: A REVIEW OF HOME AND COMMUNITY-BASED SERVICES VERSUS INSTITUTIONAL CARE 20-21 (2012), https://effectivehealthcare.ahrq.gov/ehc/products/369/1277/CER81_Long-Term-Care_FinalReport_20121023.pdf (surveying studies comparing nursing homes, assisted living, and HCBS programs and finding insufficient evidence on cost savings and most outcomes); David C. Grabowski, *The Cost-Effectiveness of Noninstitutional Long-Term Care Services: Review and Synthesis of the Most Recent Evidence,* 63 MED. CARE RES. & REV. 3, 20 (2006); Roger J. Stancliffe et al., *The Economics of Deinstitutionalization*, *in* COSTS AND OUTCOMES OF COMMUNITY SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES (Roger J. Stancliffe & K. Charlie Lakin eds., 2004) (showing the degree of cost savings as related to the degree of deinstitutionalization in a state).

84 *See* Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation,* 34 CARDOZO L. REV. 1, 14 (2012).

85 *Id.* at 15.

86 *Id.* at 26. The Supreme Court's 1982 decision in *Youngberg v. Romeo* held that institutionalized persons have "constitutionally protected interests in conditions of reasonable care and safety." 457 U.S. 307, 324 (1982).

87 28 C.F.R § 35.130(d) (2016).

88 Some deinstitutionalization advocates have even opposed care in multi-unit community-based settings and have attempted to label them "institutions" for purposes of *Olmstead* challenges. Bagenstos, *supra* note 84, at 48-49.

89 527 U.S. 581, 601 (1999) (reasoning that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment").

90 *See* 28 C.F.R. § 35.130(b)(7) (2016). The exception is when modification would

It is telling that a number of family members of people with disabilities initially were part of the coalition but later splintered off because of concerns that the legal strategies pursued would unsettle institutions without offering alternatives,[91] leaving them with unmanageable caregiving obligations. As they anticipated, the litigation created a tug of war for funding between institutions and programs for home- and community-based services. When enough people moved out of institutions, the fixed costs became too high to keep them open for individuals (or their guardians) who preferred institutional care, and a majority of public institutions closed.[92]

In parallel to this litigation, Medicaid policies were increasingly making it easier for states to deinstitutionalize long-term care. Most importantly, Congress passed section 1915(c) of the Social Security Act in 1981, which allowed states to seek waiver approval to offer home- and community-based services instead of the institutional care that they otherwise were required to provide for all qualifying beneficiaries.[93] These waiver programs now operate in nearly all states and constitute two-thirds of Medicaid spending on home- and community-based services.[94]

Policies that create incentives for states to shift to home- and community-based care continued in the subsequent decades. In 1991, the Department of Health and Human Services developed programs where states could offer Medicaid beneficiaries the ability to "self-direct" long-term care benefits,[95] which means they may pay any capable providers of services, including parents of children with disabilities and spouses.[96] The Deficit Reduction Act of 2005 and ACA created and extended a program called Money Follows the Person, which offers enhanced federal Medicaid matching funds to a state for twelve months after the state discharges an individual from institutional care

---

"fundamentally alter the nature of the service, program or activity." *Id.*

91 Some parents pursued separate litigation to improve the conditions in institutions. DAVID J. ROTHMAN & SHEILA M. ROTHMAN, THE WILLOWBROOK WARS 45-50 (1984).

92 Bagenstos, *supra* note 84, at 7-9, 30; Stancliffe, et al., *supra* note 83, at 295.

93 *Medicaid Benefits*, CTRS. FOR MEDICARE & MEDICAID SERVS., http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Medicaid-Benefits.html (last visited Aug. 15, 2016); *see also* STONE, *supra* note 69, at 9-10 (summarizing the 1915(c) home- and community-based services program). Waivers allow states to target services by age, diagnosis or geography, rather than having to be available statewide. *Id.* at 9.

94 TERENCE NG ET AL., KAISER COMM'N ON MEDICAID & UNINSURED, MEDICAID HOME AND COMMUNITY-BASED SERVICE PROGRAMS: 2012 DATA UPDATE 6-7 (2015), http://files.kff.org/attachment/report-medicaid-home-and-community-based-services-programs-2012-data-update (estimating 74 percent of funds on home- and community-based services are spent under 1915(c) waivers).

95 Jeffrey S. Crowley, *Medicaid Long-Term Services Reforms in the Deficit Reduction Act*, KAISER COMM'N ON MEDICAID & UNINSURED 15 (2006) (describing Section 1115 waivers for Cash and Counseling).

96 Benefits cannot be used to pay non-relative who owns or operates the facility or home in which the beneficiary lives, presumably to prevent moral hazard. *Id.*

to home care.[97] Nearly all states participate in this program, which, as of mid-2015, had prompted the transition of 50,000 individuals out of institutions and into home settings.[98] In effect, these two programs pay states a premium to move people out of institutions.

The result of this litigation and the policy reforms of the late twentieth century is that after several decades of momentum in the other direction, the law has quietly reaffirmed and solidified the home as the primary locale for long-term care. Federal policy began the large-scale dismantling of public institutions that states had established, a dismantling completed by civil rights litigation. In their place, Medicaid initially favored private institutions, but in recent years, this institutional bias has receded, replaced by favor for programs for home- and community-based services. The law has thus shifted long-term care back into the home and structurally reinforced its place there.

C. The Resulting Structure of Long-Term Care

Increasing reliance on home- and community-based services offers considerable benefits from a care-recipient perspective. It has freed many people from subpar conditions in facilities. People can stay in their homes and live as independently as possible, which can be transformative.[99] But the consequence of this reform has been to intensify and cement obligations for friends and family.

The number of people living in institutions has sharply declined. The census of people with developmental disabilities in state institutions is only sixteen percent of what it was at its peak in 1967, and the population of state and local psychiatric hospitals is nine percent of its peak and declining.[100] Age-adjusted institutional use among older Americans decreased by thirty-seven percent between 1984 and 2004.[101] The actual number of older people

97 *Id.* at 9-11;, *Medicaid Long-Term Services and Supports: Key Changes in the Health Reform Law*, HENRY J. KAISER FAMILY FOUND. 1 (2010), https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8079.pdf. The Deficit Reduction Act also enabled states to expand eligibility for these services for higher earners without having to go through the waiver approval process. *Id.*

98 *Money Follows the Person: A 2015 State Survey of Transitions, Services, and Costs*, KAISER COMM'N ON MEDICAID & UNINSURED 1 (2013) (reporting over 50,000 transitioned and another 10,000 in progress).

99 *See, e.g.*, Watson, *supra* note 12, at 937.

100 Bagenstos, *supra* note 84, at 29. The census of people with a developmental disability in state institutions peaked in 1967 at just under 200,000. *Id.* at 7. The census of people with psychiatric disabilities in state institutions peaked in 1955 at just under 560,000. *Id.* at 9.

101 DONALD L. REDFOOT & ARI HOUSER, AARP PUB. POL'Y INST., MORE OLDER PEOPLE WITH DISABILITIES LIVING IN THE COMMUNITY: TRENDS FROM THE NATIONAL LONG-TERM CARE SURVEY, 1984-2004, at 3 (2010), http://assets.aarp.org/rgcenter/ppi/ltc/2010-08-disability.pdf (using age-adjusted data based on the National Long-Term Care Survey).

living in institutions declined from a high of 2 million people in 1989 to 1.4 million in 2004, even as the absolute number of older Americans grew.[102] By one estimate, if the rates of institutional use and disability had both remained constant, nearly 750,000 additional older people would have been living in institutions by 2004.[103] Likewise, by one estimate nearly 950,000 would have been in mental institutions in 2000; only 50,000 individuals were in 2003.[104] Medicaid spent $24 billion less on nursing homes in 2004 than the program would have if institutionalization rates had remained constant from 1984.[105]

What is more, there has been a substantial increase in the number of people with the very highest levels of disability living at home.[106] As one example, from 1999 to 2004, there was a twenty-four percent increase in the number of people living in home or community settings who need help toileting and a nearly twenty percent increase in the number who need mobility assistance.[107] The greatest increases occurred among the oldest old,[108] among widowed or unmarried people, especially women,[109] and among lower-income beneficiaries.[110] This means that the number of poor, sick, old people living at home is increasing, due largely to Medicaid policies.

Importantly, funding for care in home settings has been insufficient. States have struggled to fund home- and community-based services.[111] The Medicaid waiver programs for these services must be budget neutral, or cost a state no more than what it would have spent to provide institutional care for the same beneficiaries. Yet, studies that compare a similar person in home versus institutional care suggest home-based care is not less expensive, as anticipated, due in part to scale disadvantages of care in smaller settings and also to the costs of developing networks of caregivers, crisis services, and case management.[112]

When a beneficiary is living in a nursing home, personal care needs are part of the total Medicaid-funded package. But when a beneficiary is living at

---

102 *Id.* at 21.

103 *Id.* at 25 (based on institutional use in 2004).

104 Bagenstos, *supra* note 84, at 9.

105 REDFOOT & HOUSER, *supra* note 101, at 24.

106 *Id.* at 25 (reporting that the share with disabilities in two or more ADLs increased from 57.5 to 69.5% from 1984 to 2004).

107 *Id.* at 27.

108 *Id.* at 28 (citing an 85% increase in people ages 85-94 and 240% increase in people over 95 years old with disability in two or more ADLs living in the community).

109 *Id.* at 28 (citing an 81% increase for widowed people, as compared to a 39% increase for married people, and a 79% increase for women, as compared to a 45% increase for men, living with disabilities in multiple ADLs in the community).

110 *Id.* at 44 (three out of five older persons living in the community with disabilities in two or more ADLs report incomes less than $20,000).

111 NG ET AL., *supra* note 94, at 12-13.

112 See studies cited *supra* note 82.

home, individual care needs can be and have been carved out. Unmet needs in nursing homes are more visible and reprehensible, but unmet needs in home settings are private and invisible to anyone other than close friends and family.

Most people in home- and community-based long-term care waiver programs have some unfunded care needs. To meet budget neutrality requirements, states have developed these programs with gaps—excluding some disabling conditions, limiting enrollment, or prohibiting aides or assistants from helping with some personal care activities, such as bathing or dressing.[113] Moreover, in 2013 more than 536,000 people were on waiting lists for these programs with an average wait time of over two years.[114] States also carve out and underfund personal care services for beneficiaries in the regular state programs. The few states that do pay for personal care limit it: for example, Utah and West Virginia allow only sixty hours of personal care per month, and Utah requires care be supervised by a registered nurse.[115]

To make matters worse, as part of a 1997 payment reform, Medicare reduced funding for post-acute home health care.[116] In the three years following these changes, Medicare spending on home health fell from $17.7 billion to $8.5 billion, and the number of Medicare home health beneficiaries declined by 30 percent.[117] Even though this funding was for medical care, never for personal assistance, its decrease has meant less nursing assistance and rehabilitative care in the home, so informal caregivers are now doing what medical professionals once did.

As a result of all of these policies, the average care recipient is experiencing a decline in formal paid care through social insurance programs, with the steepest decline in skilled care for those with more severe disabilities.[118] For the lucky ones, family members or friends are stepping in to fill this gap in social insurance benefits. One study commented: "if patient care did not suffer as a result of reduced support from formal care sources, increased reliance on family caregivers is likely to have played an important

113 NG ET AL., *supra* note 94, at 12-14.

114 *Id.* at 3

115 *Medicaid Benefits: Personal Care Services*, HENRY J. KAISER FAMILY FOUND. (2012), http://kff.org/medicaid/state-indicator/personal-care-services.

116 ARI HOUSER ET AL., AARP PUB. POL'Y INST., TRENDS IN FAMILY CAREGIVING AND PAID HOME CARE FOR OLDER PEOPLE WITH DISABILITIES IN THE COMMUNITY: DATA FROM THE NATIONAL LONG-TERM CARE SURVEY 36 (2010), http://assets.aarp.org/rgcenter/ppi/ltc/2010-09-caregiving.pdf.

117 *Id.* (declining from 3.6 million to 2.5 million beneficiaries).

118 *Id.* at 32 (reporting a decline between 1999 and 2004 on the average hours of skilled care per individual with three or more ADL limitations).

role in minimizing adverse consequences."[119] In fact, nearly three-quarters of older people living in the community now receive family care only.[120] The work for the average informal caregiver has increased in level, complexity, and intensity.[121]

***

Modern long-term care policy has pivoted to better serve care recipients' preferences and autonomy by financing care in home settings instead of in institutional ones. In concept, this shift is positive because it enables people with disabilities to live as they wish. But the laser focus on risk from the care-recipient perspective has overshadowed attention to competing risks, including those faced by family and friends.[122] Under the auspices of serving the best interests of individuals with disabilities, the law has cemented and intensified responsibility for their friends and family—their next friends.

II. REIMAGINING LONG-TERM CARE RISK FROM THE NEXT-FRIEND PERSPECTIVE

What if we instead considered long-term care risk from the perspective of the closest friends and family of someone who is chronically ill or disabled? From this perspective, the possibility of becoming responsible for another's long-term care can pose a major threat to an individual or family's security and wellbeing.

Long-term care law and social policy has left gaping holes. Family and friends—"next friends"—have filled these gaps, most often by providing long-term care themselves, in part because in most cases no other good option exists. This tradition of long-term care as a private obligation is not new. But the world has changed in ways that make de facto reliance on friends and family increasingly untenable. Even if someone cares for another willingly, and even if she derives deep pleasure from it, she often does so at a high cost to herself. Whatever the friend or family member was engaged in before—be it paid employment, raising a family, getting an education, serving her community, nurturing a new relationship, or building a business—will be put on hold and possibly abandoned altogether. For many, this disruption takes a significant toll.

---

119 *Id.* at 36.

120 *Id.* at 20.

121 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 23 (noting that the "proportion of caregivers of adults who provide help with at least one ADL increased from 50% in 2004 to 58% in 2009").

122 *Cf.* ULRICH BECK, RISK SOCIETY 31 (Mark Ritter trans., 1992) (describing how the emphasis on some risks can serve to overshadow others).

Legal scholarship has approached this problem in two ways. Health, elder, and disability law and policy scholars generally think of long-term care as an insurance problem. However, this literature treats care-recipient risk as the sole, or primary, insurable risk.[123] Some scholars acknowledge the burdens faced by informal caregivers and advocate for policies that offer better support, compensation, or more accommodating workplaces.[124] But even these scholars presume, explicitly or implicitly, continued reliance on family care in ways that ensconce it.

Second, there is a rich and complex literature by feminist legal scholars focused on caregiving. The main thrust of this work has been to highlight the undervaluation and gendered nature of care work, mostly with regard to childcare[125] and to a lesser extent long-term care.[126] Scholars in this tradition

123 *See, e.g.*, Bagenstos, *supra* note 73; Karen Syma Czapanskiy, *Disabled Kids and Their Moms: Caregivers and Horizontal Equity*, 19 GEO. J. ON POVERTY L. & POL'Y 43 (2012) (analyzing the Department of Veterans Affairs' caregiver program in order to highlight the lack of public services that benefit caregivers of disabled children); Thomas P. Gallanis & Josephine Gittler, *Family Caregiving and the Law of Succession: A Proposal*, 45 U. MICH. J.L. REFORM 761 (2012) (proposing to amend succession law to provide an elective share to a family member who was a primary caregiver, providing unpaid informal care to an elderly decedent); Christopher C. Jennings & Christopher J. Dawe, *Long-Term Care: The Forgotten Health Care Challenge: Leading the Way to Broader Reform*, 17 STAN. L & POL'Y REV. 57 (2006) (arguing for a private-public financing method for long-term care); Richard L. Kaplan, *Honoring Our Parents: Applying the Biblical Imperative the Context of Long-Term Care*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y 483 (2007) (proposing that Medicare pay for all nursing home care and that any home care remain private responsibility); Marshall Kapp, *Home and Community-Based Long Term Services and Supports: Health Reform's Most Enduring Legacy?*, 8 ST. LOUIS U. J. HEALTH L. & POL'Y 9 (2014) (describing the shift to home- and community-based care); Daniela Kraiem, *Consumer Direction in Medicaid Long Term Care: Autonomy, Commodification of Family Labor, and Community Resilience*, 19 AM. U. J. GENDER SOC. POL'Y & L. 671 (2011) (critiquing consumer-directed long-term care programs for effects on paraprofessional and family care workers and arguing for better supports for caregivers); Watson, *supra* note 12 (providing a history of long-term care policy and a critique of Medicaid's institutional bias).

124 *See, e.g.*, Czapanskiy, *supra* note 123, at 65-71 (proposing equity between state support for parents providing long-term care for children and the Department of Veterans Affairs' support for family caregivers); Gallanis & Gittler, *supra* note 123 (proposing to amend succession law to provide an elective share to a family member who was a primary caregiver); Richard L. Kaplan, *Federal Tax Policy and Family-Provided Care for Older Adults*, 25 VA. TAX REV. 509 (2005) (advocating for tax credits for family caregivers); Carol Levine, *Home Sweet Hospital: The Nature and Limits of Private Responsibilities for Home Health Care*, 11 J. HEALTH & AGING 341, 349-52 (1999) (proposing various supports for family caregivers, including more leave under the Family and Medical Leave Act, hospice funding, and home care benefits to supplement family care).

125 This body of work is larger than what I could possibly capture here. *See, e.g.*, ALSTOTT, NO EXIT, *supra* note 22 (claiming that society owes an obligation to parents to help preserve their autonomy in exchange for the "no exit" obligation that they provide continuity of care for their children and make the sacrifices necessary to do so); MARTHA ALBERTSON

have made compelling arguments for state support of caregiving based on the idea of caregiving as a public responsibility,[127] a public good,[128] a basic household need,[129] or in order to help preserve women's attachment to the workplace.[130]

This Article offers a reframing of the problem of long-term care that speaks to both groups. To the first, it suggests we consider next-friend risk a coequal, insurable risk of long-term care. Elucidating the possible economic and social harms a presumptive caregiver could face reveals a problem with the way that current policies steer some people into caregiving roles at the

---

FINEMAN, THE AUTONOMY MYTH 38 (2004) ("Justice demands that society recognize that caretaking labor produces a good for the larger society. Equality demands that this labor must not only be counted, but also valued, compensated, and accommodated by society and its institutions . . . ."); JOAN WILLIAMS, UNBENDING GENDER: WHY FAMILY AND WORK CONFLICT AND WHAT TO DO ABOUT IT (2000) (arguing for a joint-property proposal to value caregiving work in the home); Paula England & Nancy Folbre, *Who Should Pay for the Kids?*, 563 ANNALS AM. ACAD. POL. & SOC. SCI. 194 (1999) (contending that children are a public good and thus we should all help pay for the costs of raising them); Martha M. Ertman, *Commercializing Marriage: A Proposal for Valuing Women's Work Through Premarital Security Agreements*, 77 TEX. L. REV. 17 (arguing for premarital security agreements as a way of valuing women's domestic work and ensuring them compensation in the case of divorce); Sylvia A. Law, *Women, Work, Welfare, and the Preservation of Patriarchy*, 131 U. PA. L. REV. 1249 (1983) (showing that labor and welfare policy both prevent women from working outside the home and undervalue the work they do within it); Gillian Lester, *A Defense of Paid Family Leave*, 28 HARV. J.L. & GENDER 1 (2005) (defending paid leave as a way to increase women's workforce participation); Katherine B. Silbaugh, *Turning Labor into Love: Housework and the Law,* 91 NW. U. L. REV. 1 (1996) (showing how the law devalues domestic labor); Noah Zatz, *Supporting Workers by Accounting for Care*, 5 HARV. L. & POL'Y REV. 45(2011) (arguing that we count childcare as part of the basket of goods for income-based programs and family caretaking as a form of work for benefits contingent on working).

126 Peggie Smith focuses explicitly on elder care, which she calls the "work-family issue of the 21st Century." Peggie Smith, *Elder Care, Gender, and Work: The Work-Family Issue of the 21st Century*, 25 BERKELEY J. EMP. & LAB. L. 351, 351 (2004) [hereinafter Smith, *Elder Care*]. Others address both childcare and long-term care together. *See, e.g.,* FINEMAN, *supra* note 124 (describing all care work as the source of derivative dependency); Lester, *supra* note 124 (offering a normative argument for paid leave for childcare and eldercare); ALSTOTT, NO EXIT, *supra* note 22 (discussing caregiving for children with disabilities). Peggie Smith's work also examines long-term care from a labor perspective, showing how the devaluation of care work equally affects formal long-term caregivers. *See* Peggie Smith, *Home Sweet Home? Workplace Casualties of Consumer-Directed Home Care for the Elderly*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y 537 (2007) [hereinafter Smith, *Home Sweet Home*]; Peggie Smith, *Aging and Caring in the Home: Regulating Paid Domesticity in the Twenty-First Century*, 92 IOWA L. REV. 1835 (2007). There is also a rich body of work on informal caregiving and long-term care by sociologists, historians, economists. *E.g.*, EMILY ABEL, WHO CARES FOR THE ELDERLY? (1991); BORIS & KLEIN, *supra* note 31; HARTOG, *supra* note 29.

127 *See* ALSTOTT, NO EXIT, *supra* note 22.

128 *See* FINEMAN, *supra* note 125; England & Folbre, *supra* note 125.

129 *See* Zatz, *supra* note 125.

130 *See* Lester, *supra* note 125.

expense of other roles. Proposals to support informal caregivers privilege women's private caregiving at the expense of their long-term security and engagement in important realms outside of the home. Any solution to the problem must correct for this overvaluation.

To the feminist legal scholars, this Article offers a way of articulating the costs caregivers face as a manifestation of a coherent social risk and frames the state's responsibility in terms of risk spreading.[131] Focusing on long-term care, instead of childcare more broadly, lends to this approach. The responsibility for someone else's long-term care is generally less predictable and more skewed in duration and intensity than typical childcare needs. Resulting costs fundamentally undermine caregivers' financial, emotional, and physical wellbeing.[132]

Thinking about these costs in terms of social risk does not require someone to believe that care is a normative good or that society owes any obligation to people who do it well (even though a belief that these costs arise in service of doing something that we value can enhance a claim to shared resources). So long as enough people have experienced or worry about the possibility of becoming responsible for an aging parent, an ill spouse, or a child with a disability, they can relate to it as a commonly shared threat to security.

This Part examines what it would mean if, instead of deeming responsibility for long-term care as a private obligation, we treated the potential for becoming responsible for another as next-friend risk. Imagining next-friend risk could justify a fundamental change in how the state finances long-term care.

A. Long-Term Care as a Private Obligation

To conceive of a coherent idea of next-friend risk, it is necessary to identify who bears this risk and how it arises. These questions are complex because the obligation to care for someone is not inscribed in any one place, but rather is communicated through social norms and ethical beliefs, and sometimes through the law. The many sources that generate this obligation do not, however, diminish its veracity; quite the opposite, they mutually reinforce

131 Some scholars advocate for more circumscribed social insurance solutions, including Anne Alstott in the chapters of No Exit focused on parents caring for a child with disability and Gillian Lester with regard to paid leave to enable workers to take a leave for family care. ALSTOTT, NO EXIT, *supra* note 22; Lester, *supra* note 125. But none has intended to articulate a coherent theory of risk for all long-term caregivers nor to justify a comprehensive solution.

132 Anne Alstott argues that even more routine childcare can do the same. ALSTOTT, NO EXIT, *supra* note 22.

it, so that few people choose to walk away from a family member or friend in need of long-term care.

It is not always clear ex ante who will take responsibility for another's care. One expert writes: "Family responsibility is an amorphous concept, with fluid boundaries and interpretation. It may derive from religious teachings, cultural tradition, emotional bonds, gratitude for past acts, or a sense of obligation apart from love."[133] Regardless of why, the reality is that friends and family provide long-term care even at significant costs to themselves and even when not legally obligated to do so—prompting one scholar to call them "trapped kin."[134]

1. Social Norms and Long-Term Care

Two different categories of arguments are proffered to explain why family members provide long-term care for each other. One view is that family care occurs because some people (usually women) have a "natural" inclination or a preference for caregiving. Thus, they and others are best off when they engage in caregiving, instead of other pursuits. In the past several decades, however, arguments in this vein have been challenged and discredited as tautological and often in service of certain political and economic goals.[135] Although many of us have a desire to care for those closest to us, explaining the decision that some people make to provide long-term care for others to be the result of rational choice or efficient specialization is unsatisfying, considering that in most cases it is the only option.

A second view is that norms—moral, religious, social, cultural, or legal—and institutions shape a strong notion of individual, typically gendered obligation to provide care.[136] This is the idea that obligation is constructed in part or whole. As Martha Fineman has described, "[C]hoice occurs within the constraints of social conditions, including history and tradition. Such

---

133 Levine, *supra* note 124, at 344.

134 HARTOG, *supra* note 29, at 278.

135 *See* Rhonda J. Montgomery, *The Family Role in the Context of Long-Term Care*, 11 J. AGING & HEALTH 383, 395 (1999) (discussing studies that discredit this notion). Martha Fineman calls this argument "efficiency as exploitation." FINEMAN, *supra* note 125, at 44. One version of this idea is the human capital theory assertion that women have a comparative advantage for caregiving, which rationalizes their specialization in housework and men's in wage-earning work. Gary Becker argues, for example, that women's disadvantage in the workplace stems from specialization in childcare and housework, rather than discrimination. GARY BECKER, A TREATISE ON THE FAMILY 22 (1981). For a longer discussion of this use of human capital theory, its circularity, and studies that disprove it, see Vicki Schultz, *Life's Work*, 100 COLUM. L. REV. 1881, 1893 (2000).

136 *See, e.g.*, Amy Ziettlow & Naomi Cahn, *The Honor Commandment: Law, Religion, and the Challenge of Elder Care*, 30 J.L. & RELIGION 229 (2015) (examining through qualitative empirical research how the Judeo-Christian "honor commandment" influences adult children's engagement in their parents' elder care).

traditions funnel individual decision making into prescribed channels, often operating along practical and symbolic lines to limit and close down options."[137] She describes how everything from outdated historical traditions, to negative media attention on nannies or daycare, to the structure of the public school system with short school days and summer recesses create biases toward private caregiving. [138] Others have examined how sex discrimination in the workplace,[139] laws that do not tax the value of household labor,[140] and marriage and divorce laws[141] all create incentives for women to choose caregiving for family over other work. Fully describing the social norms and institutions that shape such decisions is beyond the scope of this Article, but a few brief illustrations specific to long-term care illuminate how a sense of obligation might be communicated or reinforced.[142]

As with childcare, women disproportionately provide long-term care. Gendered caregiving norms persist even though many women are less well-situated than many men for the physical labor of long-term care. Gendered expectations are shaped by families themselves: a "good" daughter, sister, or wife will care for her mother, brother, or husband.[143] That said, a significant and increasing number of men also provide long-term care.[144] The problem described herein is at the same time gendered and universal.

The purpose of family is even reduced, at times, to its role in long-term caregiving. The idea is that people have children in part to ensure someone to care for them when they get old,[145] a phenomenon one scholar describes as "an efficient self-insurance strategy adopted by families."[146] To address the problem of elderly with unmet care needs, he even proposes taxing the aged

137 FINEMAN, *supra* note 125, at 41.

138 *Id.*

139 *See* Vicki Schultz, *Telling Stories About Women and Work: Judicial Interpretations of Sex Segregation in the Workplace in Title VII Cases Raising the Lack of Interest Argument*, 103 HARV. L. REV. 1749 (1990).

140 *See* Nancy C. Staudt, *Taxing Housework*, 84 GEO L.J. 1571, 1589 (1995).

141 *See* Anne L. Alstott, *Private Tragedies? Family Law as Social Insurance*, 4 HARV. L. & POL'Y REV. 3, 27 (2010); Vicki Schultz & Michael Yarbrough, *Will Marriage Make Gay and Lesbian Couples Less Egalitarian? A Cautionary Tale* (draft on file with author).

142 For a concise discussion of this idea, see Montgomery, *supra* note 135, at 384-90.

143 Historically, such requests were often accompanied by promises of property or another bequest. HARTOG, *supra* note 29, at 274-75.

144 *See* Jennifer L. Wolff & Judith D. Kasper, *Caregivers of Frail Elders: Updating a National Profile*, 46 GERONTOLOGIST 344, 348 (2006).

145 *See generally* HARTOG, *supra* note 29 (discussing the complex and changing relationship between increasingly aged parents and their children).

146 Douglas A. Wolf, *The Family as Provider of Long-Term Care: Efficiency, Equity, and Externalities*, 11 J. AGING & HEALTH 360, 368-69 (1999) (elaborating on a theoretical model developed by Mark Pauly).

without children for externalizing costs onto the public system and adopting measures to increase fertility, particularly in the case of childless families.[147]

Medical practitioners often reinforce the concept of obligation to family care. One long-term care expert describes her experience after her husband became disabled in an accident, and a nurse foisted her husband's soiled pants on her, stating: "Take these away. Laundry is your job."[148] She also describes being labeled a "selfish wife" by a social worker, who was trying to discharge her husband from the hospital, for her refusal to take him home before she had established professional home care.[149] This view presumes that regardless of her work or other obligations her care for her husband should come first.[150]

The law reinforces the norm of familial long-term care, in both implicit and explicit ways. The evolution of long-term care policy in Part I illustrates an implicit way that legal institutions rest on the expectations that friends and family will provide care. Medicaid long-term care benefits with gaps would be untenable if family and friends did not step in to fill these gaps. Sometimes obligations in the law are more explicit. For example, until recently, Medicare only covered hospice care if the beneficiary had a primary caregiver in place (typically a family member).[151] For certified home health agencies, the availability of family care at home is still a chief consideration in opening a case to authorize Medicare-reimbursed home care.[152]

Explicit legal obligations, even though largely dormant now, have helped shape expectations of private caregiving. All states have filial support laws, modeled on English Poor Laws of 1601, which create explicit obligations to pay for care for indigent family members.[153] Over half of the states' laws require adult children to care for or financially support indigent parents.[154] Although enforcement of these laws has waned since the New Deal's creation of a social safety net, they can nonetheless still shape social expectations, especially if periodically revived. Despite lying dormant for a while, filial support laws have been invoked again in recent years in several states,

147 *Id.* at 373-74.

148 Carol Levine, *The Loneliness of the Long-Term Caregiver*, 340 NEW ENG. J. MED. 1587, 1588 (1999). Such a statement is also a reflection of the historical conflict between providers of medical and non-medical care over status and role.

149 *Id.*

150 Research shows that medical professionals offer greater supports to male caregivers and express lower expectations for them to provide care directly. *See* Montgomery, *supra* note 135, at 392.

151 *See* Levine, *Home Sweet Hospital*, *supra* note 124, at 349.

152 *See* Levine, *supra* note 68, at 315-16.

153 *See* Pearson, *supra* note 48, at 270; *see also* Sande L. Buhai, *Parental Support of Adult Children with Disabilities,* 91 MINN. L. REV. 710, 717-20 (2007) (describing the modern development of familial support obligations for disabled adult children and how these obligations in some ways resemble the original English Poor Laws).

154 Pearson, *supra* note 48, at 278.

including in cases requiring adult children to reimburse a parent's medical[155] and nursing home expenses.[156] These laws might be revived more frequently as Baby Boomers impose higher costs on state Medicaid programs.[157] As late as the early twentieth century, many states passed laws that obligated parents to care for *adult* children with disabilities—in some cases only if the disability developed when the child was still a minor and, in others, even if a grown child became disabled later in life.[158]

Common law has also defined the boundaries of family caregiving obligations. Historian Hendrik Hartog has documented the evolution of legal standards for elder care in the mid-nineteenth to twentieth century at a time when, as he describes, free market opportunities were seen as emancipating adult children from their parents.[159] During this period, as they aged, people used their estates, especially property, to bargain for care by family members, and "contract created or re-created the family as a corporate unit."[160] What had once been outside of the zone of commodification—tending to a family member—became a bargaining chip for payment or property. Probate decisions at times deemed a potential beneficiary more deserving of inheritance if she fulfilled a promise to care for her aging parents.[161] These cases defined the level of care that was expected from family by establishing what was above this level and could thus count as legally enforceable consideration.[162]

Even in light of an overall trend of decreasing legal presumptions of obligation, important exceptions reflect lingering gendered expectations. For example, Hartog describes that litigation requesting fair compensation for care work required a showing of "exceptional" work; somehow the care work by men was usually perceived as more exceptional than that by women.[163] This idea that care is not exceptional (and thus requires no compensation) when done by women arises even in modern cases, such as the 1993 California case *Borelli v Brusseau*.[164] The court found a wife's agreement to provide intensive

---

155 *See* Savoy v. Savoy, 641 A.2d 596, 600 (Pa. Supr. Ct. 1994); Prairie Lakes Health Care Sys., Inc. v. Wookey, 583 N.W.2d 405, 419 (S.D. 1998).

156 *See* Presbyterian Med. Ctr. v. Budd, 832 A.2d 1066, 1077 (Pa. Super. Ct. 2003); Health Care Retirement Corp. v. Pittas, 46 A.3d 719, 724 (2012).

157 *See* Pearson, *supra* note 48, at 302.

158 *See* Buhai, *supra* note 153, at 716, 723, 730.

159 HARTOG, *supra* note 29, at 21.

160 *Id.* at 32.

161 *Id.*

162 *Id.* at 66.

163 *Id.* at 257-58.

164 16 Cal. Rptr. 2d 16 (Ct. App. 1993). *But cf.* O'Brien v. O'Brien, 489 N.E.2d 712, 715-16 (N.Y. 1985) (recognizing the value of contributions made as a "spouse" and "homemaker" in a divorce action). Most modern cases go the way of *O'Brien*, not *Borelli*.

care for her disabled husband at home in return for a promise of part of his estate as without consideration.[165] As the dissent in *Borelli* argues (emphatically), this court's decision, relying on precedent from 1937 and 1941, was out of sync both doctrinally and with late twentieth-century social norms.[166] Nevertheless, it is an example of lingering articulation of the norm that women in kinship relationships are expected to provide long-term care and thus should neither expect nor receive anything, financial or otherwise, in return.

In one case, a California court ordered parents to pay $3500 a month to a fifty-year old son who became disabled after nearly two decades of work as a lawyer.[167] In an attempt to ensure that poor people with disabilities get needed care, and also that they do not become a public expense, the law has expressly obligated family members to serve as caregivers.

Gendered notions of familial obligation surface explicitly at times in policymaking as well, leaving little to the imagination in terms of what drives policy decisions. In congressional hearings on home health care, Representative Tom Coburn suggested that paid care is inappropriate when a family member could provide it. He attempted to illustrate the inefficiency of government-funded home care by criticizing the fact that a diabetic patient was using publicly financed caregivers despite the fact that his "wife was a nurse, trained to measure sugars and give injections."[168] Coburn's presumption was that the wife should take on the role of his caregiver, nursing her husband, rather than others, as her job.

What is clear is that these various expressions of social expectations for family care, even if waning somewhat in recent years, can influence the way people respond when a family member or friend is in need of long-term care. Sociologist Sandra Levitsky found that among unpaid family caregivers, most discussed their own circumstances—even when precarious—in "legitimating" terms as their responsibility and duty.[169] Most informal caregivers struggled to imagine a state role in long-term care, unless they had personally observed

---

165 *Borelli*, 16 Cal. Rptr. 2d at 17, 20 ("Personal performance of a personal duty created by the contract of marriage does not constitute a new consideration supporting the indebtedness alleged in this case.")

166 *Id.* at 22 (Poché., J., dissenting).

167 *See* Petition to Enforce Parental Duty to Support Adult Indigent Child, Culp v. Culp, D279304 (Ventura Super. Ct. Dec. 29, 2000).

168 DEBORAH STONE, RADCLIFFE PUB. POL'Y CTR., REFRAMING HOME HEALTH-CARE POLICY 21 (2000), https://policyparadox.files.wordpress.com/2014/10/reframing-home-health-2000.pdf (citing *Medicare Home Health Care, Skilled Nursing Facility, and Other Postacute Care Payment Policies: Hearing Before H. Comm. on Ways & Means, Subcomm. on Health*, 105th Congress 24).

169 Sandra R. Levitsky, *What Rights? The Construction of Political Claims to American Health Care Entitlements,* 42 L. & SOC'Y REV. 551, 564 (2008).

how Medicaid could cushion the burden of caregiving.[170] The bottom line is that a complex set of social and legal norms have shaped expectations that family and friends, especially women, will provide long-term care.

2. The Numbers on Informal Caregiving

The manifestation of a sense of private obligation is readily evident in the number of people who take on responsibility for the long-term care of another and the intensity of the care they provide. By one estimate, over forty million people provided some unpaid assistance to someone with functional or cognitive limitations in 2013.[171] One study of Baby Boomers caring for their parents found that the percentage of people providing basic personal care to parents more than tripled between 1994 and 2008.[172] Most informal caregivers care for family, primarily for parents but also for grandparents, siblings, spouses, and children.[173] Yet, estimates suggest that as many as one-fifth of informal caregivers provide care for a non-relative, including eleven percent for a friend,[174] illustrating how obligation reaches beyond narrow definitions of family.

Two-thirds of informal caregivers are women.[175] Gendered differences exist beneath the surface as well. For example, when compared to sons caring for parents, daughters tend to provide more hours of care, engage in more care tasks, and more often live with the parent.[176] Furthermore, as care needs intensify, daughters more often continue caregiving than sons, who hire out care.[177] The average age of an informal caregiver is forty-eight years old.[178] This means that the burden of providing informal long-term care especially

170 *See id.* at 578-79.

171 Reinhard et al., *supra* note 26, at 1 (2011).

172 METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 7.

173 *See* NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 18 (reporting that 86% of survey respondents reported caring for family, including 36% for parents, 14% for children, 8% for parents-in-law, 8% for grandparents, 5% for a spouse or partner, and 5% for a sibling); Karen Donelan et al., *Challenged to Care: Informal Caregivers in a Changing Health System,* 21 HEALTH AFF. 222, 224 (2002) (reporting that 79% of survey respondents providing informal care said they cared for family: 42% for parents, 17% for grandparents, 7% for siblings, and 6% for children).

174 *See* NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 18; Donelan et al., *supra* note 173, at 224.

175 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 14.

176 Rhonda Montgomery et al., *Family Caregiving*, *in* HANDBOOK OF GERONTOLOGY: EVIDENCE-BASED APPROACHES TO THEORY, PRACTICE AND POLICY (James A. Blackburn & Catherine N. Dulmus eds., 2007).

177 *See* NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 17.

178 *Id.*

affects women during years that are critical for careers and, increasingly, for raising children as the average maternal age rises.[179]

Differences in rates of long-term caregiving exist also across race and income, although they are not as stark. The prevalence of informal caregiving is highest in Hispanic and African-American households and lowest in Asian-American ones, in part driven by disparate levels of need.[180] Informal caregivers are disproportionately low-income: one study estimates 44 percent of working age caregivers are in households below 200 percent of the federal poverty level, as compared with 33 percent of non-caregivers.[181]

The variation in informal caregiving is significant, measured both in duration and in intensity of care. On average, the duration of caregiving is 4.6 years, skewed upward by the 3 in 10 caregivers who provide care for five years or more.[182] The average caregiver provides just over twenty hours of care per week, but thirteen percent of people provide forty hours or more of care per week.[183] Over fifty percent of informal caregivers provide assistance with at least one activity of daily living, most often transferring or getting dressed, and all with at least one instrumental activity of daily living, such as housework, grocery shopping, or preparing meals.[184]

Changes in medicine and medical reimbursement have increased the intensity of informal care.[185] Medicare reform in 1983 reduced payment for care in hospital settings, leading to what is often called "quicker and sicker" discharge.[186] Sociologist Cameron Macdonald calls these policies "healthcare

---

179 *See* JOYCE A. MARTIN ET AL., BIRTHS: FINAL DATA FOR 2009, NATIONAL VITAL STATISTICS REPORTS 6 fig. 4 (2011), http://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_01.pdf.

180 *See* NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 12 (reporting a prevalence of caregiving of 36.1% of Hispanic, 33.6% of African-American, 30.5% of White, and 20.0% of Asian-American households); Alice Ho et al., *A Look at Working-Age Caregivers' Roles, Health Concerns, and Need for Support*, COMMONWEALTH FUND 7 (2005), http://www.commonwealthfund.org/~/media/files/publications/issue-brief/2005/aug/a-look-at-working-age-caregivers-roles--health-concerns--and-need-for-support/854_ho_lookatworkingcaregiversroles_ib-pdf.pdf.

181 Ho et al., *supra* note 180, at 2. Of course, these households might be lower income because of caregiving obligations.

182 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 19.

183 *Id.* at 21.

184 *Id.* at 22-24. Those caring for children help with most Childcare Support Activities (CSAs). *Id* at 27.

185 *See generally* Sara M. Moorman & Cameron Macdonald, *Medically Complex Care and Caregiver Strain: Results from the Cash and Counseling Demonstration and Evaluation Study*, 53 GERONTOLOGIST 417 (2012) (describing the increase of medicalization of home care and its effects on family caregivers).

186 REDFOOT & HOUSER, *supra* note 101, at 8 (describing the creation of the Medicare Prospective Payment system to reimburse a fixed amount for an episode of care, resulting in shorter hospital stays).

offloading" because of the way that they shift the burden of care from medical institutions to families.[187]

As a result, informal caregivers report providing higher-intensity levels of care.[188] One study found that over forty percent of informal caregivers were performing at least one medical task, including wound care, intravenous medication, and operating dialysis and home infusion machines.[189] Some of the equipment involved is complex, including connecting ventilators to tracheostomy sites, responding to alarms and failures, programming feeding tubes and monitoring for blockages or signs of infection, and noting medical complications quickly, including signs of pneumonia.[190] Most informal caregivers have little or no training and provide care in a home setting with no help from paid aides, housekeepers, or others.[191] One-quarter said they were performing medical tasks because their care recipient had been sent home "too soon," and one in eight reported being aware of a mistake they had made in medical management, showing that this higher-intensity care puts family caregivers in a vulnerable position where they may make errors that harm a loved one.[192] Not surprisingly, the negative health, financial, social, and professional impact is greater among caregivers who assist in health care activities.[193]

As one informal caregiver and scholar described: "I feel abandoned by a health care system that commits resources and rewards to rescuing the injured and the ill but then consigns such patients and their families to the black hole of chronic 'custodial' care."[194] What next friends do for others is herculean, both in terms of the time spent and the ways that they offer assistance.

B. Obligation in a Changing World

The world has changed in ways that make this type of intense, private obligation untenable. Long-term care needs are growing with the shifting demographics of the population. Medical advances are keeping people alive longer and sicker. In 2009, the life expectancy at birth for an American was nearly seventy-nine years, ten years longer than it was in the mid-twentieth

187 Cameron Macdonald, Is There A Doctor in the House?: Family Members Providing Complex Medical Care at Home (unpublished manuscript) (on file with author).

188 Donelan et al., *supra* note 173, at 224.

189 *Id.* at 225-226.

190 *See* Moorman & Macdonald, *supra* note 185, at 408.

191 *See* NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 32, 59.

192 Donelan et. al., *supra* note 173, at 226-27.

193 *See* Jennifer L. Wolff et al., *A National Profile of Family and Unpaid Caregivers Who Assist Older Adults with Health Care Activities*, 176 JAMA INTERNAL MED. 372 (2016)

194 Levine, *supra* note 148, at 1588.

century and twenty years longer than the beginning of the twentieth century.[195] Heroic trauma care and miracle drugs are preserving and extending lives of people with serious injury.[196] And the number of "old old" is growing as a percentage of the population.[197] More Americans suffer from chronic disease than ever before, and some studies suggest the proportion of Americans with chronic conditions may continue to rise.[198] Plus, rates of childhood disability have increased as much as sixteen percent from 2001 to 2010.[199]

As the Baby Boomers transition from the caregiving to the care-receiving generation, the probability of caring for an aging family member or friend is increasing. The ratio of people in need of care to potential caregivers is increasing as people live longer and have fewer kids, translating into a higher likelihood that any one individual will become responsible for another.[200]

At the same time, family and community are evolving in ways that destabilize the provision of informal caregiving in households. A higher percentage of women are in the labor force than ever before: from one-third in 1950 to nearly two-thirds at the beginning of the twenty-first century.[201] The frequency of single-parent households has also risen, from twenty percent in 1980[202] to thirty-four percent in 2011.[203] And for households where there is a married couple, the percentage in which both spouses work out of the home

---

195 *See* Elizabeth Arias, *United States Life Tables, 2009*, NAT'L VITAL STAT. REP., Jan. 6, 2014, at 2, 52-53 tbl.21, http://www.cdc.gov/nchs/data/nvsr/nvsr62/nvsr62_07.pdf.

196 *See* Batavia et al., *supra* note 48, at 523 (citing studies about the changing nature of disability).

197 Arias, *supra* note 195, at 47.

198 Gerard Anderson & Jane Horvath, *The Growing Burden of Chronic Disease in America,* 119 PUB. HEALTH REP. 263, 267 (2004) (reporting that 125 million Americans, or 45% of the population, had one or more chronic health conditions in 2000 and projecting an increase over the next 30 years (citing to a confidential client memorandum from Rand Corporation that was created for Johns Hopkins)). Research reported the proportion of informal caregivers caring for someone with Alzheimer's or dementia rose from 6 to 12 percent from 2004 to 2009. NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 41.

199 *Childhood Disability Rate Jumps 16% over Past Decade*, AM. ACADEMY PEDIATRICS, (May 5, 2013), http://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Childhood-Disability-Rate-Jumps.aspx.

200 *See* Brandon, *supra* note 16 (reporting that the proportion of Americans aged 65 and older has grown from 4.1% in 1900 to 13% in 2012).

201 Fullerton, Jr., *supra* note 14, at 4 tbl.1.

202 U.S. CENSUS BUREAU, *supra* note 14, at 840 tbl. 1337.

203 U.S. CENSUS BUREAU, AMERICA'S FAMILIES AND LIVING ARRANGEMENTS: 2011, tbls. FG6, F1, http://www.census.gov/population/www/socdemo/hh-fam/cps2011.html (calculated by dividing total number of one-parent households living with their own children under age 18 in table FG6, 11,759, by total number of households with parents living with their own children in F1).

increased from just over forty-four percent in 1967 to sixty percent at the beginning of the twenty-first century.[204]

At one time, people lived in communities where they could share care obligations, but people are leaving their communities more often than before. In 2010, 41 percent of Americans lived outside the state in which they were born, as compared to 26.5 percent in 1950.[205] Sixty-three percent of adults have moved to a new community at least once in their lives, while only thirty-seven percent have never left their hometowns.[206]

All of these changes make the burdens that have been shouldered privately increasingly untenable for many, exposing long-term caregiving because it no longer folds quietly into the familial fabric. The combination of law and policies that move care back into the home, in addition to the changing home environments, has resulted in costs too significant to ignore.

C. The Cost of Private Obligation: The Invisible Copayment

When someone becomes responsible for another's long-term care, the burdens can be high.[207] Some of these burdens can be quantified in monetary terms. Others, even if not easily measurable financially, are no less harmful, including damage to intimate relationships or health and an inability to pursue life goals. These costs are, in effect, the invisible copayment of current long-term care social insurance programs.

It is normatively and empirically difficult to put a value on the invisible copayment.[208] As noted above one conservative estimate of replacement wages for the hours of informal caregiving for adults in 2013, when valued at

---

204 U.S. BUREAU OF LABOR STATISTICS, WOMEN IN THE LABOR FORCE: A DATABOOK 84-85 tbl. 24 (2014). A married-couple household is defined as a husband and wife, with or without children, who maintain their own household. *Id.* The number of dual-earner families decreased in the last years of collected data (2009-2011), during the recession. *Id.*

205 Ren, *supra* note 15, at 4.

206 PAUL TAYLOR ET AL., PEW RESEARCH CTR., AMERICAN MOBILITY: WHO MOVES? WHO STAYS PUT? WHERE'S HOME? 1-2 (2008), http://pewsocialtrends.org/files/2011/04/American-Mobility-Report-updated-12-29-08.pdf.

207 How one defines "burdens," "harm," or "costs" greatly shapes the content of what is considered risk. For the moment, I intentionally discuss cost broadly, in both monetary and nonmonetary terms, in terms of lost income and lost opportunity. In Part III, I address different ways people might define harm and how that would affect someone's definition of next-friend risk.

208 As explained in Part III *infra*, the metrics used to estimate this value implicitly express how we define the harm, in terms of time and money spent or opportunity or autonomy lost. In this Article, I am taking a relatively agnostic approach to this question, because with any approach, the costs would be extremely high and lend support to the position that next-friend risk is worthy of greater attention.

average caregiving wages of $12.51 per hour, is $470 billion.[209] Other estimates that measure that costs instead as opportunity costs to informal caregivers are similar in magnitude.[210] For a subset of informal caregivers, who leave or reduce work to provide care, the total financial losses can be staggering. The average informal caregiver who leaves the workforce to care for a parent faces losses including foregone income, pensions, earned interest, benefits, and retirement benefits, including Social Security. One study estimates these losses to be $300,000, on average, and others estimate them to be as high as $600,000 for some caregivers.[211] For someone caring for a parent who reduces working hours but does not leave a job, studies estimate average losses still near $200,000.[212] Among all informal caregivers twenty percent take a leave of absence.[213] More than one-third of those caring for their parents leave the workforce or reduce working hours.[214] Considering that the median household net worth was just under $70,000 in 2011,[215] losses at this level are devastating for all but the wealthiest households. An estimate of the aggregate costs of Baby Boomers caring for their parents, measured in lost wages, Social Security, and pension, is nearly $3 trillion dollars.[216] Not surprisingly, one-third of caregivers report moderate to high financial hardship due to caregiving.[217]

Because of its gendered nature, informal caregiving contributes to wage and employment gaps.[218] Women are more likely than men to disrupt or leave work for caregiving.[219] Evidence shows that extended periods of leave from

---

209 *See* sources cited *supra* note 26.

210 *See, e.g.,* Chari et al, *supra* note 26, at 877 (estimating opportunity costs of elder care to be $522 billion annually).

211 METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 15 (estimating average losses of $283,716 for men and $324,044 for women among Baby Boomers caring for their parents); METLIFE MATURE MKT. INST., THE METLIFE JUGGLING ACT STUDY: BALANCING CAREGIVING WITH WORK AND THE COSTS INVOLVED 5-6 (1999), http://www.caregiving.org/data/jugglingstudy.pdf (reporting an average wage loss of $566,443, with a median wage loss of $243,761; the study also found an average Social Security loss of $25,494 and pension loss of $67,202), *see also* Skira, *supra* note 18, at 82 (estimating a median loss of $164,726 over two years).

212 METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 14.

213 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 9.

214 METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 10.

215 U.S. CENSUS BUREAU, NET WORTH AND ASSET OWNERSHIP OF HOUSEHOLDS: 2011, http://www.census.gov/people/wealth.

216 METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 15.

217 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 51.

218 Skira, *supra* note 18, at 63-64, 79.

219 METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 10; *see also* U.S. DEPT. OF LABOR, FMLA SURVEY: BALANCING THE NEEDS OF FAMILY AND EMPLOYERS tbl. A2-2.6 (2001) (reporting that 32.2% of women who took leave from work in 2000 used it to care for an adult or child (excluding newborns), as compared to 28.9% of men who took leave).

work significantly hamper professional advancement.[220] Even those who stay in the workplace are unlikely to be able to perform as strongly as those not providing long-term care. Long-term caregivers are twice as likely to miss six or more days of work than non-caregivers.[221] By one estimate, U.S. businesses experience nearly $30 billion a year in lost productivity from full-time employees who are caring for family because of absenteeism, distraction, and reduced hours.[222] Employers pay about eight percent more for health care for employees who care for an older person, totaling over $13 billion per year.[223] Employers are, in turn, less likely to invest in employees who provide long-term care.[224]

Informal caregiving can contribute to a cycle of poverty, especially since informal caregivers are more likely to be in low-income households.[225] Political scientist Joe White describes: "Reliance on intra-family transfers carries the same risks as personal investments, especially since individuals with low incomes tend to have children with low incomes, and so a parent's misfortune would be doubly visited upon his or her children."[226] To the extent someone depletes her resources or forgoes savings and retirement benefits to care for another, she will be less likely to be able to afford care for herself later if needed. Thus, family caregiving can solidify class lines as each generation sacrifices its financial security for another one.

Quantifying harm only in terms of hours of unpaid care or lost income, however, does not begin to capture the impact of informal caregiving on people's lives. A considerable body of research measures "secondary strains,"

---

220 *See, e.g.*, Joyce P. Jacobsen & Laurence M. Levin, *Effect of Intermittent Labor Force Attachment on Women's Earnings*, MONTHLY LABOR REV., Sept. 1995, at 14, 18 ("Even women whose labor force gap occurred more than 20 years ago still earn between 5 percent and 7 percent less than women who never left the labor force and have comparable levels of experience . . . .").

221 Ho et al., *supra* note 181, at 3.

222 REINHARD ET. AL., *supra* note 26, at 7.

223 NAT'L ALLIANCE FOR CAREGIVING ET AL., THE METLIFE STUDY OF WORKING CAREGIVERS AND EMPLOYER HEALTH CARE COSTS: NEW INSIGHTS AND INNOVATIONS FOR REDUCING HEALTH CARE COSTS FOR EMPLOYERS 4 (2010), https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working-caregivers-employers-health-care-costs.pdf (using a conservative estimate).

224 *See* Anne Beeson Royalty, *The Effects of Job Turnover on the Training of Men and Women*, 49 INDUS. & LABOR REL. REV. 506, 520 (1996) (stating that employers are 25% more likely to provide training to men than women due to the assumption that women will leave the workforce for family reasons).

225 Yeonjung Lee et al., *The Vicious Cycle of Parental Caregiving and Financial Well-being: A Longitudinal Study of Women*, 70 J. GERONTOLOGY SERIES B: PSYCHOL. SCI. & SOC. SCI. 425, 426 (2015).

226 Joseph White, *(How) Is Aging a Health Policy Problem?,* 4 YALE J. HEALTH POL'Y L. & ETHICS 47, 56 (2004).

including effects on "family and occupational role and social and recreational activities, and intrapsychic strains such as loss of self-esteem, loss of self, role captivity, and lowered sense of competence."[227] This research documents significant health effects and psychosocial and behavioral impacts. The self-reported health of informal caregivers is worse than that of non-caregivers, and it declines the longer someone provides care.[228] In one study, over two-thirds of respondents reported that long-term caregiving was the top source of stress in their lives.[229] Research has shown that forty to seventy percent of people caring for older adults have symptoms of depression and twenty-five to fifty percent meet diagnostic criteria for major depression, far outpacing the rates in the general population.[230] Significantly, health status is worse for an informal caregiver who felt she had no choice in whether to provide care.[231]

Even beyond measurable physical and psychosocial harms, taking responsibility for the long-term care of another, especially for someone who requires prolonged intensive care, can consume life in ways difficult to quantify but nonetheless important. Long-term care responsibility can harm existing relationships or create barriers to entering into new intimate relationships. Anne Alstott has argued that social policy should be just as concerned about a wider range of risks that can threaten wellbeing and security, which she refers to as disruptions in "affective life."[232] In one study, one-half of caregivers reported sacrificed time with friends and family.[233]

An informal caregiver could lose the chance to engage in other activities that define her, fulfill her, or create future opportunity for her. Both because of the economic insecurity it can create and equally because of the way it can absorb a great proportion of someone's time and mental space, responsibility for another's long-term care can impede pursuit of one's life goals—what some call self-determination, self-actualization,[234] or engagement in "the life

---

227 Montgomery et al., *supra* note 176, at 6.

228 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 47. One-third of caregivers report moderate to high physical strain. *Id.* at 49. Three-fifths report at least one chronic condition, as compared with one-third of non-caregivers. Ho et al., *supra* note 181, at 2.

229 Lynn Feinberg et al., *Valuing the Invaluable: 2011 Update—The Growing Contributions and Costs of Family Caregiving*, AARP PUB. POL'Y INST., 7 (2011), https://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf.

230 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 (Family Caregiver Alliance ed., 2006).

231 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 20-21, 50 (43 percent of caregivers report feeling this way, half of whom serve as a primary caregiver).

232 Alstott, *supra* note 141, at 5.

233 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 50-51.

234 Self-actualization is the highest level of Maslow's hierarchy of needs. *See* Abraham H. Maslow, *A Theory of Human Motivation*, 50 PSYCH. REV. 370, 382 (1943) ("[Self-actualization] refers to the desire for self-fulfillment, namely, to the tendency for him to become actualized in what he is potentially. This tendency might be phrased as the desire to become

of a civilized being."[235] Although more difficult to measure, these harms are nonetheless devastating.

In sum, even if people take on caring for another with great generosity and love, long-term care is extremely demanding. Even in the best of circumstances, it will take a toll.

D. Reimagining Private Obligation as Social Risk

What if we reimagine these costs as the result of next-friend risk, rather than an individual obligation? Long-term care clearly undermines the security of modern American families and can be understood as a source of risk for next friends.

What does it mean for something to be a "risk"? Technical definitions describe risk in actuarial terms as a probabilistic harm from a particular hazard.[236] Next-friend risk clearly fits this conception. Most of us *could* end up responsible for the long-term care for another, even if not all of us *will*. The costs that result are stochastic, skewed, and, in the worst cases, devastating.[237] Responsibility is only triggered when illness or injury affects a family member or friend, rarely due to the fault of a next friend, as examined in more detail below. Even if someone finds providing long-term care for a loved one rewarding, it is not a role that most people anticipate and embrace. [238] Taking an ex ante, collective view, the possibility of responsibility for the long-term care of another shares many attributes with other phenomena that we have treated as serious social risks—from workplace injury to the potential of poverty in old age from outliving ones savings.

Yet not all probabilistic harms are considered and treated as salient social risks. Sociocultural risk scholars examine how what a society defines as risk is

---

more and more what one is, to become everything that one is capable of becoming.").

235 T.H. MARSHALL. CITIZENSHIP AND SOCIAL CLASS: AND OTHER ESSAYS 11 (1950).

236 *E.g.*, FRANK KNIGHT, RISK, UNCERTAINTY, AND PROFIT 19-20, 224-25, 231-32 (1921) (defining risk as quantitative and anything "non-quantitative," in contrast, as "uncertainty"); *see also* Nick J. Fox, *Postmodern Reflections on 'Risk', 'Hazards' and Life Choices*, *in* RISK AND SOCIOCULTURAL THEORY: NEW DIRECTIONS AND PERSPECTIVES (Deborah Lupton ed., 1999) (describing how risk can mean the potential for significant loss or reward but is more often thoughts about in terms of loss).

237 Even though next-friend risk is random to the extent it is impossible to know whether and when a friend or family member will become ill or disabled, some characteristics nevertheless increase any one individual's chance of experiencing it by making them more likely to be responsible for others, such as being a member of a small family or being a woman. Other characteristics, such as being part of a middle-class family might decrease next-friend risk. Cameron Macdonald has shown that middle class families more often live in communities with extended support networks, decreasing any one person's likely burdens. Macdonald, *supra* note 187.

238 *See* Lester, *supra* note 125, at 12, 15.

socially mediated.[239] French historian and philosopher François Ewald takes an especially relativist stance: "anything *can* be a risk; it all depends on how one analyzes the danger, considers the event."[240] Unlike Ewald, most scholars in this tradition believe that some measurable danger underlies what we see as risk.[241] In other words, risk is both objective and socially mediated. This way of defining risk explains why even if a hazard is not presently thought of as a social risk, it does not mean it could and should not be. Calling a phenomenon "risk" signals two things: that it causes probabilistic harm and also that it is salient as such.

Certain harms have greater salience as risky, based on how they are framed, by whom, and with what agenda in mind. Sociologist Ulrich Beck describes an "overproduction of risks," when interested parties magnify some risks in order to, in turn, diminish concomitant risks. As an example, he explains that "the dramatization of climactic consequences 'minimizes' the risk of nuclear energy."[242] This practice is pervasive. The risk from overly aggressive (and perhaps unscrupulous or criminal) banking practices is tolerated in light of claims that certain financial institution are "too big to fail."[243] In *Mutual Pharmaceutical Co. v. Bartlett*, a lawsuit claiming serious injury from a generic anti-inflammatory drug, the pharmaceutical company's lawyers highlighted the harm of rising health care costs due to brand-name drugs in order to suggest that the low risk that a generic drug would cause someone's skin to burn and slough off, as it did to Karen Bartlett, was not unreasonably dangerous.[244] A web of interested parties and complex dynamics shape the collective concern with certain risks and not with others.[245]

---

239 *See, e.g.*, BECK, *supra* note 122, at 21 ("Risk may be defined as a *systemic way of dealing with hazards and insecurities and introduced by modernization itself.*"); MARY DOUGLAS & AARON WILDAVSKY, RISK AND CULTURE (1982) (proposing a cultural theory of risk); Mitchell Dean, *Risk, Calculable and Incalculable*, *in* RISK AND SOCIOCULTURAL THEORY, *supra* note 236, at 131; François Ewald, *Insurance and Risk*, *in* THE FOUCAULT EFFECT 197 (Graham Burchell et al. eds., 1991); Ewald, *supra* note 24; Steve Rayner, *Cultural Theory and Risk Analysis*, *in* SOCIAL THEORIES OF RISK (Sheldon Krimsky & Dominic Golding eds. 1992); *see also* BAKER & SIMON, *supra* note 23; DEBORAH LUPTON, RISK (1999) (providing an overview of different schools of sociocultural risk scholarship). Social typically is used to refer to society at large and cultural to sub-groups within it.

240 Ewald, *supra* note 239, at 199.

241 *See* Nick Fox, *Postmodern Reflections on 'Risk', Hazards' and Life Choices*, *in* RISK AND SOCIOLOGICAL THEORY, *supra* note 236, at 1, 4-6 (arraying sociocultural risk scholarship ranges from realist to relativist).

242 BECK, *supra* note 122, at 31.

243 *See* Eric Dash, *If It's Too Big To Fail, Is It Too Big To Exist?*, N.Y. TIMES (June 21, 2009), http://www.nytimes.com/2009/06/21/weekinreview/21dash.html (explaining popularization of phrase).

244 *See* Brief of Petitioner at 4, Mut. Pharm. Co. v. Bartlett, 133 S. Ct. 2466 (2013), 2013 WL 457382, at *4 (describing the balance Congress sought to strike between cost and safety in the Hatch-Waxman Act); *see also* Jan Crawford, *Can a Patient Sue a Generic Drug*

However, conceptions of risk can evolve so that something that was previously seen as individual cost or misfortune comes to be thought of as a salient social risk. John Witt describes this type of transformation behind the creation of workman's compensation.[246] Workplace injuries occurred before industrialization, but by the end of the nineteenth century they manifested in more frequent, more devastating, and more visible ways.[247] In light of this evolution, advocates worked to transform workplace injury from something conceived of as a source of individual misfortune or fault to a risk inherent in industrialization. This was achieved by framing the injuries as an unavoidable threat to the economic security of American families.[248] This framing made a collective solution seem imperative. In turn, the creation of a collective approach to pay for workplace injuries became the springboard for a "new conception of social responsibility . . . that aimed not just to spread the risks of injury, but also to take on more fundamental risks such as poverty."[249]

The idea of social responsibility to address such risks laid the foundation for the New Deal, creating what one scholar characterized as a "palpable experience of solidarity that helped underwrite the forms of collectivism that were successfully implemented."[250] In fact, risk displaced other justifications for state support, as part of what has been described as a modern shift from a "welfare society" to a "risk society."[251] Costs understood to be the result of uncontrollable threats to family or individual security made a greater claim to state resources.[252] Redistribution was not the explicitly stated goal; security was.

As other harms were perceived as similar in nature to workplace injury—unavoidable and significant—they became worthy targets for social insurance.[253] For example, as hospitals modernized and medical care became

---

Manufacturer?, CBS NEWS (Mar. 19, 2003), http://www.cbsnews.com/8301-18563_162-57575231/can-a-patient-sue-a-generic-drug-manufacturer.

245 *See* Martha McCluskey, *supra* note 23, at 146 (describing a shift from concern with the risk faced by workers to that by employers and big business, affected partially by fixation on moral hazard).

246 WITT, *supra* note 24.

247 *Id.* at 24.

248 *Id.* at 129-30 (describing how activist Crystal Eastman transformed the debate of workplace accidents from centering on individual fault to "the image of the wounded family").

249 *Id.* at 150.

250 Simon, *supra* note 23.

251 BECK, *supra* note 124, at 19-20.

252 *See* Landis, *supra* note 24, at 271; LANDIS DAUBER, *supra* note 24; Ewald, *supra* note 239, at 209-10; Ewald, *supra* note 24, at 281 ("It is a commonplace that, during the twentieth century, law and responsibility were transformed, bit by bit, into a legal system of compensation, based on risk and insurance.").

253 WITT, *supra* note 24, at 5 ("[T]he industrial-accident crisis introduced to the American legal system new ideas and institutions organized around risk, security, and the actuarial

both more expensive and more effective, the costs of medical care threatened American families' financial security, and insurance for medical care was needed to protect the family wage. Medicare and Medicaid were enacted. The creation of Social Security was in part based on the recognition that longer lives heightened the risk of a family outliving its savings and understanding this problem as a collective scourge and not as individual misfortune. Each of these challenges that had long been managed mostly privately came to be perceived as proper zones of state support.

In turn, the creation of social insurance to manage a particular harm helped to transform the social understanding of these harms from a private obligation to a collective concern. Ewald describes that insurance "makes risks appear where each person had hitherto felt obligated to submit resignedly to the blows of fortune."[254] He calls this transformation the process of the "insurantial imaginary,"[255] implying that the creation of insurance itself affirms a particular harm as risk.

In recent years, the language of risk has often been coopted by those who take the position that it is an individual's responsibility to manage risk. Risk spreading approaches are crumbling under the weight of moral hazard—the idea that too much insurance discourages efficient caution.[256] Jacob Hacker, in *The Great Risk Shift*, calls this trend the "personal responsibility crusade" and shows how it has led to policies that invisibly undercut Americans' economic security.[257] As risk has become so strongly associated with this neoliberal agenda, some scholars seek a new language to advocate for state policies that can increase security.[258]

But proponents of social change should not reject the language of risk; it has a long history of motivating monumental social policies and in the right

---

categories of insurance—ideas and institutions that to this day remain at the heart of much of our law"); Landis, *supra* note 24, at 271 (1999) ("Ultimately, whether or not an event was a 'calamity' deserving of federal intervention turned upon the ability of the claimants to argue that they, like those who previously received aid, were innocent victims of fate rather than irresponsible protagonists in their own misery."). *See generally* LANDIS DAUBER, *supra* note 24 (describing government indemnification of victims of natural disasters that were considered calamitous and unpredictable).

254 Ewald, *supra* note 239, at 200.

255 *Id.* at 209-10 (describing risk as "the principle of a new political and social economy" beginning at the end of the nineteenth century with the rise of social insurance).

256 *See e.g.*, BAKER & SIMON, *supra* note 23; HACKER, *supra* note 23.

257 HACKER, *supra* note 23, at 8. Jonathan Simon attributes this shift to the public obsession with new threats that defy risk-spreading solutions, such as climate change, crime, and cancer. Risk spreading solutions "no longer undercut the dread associated with [these threats]" and the harms that resulted are not perceived as a necessary price to pay for something "profoundly good for society." Simon, *supra* note 23, at 128, 135.

258 Martha Fineman, *"Elderly" as Vulnerable: Rethinking the Nature of Individual and Social Responsibility*, 2 ELDER L.J. 101, 136-38 (2012) (advocating for focus on "vulnerability" instead of "risk").

context could do so again. As Hacker suggests: "Americans may be willing to turn a blind eye to growing inequality, confident in the belief that their own standard of living is still rising. But economic insecurity strikes at the very heart of the American Dream."[259] It leaves even those who have done all the right things to achieve a place in the middle class fearful about having the rug pulled out from under them.

The idea of next-friend risk recasts the problem of private obligation for long-term care in a more compelling way for the public and for policymakers, many of whom worry personally about the possibility of becoming responsible for an aging parent, sick spouse, or disabled child. Recognizing next-friend risk can transform long-term care from an old-people problem into a universal concern. Public long-term care funding has been vulnerable to attack as "yet another" transfer from today's already stretched workers to the elderly. If instead we see the problem of long-term care as a threat to people's financial security and health during their prime earning and child-rearing years, solving it, in effect, is a transfer to the young, working class. Three-quarters of informal caregivers are under age sixty five and three-fifths are in the labor force.[260] In other words, any social resources and tax dollars spent on the problem would benefit the primarily working-age next friends as much as the care recipients. Seeing long-term care as a problem equally for care recipients and for next friends could broaden coalitions for reform, uniting the interests of labor, informal caregivers, older voters, and disability advocates.

Next-friend risk, however, has been sidelined. The policy focus on long-term care risk from the care-recipient perspective has served to overshadow the concomitant risk to next friends. The laws and policies described in Part I have hidden next-friend risk from the public eye, in the home and off the balance sheets, by inscribing it as private and individual—unsurprising, given the gendered nature of long-term caregiving. The notion that family care is a personal, perhaps moral, obligation that people provide willingly is politically convenient. It has enabled policymakers to avoid dealing with the full cost of long-term care, instead leaving others to experience the costs privately and invisibly.

E. The Implications of Imagining Next-Friend Risk

Understanding the possibility of becoming responsible for another as a social risk—and not as a private obligation—has at least four major substantive implications for long-term care policy.

---

259 HACKER, *supra* note 23, at 15.

260 Chari et al., *supra* note 26, at 876.

First, it changes the scale of the problem. Current social insurance policy hides costs borne by next friends. Even considering just the $470 billion estimate of the current market value of hours spent caregiving would require long-term care funding at triple current Medicaid levels.[261] Although the United States spends more per capita than other developed countries on nearly every other category of health care, it spends comparatively less on long-term care.[262] There is good reason to spend more. Even if Medicaid funding is unlikely to triple anytime soon, accurate accounting of the size of the problem could anchor policymakers on a more realistic number.

Second, as discussed just above, recognizing the problem of next-friend risk highlights its similarity to other problems that have prompted the creation of social welfare policy and social insurance to spread risk. At a moment in time when individualistic sentiment runs strong, the fact that many people can relate personally to next-friend risk could be a boon.[263] In other words, people might be motivated out of self-regard to support a solution that offers communitarian benefit. More so, where intensive care needs persist over time, few Americans could shoulder the burden privately, suggesting the necessity of a universal social insurance approach. Universal programs are also more popular and less politically vulnerable than means-tested ones, like Medicaid.

Third, even with an infusion of funding, it is necessary to see the problem from the perspective of next friends in order to design policy with the flexibility to mitigate the risk they face. Next-friend risk could be mitigated to some extent by simply increasing Medicaid funding for long-term care, but even a large increase could have limited benefit if not done with an eye toward addressing next-friend risk.

In some cases, the best way to mitigate risk is to make family caregivers whole by paying them for caregiving. In others, it is by enabling them not to

---

261 Reinhard et al., *supra* note 26, at 2.

262 MCKINSEY CTR. FOR U.S. HEALTH SYS. REFORM, ACCOUNTING FOR THE COST OF U.S. HEALTH CARE: PRE-REFORM TRENDS AND THE IMPACT OF THE RECESSION 9 (2011), http://healthcare.mckinsey.com/sites/default/files/793268__Accounting_for_the_Cost_of_US_Health_Care__Prereform_Trends_and_the_Impact_of_the_Recession.pdf (estimating that the United States spends almost $275 billion less than expected on long-term and home care, meaning that just spending at expected would double the current U.S. spending levels; for comparison, the United States spend $522 billion more than expected (approximately 50% more) on outpatient care and $120 billion more than expected (approximately 30% more) on drugs and nondurables); *see also* David Squires & Chloe Anderson, *U.S. Health Care from a Global Perspective: Spending, Use of Services, Prices, and Health in 13 Countries*, COMMONWEALTH FUND 7-8 (2015), http://www.commonwealthfund.org/publications/issue-briefs/2015/oct/us-health-care-from-a-global-perspective (showing that the United States spends relatively more on health care and less on social services than comparable studies).

263 *Cf.* Walter Korpi & Joakim Palme, *The Paradox of Redistribution and Strategies of Equality: Welfare State Institutions, Inequality, and Poverty in the Western Countries*, 63 AM. SOC. REV. 661, 664-65 (1998) (suggesting that redistributive institutions have societal feedback effects).

provide care in the first place and thus limit the extent of the negative impact on their careers or lives. It is possible to mitigate risk fully from the care-recipient perspective, but to leave next friends vulnerable by, for example, pouring money into current Medicaid programs that have a bias for family care. Even if Medicaid compensated all hours of informal care at a fair wage, it would perpetuate harm—financial and nonmonetary—for kin who are better off in the long run if they do not provide care, but who have no other option. Conversely, if a huge infusion of funding were made available only to pay for outsourced care, the same would occur. Some people would be unable to find a satisfactory way to pay for care and would instead provide care themselves, even without pay. Or under some states' policies, the only outsourcing option is nursing home care. Someone unwilling to put a parent in a nursing home, or whose parent is unwilling to live in a nursing home, might instead still provide care herself.

When someone becomes responsible for the care of another, she should be able to decide whether to provide care herself or to pay someone else to do it (or some combination). Insurance must be designed to enable a next friend to toggle more freely between these two choices and thus to use benefits in a way that minimizes her own insecurity, however she might define it, and to balance caring for a family member with other pursuits. Current policy is focused so narrowly on care-recipient risk that it does not even see the need for this toggle. I discuss in detail below why such a toggle is imperative and what it requires. Conceptually, seeing next-friend risk reveals the need for it.

Fourth, especially if no additional money is spent, understanding next-friend risk raises the (admittedly uncomfortable) question of whether we should think differently about tradeoffs between mitigating care-recipient and next-friend risk, even if it means compromise in some cases for the care recipient. For example, if an elderly widower has a stroke, the goal of current long-term care law and policy is to protect his autonomy by providing adequate support in the least restrictive setting appropriate, as required by *Olmstead*.[264] If his daughter moves him into her home—the solution that Medicaid policies for home- and community-based care increasingly encourage—this goal 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 health and wellbeing. Such results, where each generation sacrifices its security for the previous one, are simply not sustainable.

***

264 Olmstead v. L.C. *ex rel.* Zimring, 527 U.S. 581, 607 (1999).

As the demands for care are becoming more intense and the structure of families is changing, care needs do not fit seamlessly into the household, and the risk long-term care poses to next friends is increasingly difficult to ignore. When viewed in the aggregate, next-friend risk appears as threatening as the risk of disability from the care recipient perspective and as many of the other phenomena that have motivated state action.

No social policy could neutralize all of the harm people experience when friends or family need long-term care. It is inevitably painful to see a loved one who needs help feeding herself or getting in and out of bed, even if the costs of her care are fully compensated. Nor could any policy even ameliorate all economic harms. Doing so would be too complex and too expensive. But long-term care policy could be designed to minimize next-friend risk better than it does today. Considering the risk of long-term care equally from this perspective is a first step toward better long-term care policy.

III. SOCIAL INSURANCE FOR NEXT-FRIEND RISK

A. The Case for Social Insurance for Next-Friend Risk

Imagining next-friend risk implies that it is something social insurance *could* mitigate. Here, I make the case for why it *should*. Social insurance spreads costs that a society sees as inefficient, undesirable, or unjust for an individual to bear. It can be used to promote economic efficiency or address private-insurance market failures.[265] Social insurance can also "change [the] character" of an existing market,[266] such as when people cannot afford private insurance that would be welfare enhancing,[267] for paternalistic reasons, or to advance social justice goals.[268] Social insurance policies that are more sensitive to next-friend risk could be more efficient and result in a more just distribution of the costs of long-term caregiving. As will be discussed in Part IV, these goals could be advanced by a comprehensive social insurance program or even just incremental changes to existing social insurance policies.

---

265 *See* KENNETH ABRAHAM, DISTRIBUTING RISK 10 (1986); GRAETZ & MASHAW, *supra* note 24, at 18; MOSS, *supra* note 24, at 10-13 (suggesting reasons why risk-related market failures are common); Kwak, *supra* note 27, at 12.

266 *See* GRAETZ & MASHAW, *supra* note 24, at 18;

267 *See* Steven Shavell, *A General Rationale for a Governmental Role in the Relief of Large Risks*, J. RISK & UNCERTAINTY (forthcoming), https://dash.harvard.edu/bitstream/handle/1/16883007/Shavell_768.pdf.

268 GRAETZ & MASHAW, *supra* note 24, at 18-23; *see also* ABRAHAM, *supra* note 265, at 20-29 (1986) (distinguishing egalitarian justifications from utilitarian ones because they have equality at their center and not as a potential byproduct). Abraham describes libertarianism as a third influence, in addition to utilitarianism and egalitarianism, and contends that "intuitive pragmatism," a mix of these three values, informs insurance regulation. *Id.* at 29.

Mitigating next-friend risk would serve a core utilitarian goal—to protect people from income loss that can undermine economic security.[269] Marmor and coauthors describe social insurance as "a set of interventions designed to reduce the impacts of common threats across each person's life cycle, threats that simply cannot be countered effectively by individual prudence and private markets."[270] As explained above, next-friend risk poses precisely this type of threat.

Yet, social policy does not always intervene to make lives more secure, even if it could, which raises the question of why next-friend risk should be a priority. Family or friends often take responsibility for each other in cases of, for example, unemployment, property damage, or unmanageable debt. Furthermore, U.S. social welfare policy excludes most caregiving, even though spreading the costs of such activity has the potential for significant welfare benefits.[271]

One possibility is that next-friend risk in the case of long-term care is not exceptional, and the state should be equally concerned with costs family face in these other situations. Policymakers select out some from among many insurable risks.[272] From this perspective, what becomes insured is more a matter of what suits a social and political moment than any valid comparative claim to shared resources.

Yet, there are also substantive reasons why addressing next-friend risk is especially important. As Section II.A described, the social norms for taking care of a family member or friend who is physically vulnerable are strong and engender sacrifice. It is less expected that a family member would sacrifice her own financial security, family, career, or wellbeing to bail a sibling out of credit card debt or to bankroll an unemployed child indefinitely. Next-friend risk arises in service of something that we expect people to do and that we perceive as a public benefit: providing care for people with serious illness or disability.[273]

Furthermore, the consequences of not helping a sibling in credit card debt are less dire, in part because the law and private insurance already offer means for relief. A family member in debt can file for bankruptcy. Someone who loses a job can claim unemployment insurance. But in the case of long-

269 *E.g.*, GRAETZ & MASHAW, *supra* note 24, at 45.

270 MARMOR ET AL., *supra* note 24, at xx.

271 Alstott, *supra* note 141, at 27; *See generally* HACKER, *supra* note 23 (making the case for stronger social insurance programs to spread risk).

272 GRAETZ & MASHAW, *supra* note 24, at 25 ("Social insurance . . . is defined concretely for any society by the complex interaction of collective purposes and acceptable political techniques."). Ewald calls this process the combination of insurantial imaginary and political imaginary. Ewald, *supra* note 239, at 198.

273 Simon, *supra* note 23, at 128, 135.

term care, it is nearly impossible for people to meet their needs without others' help, even if they qualify for Medicaid benefits.

Next-friend risk has higher stakes. Just the possible monetary losses outlined above can set a caregiver up for a future with insufficient resources to meet her own basic needs. Few ways that family members aid each other approach this level of cost and financial insecurity. Addressing next-friend risk could thus significantly bolster the financial security of American families.

Social insurance also serves egalitarian goals. John Rawls argued that a just distribution of basic resources is defined by the share held by the worst off person in society.[274] Social insurance offers protection against the depletion of any one individual's basic resources. Graetz and Mashaw justify social insurance in such terms: "Given little information about where they would start or end up in the income distribution, it might seem in everyone's interest to agree to the collective provision of affordable . . . insurance in order that they all have reasonable protection against foreseeable risks."[275] Anne Alstott has expressed a similar goal in "liberal egalitarian" terms. She contends that "a central function of the state is to create institutions that ensure to every person the conditions of autonomy: the chance to develop the capabilities that one needs to formulate, choose, and pursue a vision of the good life."[276] Social insurance can serve as such an institution that protects conditions of autonomy, in terms of money or time.

Although people disagree on what particular basic resources or conditions are necessary to ensure opportunity,[277] it is indisputable, under any definition, that responsibility for another's long-term care would deplete these resources and disrupt such conditions. Just the potential financial losses would do so. Yet, long-term caregiving also depletes health and time, which are as

---

274 *See* JOHN RAWLS, A THEORY OF JUSTICE 72 (1971); RONALD DWORKIN, SOVEREIGN VIRTUE 73 (2000).

275 GRAETZ & MASHAW, *supra* note 24, at 19.

276 ALSTOTT, NO EXIT, *supra* note 22, at 35.

277 Professors Graetz and Mashaw focus on economic resources. *See* GRAETZ & MASHAW, *supra* note 24, at 19. John Rawls himself names liberty as the foremost primary good. *See* RAWLS, *supra* note 274, at 214. Norm Daniels extends Rawls's analysis to health as a condition of equality. NORMAN DANIELS, JUST HEALTH (2007). Amartya Sen and Martha Nussbaum contend that capabilities are better precursors to opportunity because they capture how people with various levels of ability actually engage in the world. Martha C. Nussbaum, *Long-Term Care and Social Justice: A Challenge to Conventional Ideas of the Social Contract*, *in* WORLD HEALTH ORG., ETHICAL CHOICES IN LONG-TERM CARE: WHAT DOES JUSTICE REQUIRE? 31 (2002); Amartya Sen, Equality of What?, The Tanner Lecture on Human Values (May 22, 1979), http://tannerlectures.utah.edu/_documents/a-to-z/s/sen80.pdf. Nussbaum includes goods such as "entitlement to leisure for play and the cultivation of one's faculties, political participation, and employment opportunities" among the basic "primary goods." Nussbaum, *supra*, at 56.

necessary as money as conditions to pursue life goals. Research shows that even those caregivers who see caregiving as part of their purpose in life and report personal enrichment from it are no less likely to suffer a loss of identity, referred to tellingly as "loss of self" or "role engulfment."[278]

These harms are made especially unjust by the fact that they are borne inequitably, especially by women. Their long-term care responsibilities exacerbate weaker workplace attachment and the wage gap. Social policy sensitive to next-friend risk could promote conditions of autonomy for everyone and, in so doing, also reduce the disparate impact of next-friend risk on women's careers, earnings, health, and wellbeing.

B. Principles To Guide the Design of Social Insurance for Next-Friend Risk

Designing social insurance in a way that promotes greater security and simultaneously protects a next friend's ability to make life choices is not simple. Imagine if the state were to provide all long-term care in-kind, perhaps with the option for either nursing home care or formal caregivers at home. This approach could reduce the insecurity that informal caregivers face, by taking them out of the business of long-term caregiving altogether. They would be free to engage in their professions, child-rearing, civic work, education, and leisure activities, as before, and to spend time with a friend or family member as they wish but not as the primary caregiver. This approach is conceptually simple. Yet, it would be both difficult to implement, at least in the short term, and incomplete. Even with the current reliance on family and friends, there is a substantial shortage of formal care providers, as discussed below. No feasible path forward could cut all family and friends out, especially in the short term.

Further, providing only in-kind benefits would not achieve the goal of greater security for everyone.[279] Some people would decline an in-kind benefit to provide unpaid informal care themselves, either because they want to do so or because a family member refuses anything but family care. Even if someone deeply values providing care—enough to do it for free when other options exist—we might nonetheless want to protect her from experiencing insecurity if she chooses to do so, especially if we value caregiving by friends and family. In other words, we might not want Mother Teresa to die homeless and starving just because she truly preferred to care for others for free.

---

278 Marilyn M. Skaff & Leonard I. Pearlin, *Caregiving: Role Engulfment and the Loss of Self*, 32 GERONTOLOGIST 656, 657 (1992). "Loss of self" was found to be more common among spouses, women, and younger caregivers. *Id.* at 660.

279 It might, however, be a more effective way to achieve other goals, such as stronger workplace attachment for women and narrowing the gender gap in the workplace.

Likewise, for all of the reasons already articulated, shifting to a system of only family care, even if compensated, would not be a good solution either. It would require more people to disrupt other pursuits, even when doing so is not in their best interests.

A comprehensive approach must recognize and support the two ways that someone could respond to a family member or friend in need—by providing or paying for care. The best policies would be designed to allow someone to toggle between these two choices, to protect her security and, equally, her self-determination.

One version of a toggle might require social insurance policies that are neutral on their face. Policies could allow next friends to use benefits interchangeably to provide care or to pay someone else to do so. This approach is common in other countries with universal long-term care insurance.[280]

Each next friend could weigh potential harms and benefits and decide how best to minimize her own risk in a context where harms and perceptions of harms vary considerably from person to person. For example, imagine a daughter is working toward a master's degree in business or is writing a novel when her father has a stroke. She might, on one hand, believe that finishing her degree or the novel is the best way to protect her future security or to pursue her dreams. Or she might prefer to put these pursuits on hold. More facially neutral long-term care policies would at least give her the opportunity for such deliberation.

Furthermore, more flexible policies are sensitive to the complexity of factors that go into such decisions, balancing the needs of care recipients and their next friends. In some cases, the care recipient might prefer care by a friend or family, or family might be better able to address a care-recipient's needs.[281] Some studies suggest that treatment outcomes can be better when a loved one provides care.[282] In other cases, it might not be best for a family member to provide care, such as when more specialized care is needed, when a parent was or is abusive, or when the parent is reticent to burden family or friends with caregiving but willing to accept paid, professional help. In many cases, a combination of providing and paying for care might be best. As Carol Levine, a prominent long-term care scholar and the primary caregiver for seventeen years for her husband, who was paralyzed from the neck down in a

280 *See* discussion *infra* Section IV.A.2 for examples of this approach.

281 *See, e.g.*, Wolf, supra note 146, at 366-67 (contending that a family member might be better positioned to manage money or prepare meals or to generate economies of scale with cohabitation).

282 *See, e.g.*, Joseph E. Gaugler, *Family Involvement in Residential Long-Term Care: A Synthesis and Critical Review*, 9 AGING & MENTAL HEALTH 105, 111 (2005) (reporting that family involvement in caregiving has been shown to decrease mortality, infection, and hospitalization).

car accident, aptly describes: "Total self-sacrifice may be ennobled in legend; it is a decidedly unsatisfactory way to live one's life and a poor basis for public policy."[283] The point is that there is no single right answer on how to structure long-term care provision for every circumstance. Policies must be designed in a way that creates space for this variability.

Simply creating an option to outsource care in more cases would change the landscape by softening the way that the law currently creates a bias toward informal caregiving. As Gillian Lester has explained: "[I]f a state intervention makes a choice previously unavailable to some portion of the population financially more attractive, the effect will be to encourage individuals on the margin toward the new option."[284] We might think of a toggle that creates facially neutral policies as a "thin version" of state neutrality. The goal would be to strive for policies that do not, in and of themselves, strongly bias decisions on how to manage next-friend risk.

Yet a policy that is neutral on its face would not mean neutral grounds for decisionmaking when layered on top of strong preexisting biases toward familial care—individual, social, or institutional. A "thick version" of state neutrality could provide some counterweight to these biases.

For example, individuals might underestimate the burdens of long-term caregiving and overestimate the benefits.[285] People might underestimate the long-term effect on career advancement or the many sources of income and assets that will be compromised, including health benefits, social security, or pensions. They could easily underestimate the length of time care will be needed; elderly parents suffer diseases that can persist for many years, yet doctors cannot provide good estimates of likely mortality.[286] Likewise, next friends might suffer from "optimism bias" and overestimate the benefits of providing care personally, including psychic rewards, possible inheritance, or even the benefit to the care recipient of family providing care.[287] Or the horror stories about problems that arise in nursing homes might be overly influential.[288]

---

283 Levine, *Home Sweet Hospital,* supra note 124, at 348.

284 Lester, *supra* note 125, at 6.

285 *Cf.* Christine Jolls et al., *A Behavioral Approach to Law and Economics*, 50 STAN. L. REV. 1471, 1476-79 (1998) (describing the research on bounded rationality—the reasons why actual behavior differs from rational behavior); Russell Korobkin & Thomas Ulen, *Law and Behavioral Science: Removing the Rationality Assumption from Law and Economics*, 88 CALIF. L. REV. 1051 (2000) (outlining empirical evidence inconsistent with the rationality assumption).

286 *Cf.* Korobkin & Ulen, *supra* note 285, at 1083 (describing the possibility for suboptimal decisionmaking in ambiguous situations).

287 Neil D. Weinstein, *Unrealistic Optimism About Future Life Events*, 39 J. PERSONALITY & SOC. PSYCHOL. 806, 806 (1980).

288 *Cf.* Korobkin & Ulen, *supra* note 285, at 1100 (describing "anchoring" errors); Jennifer Steinhauer, *Shock but No Longer Surprise over Nursing Home Problems*, N.Y. TIMES

Furthermore, the background social norms and social institutions discussed in Part II create a non-neutral and self-reinforcing baseline that could overly determine decisions, especially decisions women make to provide care directly. The historical reliance on family caregiving has limited investment in compelling community-care settings and has atrophied the labor force for caregiving, which means that even with nimble policies, it may still seem there is no option but to provide care.

Policies could be designed to be sensitive to and with the aim of counterbalancing these preexisting biases.[289] At the very least, they could make transparent the costs and benefits of different choices to prompt people to consider them.[290] Medicaid policies could highlight the benefit of care in group settings or from formal caregivers, who are often better trained or equipped to provide care, and the burdens family face when providing care personally. Even more strongly, the law might, for example, be designed to discourage untrained next friends from providing care in the hardest cases, such as with dementia care, where caregivers report the highest burden.[291] Thus, there are compelling reasons to increase social insurance protections for next friends, but actually doing so is no easy task.

C. Policymaking and Dynamic Effects

Just as current policies compel informal caregiving, new policies would shape decisions as well, whether intentionally or not. Policymakers try to predict individual and social responses to policies—dynamic effects—but are not always able to do so perfectly. And these effects might change in response to changing social circumstances, requiring iteration over time to achieve policy goals.

In the case of policies aimed to address next-friend risk, social policy details could have dramatic effects on workplace participation, the future development of long-term care facilities and workforce, and kinship

---

(Nov. 9, 2000), http://www.nytimes.com/2000/11/09/nyregion/shock-but-no-longer-surprise-over-nursing-home-problems.html (noting a 30% increase in citations for inadequate care in nursing homes between 1998 to 1999).

289 *See* Christine Jolls & Cass R. Sunstein, *Debiasing Through Law*, 35 J. LEGAL STUD. 199, 199-201 (2006) (describing use of the law to steer people toward more rational decisions).

290 This type of informational approach is common in financial literacy efforts. *See* Allison K. Hoffman & Howell E. Jackson, *Retiree Out-of-Pocket Healthcare Spending: A Study of Consumer Expectations and Policy Implications,* 39 AM. J.L. & MED. 62, 65-66 (2013) (describing these financial literacy efforts).

291 JOSHUA M. WIENER ET AL., AARP PUB. POL'Y INST., CONSUMER-DIRECTED HOME CARE IN THE NETHERLANDS, ENGLAND, AND GERMANY 15 (2003), http://assets.aarp.org/rgcenter/health/2003_12_eu_cd.pdf. In these cases, relying on professional caregivers might be in the best interests of both the care recipient and the next friend.

relationships. This Section acknowledges such effects by considering one especially important policy design question: whether to compensate care a next friend provides based on lost income or market caregiving wages. This decision in effect gets to the heart of how exactly we conceive of the insurable harm—disruption of employment or time spent caregiving—and would have a significant impact on an individual's decision to provide or pay for care. This discussion is not intended to solve this question, which has fueled decades of feminist debate; rather, I use it to illustrate the importance of policy details.

The first approach, replacing lost income, captures immediate financial harm in a way familiar to American social insurance, which most often measures harm as the costs of disruption of paid work.[292] This approach, however, implies that an at-home parent, a volunteer worker, or an unemployed worker, who would not experience immediate loss of income, is not harmed.[293] It also takes a snapshot view of harm that does not capture the cascading effects caregiving might have on someone's life. If a mother were caring for her young children but intending to return to work, added responsibility to care for an aging parent or injured spouse could be the final straw that prevents her from ever reengaging in paid work.[294] Basing benefits on potential future lost wages would be pure speculation, even if such losses might have been significant. On the other hand, if a corporate executive took leave to provide care, social policy would put a high value on the harm, and the public costs of doing so would be formidable. The fact that the market values some activities more than others would be felt doubly. Social insurance policy that views harm only in terms of lost wages would replicate the wage gap and undervaluation of women's work.[295]

This approach would have cascading effects. Lower-paid or unemployed family members, more likely women, would have less incentive to take on caregiving, and they would be paid less when they do. And all else equal, a

---

292 *See* GRAETZ & MASHAW, *supra* note 24, at 27. *But see* Allison K. Hoffman, *Three Models of Health Insurance: The Conceptual Pluralism of the PPACA*, 159 U. PA. L. REV. 1873, 1890-91 (2011) (describing that social insurance can be focused on harms other than disruption of paid work, including on harms to health).

293 *Cf.* Alstott, *supra* note 141, at 6 ("[O]nce we understand social insurance as the use of law to address, in a deliberate way, the major risks of life, then the focus of present programs on the risks of paid employment begins to seem oddly narrow.").

294 *See, e.g.*, Skira, *supra* note 18 (describing the longitudinal effect of informal caregiving for aging parents on women's labor participation). Most women who stay home with children later return to work. JENNIFER CHEESEMAN DAY & BARBARA DOWNS, U.S. CENSUS BUREAU, OPTING-OUT: AN EXPLORATION OF LABOR FORCE PARTICIPATION OF NEW MOTHERS 4 (2009) (reporting that although half of women with children under 12 months are not employed, most are employed by the time the child is over 12 months).

295 *See supra* note 125.

higher earner could more freely make a decision to provide care with less financial sacrifice.

This approach would also face practical challenges. Benefits with a higher dollar value could increase concerns of moral hazard or fraud. Plus, it would be difficult to administer and finance benefits based on individual lost wages, especially if a substantial number of higher-earners took on caregiving roles. Realistically, full wage replacement is infeasible, but partial replacement is conceivable. As an example, California is one of three states with a disability program designed to compensate family caregiving by replacing lost income—the others are Rhode Island and New Jersey. In 2016 in California, which has the most generous of the three programs, the program reimburses caregivers fifty-five percent of lost earnings, but up to a maximum of $1129 per week and only for six weeks total.[296] Of course, anything less than full wage replacement relatively reduces incentives to take leave from work to provide care.

The other approach would be to compensate the hours a next friend spends caring for another at market caregiving wages. Symbolically, this approach values hours spent in terms of the service provided instead of in terms of opportunity costs.

This approach would also have strong dynamic effects. It creates greater incentives for people with lower or no salary to provide care and for higher earners not to do so. Benefits would be a job engine for the unemployed or underemployed. At the same time, this approach would perpetuate the existing gendered division of care work. Even more, it could actively discourage women from pursuing work outside of the home, by making home-based work relatively more attractive than it is now. It would reinforce expectations that the lower-earning family members (more often women) take on caregiving and that the higher earners stay in their more lucrative position. Yet, if benefits are fungible and could be used just as easily to outsource care, the lower-earning member still gains leverage, as compared to the status quo, to resist expectations that she be the one to provide the care.

On balance, paying for hours based on market wages, or, even better, a living wage[297] might be preferable. The value of benefits for home-based care would be the same regardless of whether someone chooses to provide or pay for the care. Someone would have to value providing care more than her status

---

296 *About Paid Family Leave*, ST. CAL. EMP'T DEV. DEP'T (2016), http://www.edd.ca.gov/disability/About_PFL.htm.

297 The median hourly wage for direct care workers was $10.63 in 2012. *America's Direct-Care Workforce: November 2013 Update*, PARAPROFESSIONAL HEALTHCARE INST., 2 (2013) [hereinafter *America's Direct-Care Workforce*], http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf. A full-time job at this wage is just over $21,000. For criticism of the structure of paid caregiving work, see sources cited *supra* note 126.

quo position (including any wage differential) to take it on personally, or else she could pay someone else to do it. Higher earners would still have incentive to outsource, rather than provide care, but the two options would be more comparable than in today's world with no compensation for informal caregiving in most cases. Even if this approach replicates incentives for people without wage jobs or with lower-paid jobs to take on caregiving, they would, at the least, receive monetary compensation for work they already do now without pay. To avoid this replication would require either a thick version of state neutrality that discourages people from informal caregiving altogether or policies that address the sources of underlying bias in more substantial ways.

This example illustrates how the notion of creating neutral policies may be simple in concept but not in application. The best policymakers can do is to design the most evenhanded policy possible and monitor and reconsider the effects of policy decisions over time.

D. Considerations for What Counts as Next-Friend Risk

Even those who, in theory, favor social insurance for next-friend risk might disagree on what exactly should qualify as insurable risk. Some activities seem routine and others less so. How do we know when an adult child caring for a parent is at risk as compared to just doing what children do for their parents? Is it risky simply to be responsible for another's care or only when someone lacks the resources to manage such responsibility?

These types of boundary questions undergird all insurance design, private and social. The answers determine which costs will be shared and which should remain private obligations.[298] For example, the ACA requires insurers to charge most insured individuals similar premiums, but allows them to charge smokers higher premiums.[299] Expressively, this policy signals a belief that smokers have increased their chances of harm and thus should remain privately responsible for more costs.[300] Often the principle of choice is

298 Tom Baker, *Risk, Insurance, and Responsibility*, *in* EMBRACING RISK, *supra* note 23, at 33, 45-46 ("Depending on the degree to which premiums or benefits are linked to individual characteristics or choices, the fortunes of the members of an insurance group can be linked together to a greater or lesser extent.").

299 Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, § 2701(a)(1)(A)(iv), 124 Stat. 119, 155 (codified as amended at 42 U.S.C. § 300gg(a)(1)(A)(iv) (2012)).

300 An economist would describe this behavior as moral hazard and its exclusion as efficient. *But see* Tom Baker, *Insuring Morality*, 29 ECON. & SOC. 559 (2000) (arguing that this neoclassical economic version of insurance has embedded in it notions of morality).

invoked to justify what is in or out: those costs that result from personal choices should be private, while stochastic harms should not.[301]

Line-drawing decisions are inevitably normative and often highly contested.[302] These determinations are high stakes, in part because they serve to shape how we think about social problems.[303] Richard Ericson writes: "In making risks collective and commodified, insurance alters notions of providence, responsibility and justice."[304] For example, Medicare freed employers from responsibility for retiree health care spending.[305] Conversely, the lack of cohesive state systems for long-term care insurance tacitly affirms private responsibility. The boundaries of any new approach to insure next-friend risk will likewise shape how people think about responsibility for long-term care for years to come.

In this Section, I do not attempt to firmly draw these boundaries, although I suggest that some lines are easier to defend than others. My main aim is to identify the places where the difficult questions arise and what is at stake when lines are drawn.

1. Who Bears Next-Friend Risk?

The paradigmatic case of long-term care is that of an adult child caring for an aging parent, but only about half of cases fit this picture.[306] Consider the following scenarios:

> *A young girl is diagnosed with autism. She will require significant care for her entire life. She has two siblings, and both parents work to earn enough to support the family.* (Lifelong-Care Scenario)

---

301 *See* Seana Valentine Shiffrin, *Egalitarianism, Choice-Sensitivity, and Accommodation*, *in* REASON AND VALUE: THEMES FROM THE MORAL PHILOSOPHY OF JOSEPH RAZ 270 (R. Jay Wallace et al. eds., 2004).

302 Noah D. Zatz, *Poverty Unmodified?: Critical Reflection on the Deserving/Undeserving Distinction*, 59 UCLA L. REV. 550 (2012) (discussing the normative judgment involved in defining "need").

303 RICHARD V. ERICSON ET AL., INSURANCE AS GOVERNANCE 50 (2003) (studying private insurance as a form of "governance" outside of the bounds of the state).

304 *Id.* at 48.

305 *See* STARR, *supra* note 49, at 388 (1982); *see also* FRANK MCARDLE ET AL., *Retiree Health Benefits at the Crossroads*, KAISER FAMILY FOUND. 1 fig.1 (2014), https://kaiserfamilyfoundation.files.wordpress.com/2014/04/8576-retiree-health-benefits-at-the-crossroads.pdf (illustrating a decline from 68% of large firms offering retiree health benefits in 1988 to 28% in 2013).

306 *See* NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 18.

> *A middle-aged man with a wife and no kids has bone-marrow cancer. His medical care, including chemotherapy and a bone-marrow transplant, may continue for years.* (Midlife-Disruption Scenario)
>
> *An elderly widower with two adult children, a daughter and a son, has a stroke. He had been living independently yet modestly among a community of close friends. Now he needs help with basic activities, like showering, voiding, and preparing his food.* (Aging Parent Scenario)

It is likely that the parents, the wife, and the daughter (less likely but possibly the son or a close family friend) will take on responsibility for caregiving in these cases. They are the next friends, responsible in practice, even if not required by law, for the long-term care and wellbeing of another. Are the burdens each faces similar next-friend risks, or is there something fundamentally different about these situations that warrants treating them differently?

Above, I offered one definition of risk as a probabilistic harm. To some, the Aging Parent Scenario might seem more an inevitability. It is more common that someone would need to care for a parent than for a spouse, sibling, child, or friend with serious illness and disability.[307] One implication might be that adult children should thus expect and plan for parental care. Even though more common, about one-half of people never need long-term care and, among those who need care, the amount of care needed is highly variable, ranging from very little to years of intensive care.[308] Thus, even for adult children, it would be difficult to know what level of parental care to anticipate.

Conversely, some might have an intuition against seeing the Lifelong Care and Midlife Disruption scenarios as cases of next-friend risk. Perhaps people take a gamble when they have a child or get married, and the harms that result are not morally arbitrary. Ronald Dworkin called non-arbitrary harm the result of "option luck," as contrasted with "brute luck."[309] The principle that justice demands less for harms that result from option luck has

---

307 *See supra* note 174.

308 LEORA FRIEDBERG ET AL., CTR. FOR RET. RESEARCH AT BOS. COLL., NEW EVIDENCE ON THE RISK OF REQUIRING LONG-TERM CARE 4, 23-24 (2014), http://crr.bc.edu/wp-content/uploads/2014/11/wp_2014-12.pdf (summarizing existing research and providing new estimates that indicate more people will need long-term care than earlier estimates suggest but of a shorter average duration).

309 RONALD DWORKIN, SOVEREIGN VIRTUE 73 (2000). *But cf.* Peter Vallentyne, *Brute Luck, Option Luck, and Equality of Initial Opportunities*, 112 ETHICS 529, 532-37 (2002) (arguing that brute luck might be easier to define in theory than in application).

been called "choice-sensitivity."[310] Kenneth Abraham describes that "the degree to which a risk is controllable and the degree to which the activity producing it is socially optional, would form the basis of an egalitarian standard of fair risk distribution in insurance."[311] Put simply, people should bear the costs of their own choices.

Someone's choices can undeniably increase the likelihood of becoming responsible for someone else. Some people explicitly promise to care for life partners in sickness, as well as in health. Likewise, most people choose whether to have children, knowing that raising children is a risky endeavor in ways that both can and cannot be anticipated. At the most basic level, most of us know (or should know) that there is some potential for extraordinary levels of responsibility for another when entering into a relationship. Perhaps parents, spouses, and friends have assumed the risk of such responsibility when they enter into relationships, in a way that children, grandchildren, and siblings have not.[312]

Yet, these distinctions between those relationships we choose and those we are born into are shaky. Reasonable people may actually not understand the extent of responsibility they could bear for another when they marry or have a child. Most people underestimate the chance that someone they love will become disabled or ill and need care, especially when it is a distant possibility.[313] Many people assume that their insurance—public or private—will cover long-term care, when in most cases it does not.[314] Additionally, as discussed above, the nature of care for a person with a disability is quickly becoming more medically intensive over time than most people could imagine. Thus, most people marry or have children with no concept of the potential responsibility they face if a loved one suffers from chronic illness or disability.

---

310 *See, e.g.*, G.A. Cohen, *On the Currency of Egalitarian Justice*, 99 ETHICS 906, 916 (1989) (proposing an "equal *access* advantage" theory, wherein involuntary disadvantages—those beyond the actor's control—merit compensation, while disadvantages incurred voluntarily by the actor do not). *But see* Shiffrin, *supra* note 301. (challenging the egalitarian emphasis on choice sensitivity as a problem for individual freedom). Perceptions of control have been important historically for social insurance. Advocates built support for workers' compensation by showing statistically that most workplace injuries were not a worker's fault. *See* WITT, *supra* note 24, at 142-43.

311 ABRAHAM, *supra* note 265, at 27.

312 *See* Mary Anne Case, *How High the Apple Pie: A Few Troubling Questions About Where, Why, and How the Burden of Care for Children Should Be Shifted*, 76 CHI-KENT L. REV. 1753, 1758 (2001) (arguing against employment- or state-based parental benefits because they cause the childless to subsidize those who have children, which often benefits the male worker).

313 *See* Brown & Finkelstein, *supra* note 33, at 131 (explaining why research suggests that limited knowledge or bounded rationality might limit purchase of private long-term care insurance).

314 *See* Brown et al., *supra* note 35, at 1298.

Assume for a moment, however, that people did fully contemplate this potential responsibility and still engage voluntarily in relationships. There are reasons why even in this case it might not make sense for them to fully internalize the costs. The state often helps people whose choices increase their risk of harm in order to protect such choices or to promote other important values. [315] For example, our courts invalidate indemnification clauses in agreements for participation in sports or dangerous activities [316] and agreements where patients contract away the right to sue in return for medical care, [317] when it seems unjust for individuals to bear the costs of harm. Disaster relief efforts bail out people who built their homes in flood plains, on earthquake fault lines, or along Tornado Alley because asking them to bear the costs individually would be devastating.

Social insurance often mitigates harms, even when individual agency may increase the risk. Medicare covers medical harms for people who are sicker because they did not care for their bodies in the first sixty-five years of their life. Social Security does not differentiate between those people who failed to save and those who succeeded.

François Ewald describes the paradigm of social solidarity underlying social insurance as "not based on fault but on risk."[318] What he means is that it is less important to diagnose ex post whether an individual intensified the possibility of harm she suffers. The more consequential question is whether we want individuals to bear the full cost of obligations simply because they derive in part from their own actions. We might in fact *not* want people to bear the full costs of extraordinary obligation for loved ones because it could dissuade kinship relationships. By not requiring people to bear the full cost of such choices, social insurance protects the activity in which they participate—in this case getting married or having children.

Even among choice-sensitive egalitarians, there is disagreement about what should be attributed to choice.[319] Individual decisions to partner and to have children are in most cases voluntary. But in aggregate, they are not. Imagine a society where no one developed long-lasting relationships, or no one had children. It would be a dismal and short-lived society. When considered from a collective, rather than individual, perspective, entering into kinship relationships can be seen as the kind of non-optional social activity

315 Shiffrin, *supra* note 301, at 275-84 (providing examples of "accommodation practices," where we absorb costs of others' voluntary behavior, including exemptions to the draft and exempting some people from working on religious holidays).

316 *E.g.*, Hanks v. Powder Ridge Rest. Corp., 885 A.2d 734, 742 (Conn. 2005).

317 *E.g.*, Tunkl v. Regents of the Univ. of Cal., 383 P.2d 441, 448-49 (Cal. 1963) (en banc).

318 Ewald, *supra* note 24, at 277.

319 Shiffrin, *supra* note 301, at 272.

that Abraham contends meets the egalitarian standards for risk spreading,[320] or as deserving because such relationships are something "profoundly good for society."[321]

So far, I have discussed cases where someone increases next-friend risk simply by engaging in a relationship where she makes it more likely that she will take responsibility for another's unpredictable harm. A more extreme but less common example is when someone acts in a way that increases the likelihood of someone else becoming ill or disabled. In other words, her choices increase the risk that someone for whom she is responsible would need long-term care, not just the risk that she will be responsible for it if it occurs due to random misfortune. Consider, for example, a pregnant woman whose actions increase the likelihood she will have a child with birth defects or a couple who proceeds with a pregnancy after a genetic test confirms that their baby has Trisomy 18 (Edwards syndrome)—a chromosomal abnormality that results in a child, if born alive, living a short life with intensive caregiving needs.[322]

Sometimes insurance carves out these types of situations under the label of "moral hazard," and affirms that people should have to pay for such harms themselves. But even in these more extreme situations such exclusions might be unjust. With respect to the first example, public health studies show that certain unhealthy behaviors are shaped strongly by factors outside of an individual's control, such as biology, psychology, or social environment.[323] On the second, for some people, continuing a pregnancy to full-term is not a choice at all. Requiring these individuals to shoulder the full cost of a child born with a disability would, in the first, compound socioeconomic inequities and, in the second, force people to choose between their moral beliefs and their basic security.[324]

There is no simple, principled definition of which relationships generate next-friend risk worthy of social insurance protection. Decisions about whether such relationships are in or out are informed by moral judgment about

320 ABRAHAM, *supra* note 265, at 27.

321 Simon, *supra* note 23, at 135.

322 *See, e.g.*, *What Is Trisomy 18?*, TRISOMY 18 FOUND. (2016), http://www.trisomy18.org/what-is-trisomy-18.

323 *E.g.*, Neil Pearce & George Davey Smith, *Is Social Capital the Key to Inequalities in Health?*, 93 AM. J. PUB. HEALTH 122, 125 (2003) (describing that health is related to social factors because of "the influence of social cohesion on health-related behaviors"); *see also* S.A. Reijneveld, *The Impact of Individual and Area Characteristics on Urban Socioeconomic Differences in Health and Smoking*, 27 INT'L J. EPIDEMIOLOGY 33, 35, 38 (1998) (finding that poor health behaviors in impoverished areas are due overwhelmingly to individuals' low socioeconomic status).

324 *See* Shiffrin, *supra* note 301, at 276 (describing how it is common to accommodate religious practices).

when caregiving should remain a private obligation and when it is worthy of collective support.

2. Distinguishing Risk from Routine

A second challenge is to identify what responsibilities signal that someone has experienced next-friend risk. This question demands reevaluation of what we expect from individuals and what exceeds expectations. All relationships come with responsibility. In some cases, obligations seem more routine and in others, extraordinary. For example, a daughter who grocery shops for her father and checks in on him briefly a few times a week might ensure his wellbeing with little effort. Most people would see this level of engagement as routine. Yet, if he needs eight hours of care a day and that care includes help with feeding and bathing and going to the bathroom, it seems less routine. Feeding children, bathing them, and getting them to bed are routine parts of the day for many people. Yet, around-the-clock care for a child with a serious disability or feeding, bathing, and transferring a fifty-year-old spouse into a bed are of a different nature.

What is difficult is where to draw the line between these two extremes. Some people have children who are easy to care for, and others have children who, for any number of reasons, require a much greater investment of time, energy, and, perhaps, angst. Relationships ebb and flow in what they demand from people. There is no clear line between routine and extraordinary responsibility.

One starting point would be to define next-friend risk by the triggering event. Next-friend risk is realized only when the care recipient has suffered from substantial illness or injury or has a disability that requires prolonged, intensive care. Benefits could be defined based on the disability, injury, or illness that triggered a need for care. This categorical approach is, admittedly, imprecise. A mother might engage in the exact same activities for a child without a disability as she would for one with a disability and have those activities be insurable only in the latter case. It also does not recognize the way that chronic disease evolves.[325] This approach trades off nuance for administrability and, because of the latter advantage, is often the standard used in long-term care insurance benefit determinations in countries that insure long-term care.[326]

---

325 Montgomery et al., *supra* note 176, at 23 ("Initially, the care needs of the elder may be relatively small and the corresponding care tasks may represent only minimal extensions of the familial role relationship . . . . [O]ver time, the caregiving activities transform the initial mother-daughter relationship into a *caregiving* relationship.")

326 WIENER ET AL., *supra* note 291, at 9.

Alternatively, next-friend risk could be defined in a more bottom-up way, based on the number of hours a next-friend spends in "qualifying" long-term care activities, such as helping with Activities of Daily Living. This approach is more difficult administratively, but provides a more accurate way to capture the real levels of obligation. Policies could set a baseline of care that someone would have to provide before being considered at risk—a deductible paid in dollars or hours before indemnification begins. A well-designed deductible would reduce concerns of moral hazard and reveal who are devoted next friends, because someone would have to show a level of commitment before being able to qualify for benefits.[327]

Defining when someone has experienced next-friend risk thus requires both determining what type of activity and what extent of activity qualifies, as well as what share, if any, should remain private obligation. Definitions that include more activities shift more responsibility away from an individual and to the collective. Conversely, carving out more activities preserves private obligation. Any method for making such decisions involves tradeoffs between precision and administrability and some arbitrariness.

3. Does Financial Status Quo Matter?

Should risk of harm be contingent on financial status quo? In other words, is the risk of harm merely that a next friend has to use resources, measured in time or money, to support another's long-term care, or does risk arise only when she has to use resources that she does not have to spare?

For example, in the Aging Parent Scenario, if the daughter is wealthy, she might pay for professional care without risking her family's financial security.[328] The same is true for the parents of the daughter with autism in the Lifelong Care Scenario. Perhaps they do not experience next-friend risk if they can easily afford to enroll her in a special school and to create a trust fund for her care after they die. Using state funds to support care in these cases might be unnecessary or undesirable.

Yet, a means-based definition of risk does not capture the many ways that responsibility for another can pose burdens. Even if a next friend is wealthy, if she takes on responsibility for another, she will experience costs, both financial and nonmonetary. Requiring her to deplete her own savings reinforces a system where private obligation is primary and the state's role is

327 It might also lead to a consolidation of care because, with multiple caregivers, it is possible that no one would exceed the deductible.

328 The same might be said if she has a lot of free time and provides care directly. Does her temporal status quo matter? I previously addressed this question in more detail, *see supra* Section II.C, but just note that the same analysis could apply with respect to time, as respect to money, here.

secondary.[329] Making eligibility contingent on wealth also devalues the nonmonetary costs she faces.

Attempts to define risk based on a next friend's wealth may also be futile. As noted above, few people have the resources necessary to pay for any prolonged period of long-term care—one reason why most next friends provide it in kind. Trying to isolate the few who do have such resources would require significant administrative effort with little payoff. Furthermore, if care recipients can choose any next friend, they could just designate a poor family member. Means tests would dissuade people who are in more stable circumstances from taking on the role of next friend if they cannot claim state support but a sibling or friend in a more precarious position could. The end result might be suboptimal care arrangements.

Defining risk as contingent on a next friend's financial resources would replicate current inequities in financing for long-term care. Poor next friends, who qualify for benefits, could use the benefits to choose to arrange for or to provide care. Wealthy next friends would self insure and have the same choice. But middle-income next friends would neither qualify for benefits nor have money to pay for care, leaving them in the same position many are in today: providing care because no other option is available.

Another approach, in a classic model of social insurance, defines harm based on an ex ante, population-based view. Not knowing what any one individual's lot in life will be, social insurance is designed to protect everyone from "common economic risks in a changing world."[330] Those who end up less in need of such protections because of a good lot in life are not expunged from the program ex post. For example, Medicare pays for medical care for nearly all Americans over age sixty-five, regardless of wealth level, protecting against harm from poor health in retirement. Likewise, Social Security pays benefits to all eligible retirees, regardless of private savings.

A universal approach would, in effect, define next-friend risk simply as taking responsibility for the long-term care of another. Avoiding categorical inquiry would have all of the benefits that accrue to other universal social insurance programs. Social Security and Medicare—the two social insurance programs with near universal contribution and benefits—endure as among the most popular U.S. government programs.[331] As expressed in a recent book on social insurance: "Covering most people at risk and treating everyone equally

329 *See* Zatz, *supra* note 302, at 580 (reasoning that expecting family or friends to pay for another in need can be seen as the "state . . . exploiting their generosity").

330 MARMOR ET AL., *supra* note 24, at 217.

331 *Id.* at 219 ("[B]ecause everyone is both a contributor and a potential beneficiary, the politics of social insurance tends to be of the "us-us" rather than the "us-them" form.")

as risk bearers increases the sense of social insurance's fairness."[332] Nearly eighty percent of Americans think these programs have benefitted the United States and a majority would not reduce current benefit levels to reduce the deficit or taxes.[333]

Means-testing, in contrast, is solidarity-diminishing because it draws a line between the haves, who are self-sufficient, and the have-nots, who are not.[334] Creating universal benefits can avoid such stratification. As one expert describes, it enhances the "pedigree of cultural respectability" of a program by not requiring "questions about morally freighted matters such as family income and assets, household composition, or individual work effort."[335]

Yet, a universal approach can redistribute resources from categories of people who are low risk to those who are high risk in a way that will, in some cases, be regressive. For example, if people with no siblings are at higher risk of caring for a parent and also more likely to be higher income, they might be subsidized by people who are on average lower income. Regressivity can be lessened by progressive financing. If the higher-income child contributed to the program more through higher tax rates throughout her lifetime, she could draw benefits without necessarily being subsidized by lower-income others.[336] Social Security and Medicare are both structured in this way.

A separate question is whether next-friend risk can exist at all when the *care recipient* has financial resources to pay for care.[337] When a person with a disability or illness can finance his own care, his family member, in theory, faces less responsibility. For example, if the father in the Parent Scenario were wealthy, he could pay for someone to provide his care. Or he could ask his daughter to provide the care and compensate her.[338] This issue highlights the relational aspect of long-term care risk. Social insurance benefits for the daughter of a wealthy man might effectively serve to preserve her inheritance. Some might gauge use of collective resources in this way as less just or lower priority. Others might see her inheritance as part of what she has to lose from next-friend risk.

---

332 *Id.*

333 *Id.* at 222.

334 GÖSTA ESPING-ANDERSEN, THE THREE WORLDS OF WELFARE CAPITALISM 63-64 (1990).

335 MARMOR ET AL., *supra* note 24, at 219.

336 *See* Louis Kaplow & Steven Shavell, *Why the Legal System Is Less Efficient Than the Income Tax in Redistributing Income*, 23 J. LEGAL STUD. 667, 674-75 (1994).

337 This question is relevant to care for a parent or friend but would not apply in most cases where the care recipient is a child or a spouse.

338 Of course, such a bargain is complex and often results in broken promises. *See* HARTOG, *supra* note 29.

These difficult boundary questions are a core part of any social insurance design. It is necessary first to quantify a harm someone has experienced and then, second, to decide who should pay that price.

E. Objections to Insuring Next-Friend Risk

Any expansion of social insurance is highly contested—an understatement in light of the fact that, years after its passage, the ACA remains under constant attack.[339] The standard objections involve questioning the proper role of the state, administrability, and affordability. Policies where family members can be paid for caregiving trigger heightened moral hazard and fraud objections—objections that have the rhetorical power to stop policies in their tracks. Each of these concerns, discussed in turn herein, can inform better policy design, but none is good reason to choose not to better insure next-friend risk.

An increased state role in long-term care can threaten the strong tradition and social norms of family care. The state's entry into this domestic sphere sparks concerns of commodification of family caregiving, which could mean a number of different things.[340] Sometimes, commodification objections are mere pretext for preserving the current, gendered system of caregiving or are a thinly veiled way of suggesting that care work is not something public resources should compensate. That is the very view this Article aims to challenge. A more complex version of a commodification critique is that paying for family care would diminish its value because of the "corrosive tendency of markets."[341] This view is well-intentioned, motivated by the desire to protect goodness in the connection between loved ones. Yet it is based on a fallacy that caregiving and economic activity exist independently. Caregiving has long had an implicit and explicit price, both within and outside of the family structure.[342] In other words, the worlds of money and love are already deeply blurred.

---

339 *See* Deirdre Walsh, *House Sends Obamacare Repeal Bill to the White House*, CNN (Jan. 6, 2016), http://www.cnn.com/2016/01/06/politics/house-obamacare-repeal-planned-parenthood (describing the most recent of more than sixty votes to repeal all or part of the law).

340 *See* Deborah Stone, *For Love Nor Money: The Commodification of Care*, *in* RETHINKING COMMODIFICATION 271 (Martha M. Ertman & Joan C. Williams eds., 2005).

341 MICHAEL J. SANDEL, WHAT MONEY CAN'T BUY: THE MORAL LIMITS OF MARKETS 9 (2012); *see also* Elizabeth S. Anderson, *Is Women's Labor a Commodity?*, 19 PHIL. & PUB. AFF. 71, 80 (1990) (considering the special case of surrogacy and the risk of reducing women from "persons worthy of respect" to "objects of mere use"); Viviana A. Zelizer, *Human Values and the Market: The Case of Life Insurance and Death in 19th Century America*, 84 AM. J. SOC. 591 (examining concerns of commodification of death with the introduction of life insurance and the gradual diminishing of such concerns).

342 *See* HARTOG, *supra* note 29;. Alstott, *supra* note 141; Joan C. Williams & Viviana A.

There are, however, some aspects of what family and friends and, also, paid caregivers provide that could never be priced in dollar terms.[343] But paying for the aspects that can be valued—the heavy lifting of long-term care, so to speak—need not diminish or crowd out the intimate aspects of care. In fact, empirically it does not. Studies show exactly the opposite: even paid caregivers show great affection for the people for whom they care.[344] Furthermore, even when families hire paid caregivers, family members continue to spend significant time caring but focus instead on the tasks that they are better suited than a formal caregiver at doing.[345]

A related critique is that state involvement requires an invasion of private, family space. It is true that the availability of benefits requires the state to determine eligibility, and the receipt of money necessarily invites monitoring. A universal social insurance program with categorical benefits would minimize the invasiveness of both efforts. Some research suggests that even informal caregivers who face significant burden are skeptical of state involvement, but this study also shows that the availability of social insurance relief can shift both their roles and their perspectives.[346] In other words, the privacy concerns seem less acute when a family caregiver experiences the benefits of state support.

Another objection to any expansion of social insurance is that it will crowd out private insurance solutions or private savings, which studies confirm does occur to some degree.[347] The obvious response in the case of next-friend risk is that even without public insurance, private insurance solutions have failed. The level of private savings that a next friend would need to have to effectively self-insure is impossible for nearly everyone, even if they saved aggressively. Furthermore, this concern presumes that private insurance or saving is the best first option and that state responsibility should only be a last resort—the very assumption this Article challenges.

Zelizer, *To Commodify or Not To Commodify: That is* Not *the Question*, *in* RETHINKING COMMODIFICATION, *supra* note 340, 362, 364-65.

343 *See* Margaret Jane Radin, *Market Inalienability*, 100 HARV. L. REV. 1849, 1885 (1987).

344 *See* Stone, *supra* note 340, at 275-77 (discussing studies).

345 STONE, *supra* note 168, at 20-21. *But see* Susan L. Ettner, *The Effect of the Medicaid Home Care Benefit on Long-term Care Choices of the Elderly*, 32 ECON. INQUIRY 103, 123 (1994) (showing substitution effects of a greater degree than in other studies); Norma B. Coe et al., *Family Spillovers of Long-Term Care Insurance* 18 (Nat'l Bureau of Econ. Research, Working Paper No. 21483, 2015), http://www.terry.uga.edu/media/events/documents/Norma_Coe.pdf (showing that private long-term care insurance lowers informal caregiving and the likelihood of a child living with a parent).

346 Levitsky, *supra* note 169, at 564.

347 *See* David M. Cutler & Jonathan Gruber, *Does Public Insurance Crowd Out Private Insurance?*, 111 Q.J. ECON. 391, 391 n.1 (1996).

That all said, private insurance options could be developed over time and integrated with public solutions to the degree desired. In fact, if private insurance policies were marketed to next friends to mitigate the risk they face, it might prove more saleable. Some of the bias that thwarts people from buying long-term care policies for themselves might not deter children from insuring against the risk of caring for their parents or future parents from insuring against the risk of a child with a disability. And, according to one study, if private policies included benefits to pay family members for care, there would be greater purchase of them by people who now opt out because they prefer family care over formal care.[348] Social insurance policies could continue to include incentives for the purchase of private long-term care policies, as in the long-term care partnerships.[349]

Moral hazard and fraud are simultaneously sources of genuine concern and red herrings. As Jonathan Simon has written, "The perception that fraud is rampant in welfare and social insurance systems has helped to de-legitimize broad, entitlement-based risk spreading programs. Indeed . . . moral hazard has become a block on any substantial expansion of social insurance in recent decades."[350] Moral hazard is the idea that when people are insured, they have reduced incentive to avoid losses. Moral hazard can be an ex ante failure to prevent losses (i.e., carelessness when insured) or an ex post failure to mitigate losses as inexpensively as possible (i.e., malingering).[351] Ex ante moral hazard—the idea that people will fail to prevent harm—is inapt in this context. The risk of harm is only triggered by the disability or illness of a loved one, circumstances that people avoid for independent reasons, even if insured. The more pertinent concern is that social insurance will lead to overuse of benefits. In other words, the number of people living with and caring for someone else will skyrocket in response to the availability of insurance benefits.

This so-called woodwork effect might capture two different things. It might simply mean that more people are getting the necessary care that they were not before. Meeting unmet demand in this way is what Deborah Stone

348 *See* Mommaerts, *supra* note 39.

349 *See, e.g.*, Jamie P. Hopkins et al., *Leveraging Filial Support Laws Under the State Partnership Programs To Encourage Long-Term Care Insurance*, 20 WIDENER L. REV. 165, 195 (2014) (arguing for increased enforcement of filial support laws as a "stick" to incentivize private insurance purchase by increasing personal liability); Haizhen Lin & Jeffrey T. Prince, *Determinants of Private Long-Term Care Insurance Purchase in Response to the Partnership Program*, 51 HEALTH SERVS. RES. 687, 699-700 (2016) (finding that efforts at program awareness and financial literacy may increase program success). For discussion of these programs and their shortcomings, see *supra* note 44 and accompanying text.

350 Simon, *supra* note 23, at 131.

351 *See* Tom Baker, *On the Genealogy of Moral Hazard*, 75 TEX. L. REV. 237, 270 (1996).

has called a "moral opportunity" and is the very purpose of social welfare programs.[352] It could also mean that people are exaggerating a need for care, if someone could get by on her own but will take help if a family member can get cash benefits to provide the assistance. This possibility is harder to avoid, but can be lessened through well-designed criteria for eligibility based on a disability determination. Other countries with social insurance for long-term care have developed systems where case workers or medical professionals measure and categorize levels of disability, which have worked reasonably well.[353]

Avoiding moral hazard informs the design of any social insurance program. As Anne Alstott has written, "Moral hazard permeates every form of insurance, and . . . there are a host of tools for managing it, including copayments, categorical eligibility, delayed benefits, limited benefits, self-financing, and so on."[354] With respect to long-term care, a deductible could reduce moral hazard. As suggested above, policies could set a number of hours of care that someone would have to provide or arrange and pay for before she would qualify for benefits. Even if it is a real concern, empirical evidence of long-term care social insurance that pays family members cash benefits suggests that such concerns may be overstated.[355]

Fraud may be a more challenging problem. People might misrepresent disability if they can get cash benefits for family. Or next friends might claim benefits and not provide care. Fraud enforcement with personal care services is particularly difficult because the services are diffuse in individual homes and hard to monitor. The Office of the Inspector General of the Department of Health and Human Services has already made a special effort to detect fraud in home-based personal care services under Medicaid.[356] Medical eligibility determinations can be used to root out false claims. And high penalties for fraudulent claims can be used as a deterrent. Even though there would undoubtedly be some problems with fraud, evaluation of demonstration projects, where benefits can be used to pay family for care, have also found surprisingly few cases of fraudulent use of the benefits.[357]

---

352 Deborah Stone, *Beyond Moral Hazard: Insurance as Moral Opportunity*, 6 CONN. INS. L.J. 11, 14-15 (1999).

353 *See* WIENER ET AL., *supra* note 291, at 8.

354 Alstott, *supra* note 141, at 30.

355 *See* Joshua M. Wiener & Alison Evans Cuellar, *Public and Private Responsibilities: Home-and Community-Based Services in the United Kingdom and Germany*, 11 J. AGING & HEALTH 417, 423 (1999) (explaining that in the German program, the number of enrollees was nearly the number estimated and the greater concern is underreporting of disability).

356 Office of Inspector General, *Spotlight on . . . Medicaid Personal Care Services*, U.S. DEP'T HEALTH & HUMAN SERVS. (June 7, 2011), https://oig.hhs.gov/newsroom/spotlight/2012/portfolio01.asp.

357 *See* ROBERT WOOD JOHNSON FOUND., CASH & COUNSELING PROGRAM RESULTS (2013), http://www.rwjf.org/content/dam/farm/reports/program_results_reports/2015/rwjf406468.

Concerns about quality of care when provided by family or friends is a particularly American preoccupation. Other countries with long-term care policies that offer cash benefits for family to provide care believe that, in general, people are likely to get *better* care from family than from formal caregivers.[358] Results from the Cash and Counseling Demonstration project in the United States revealed fewer cases of abuse and neglect and fewer unmet needs among beneficiaries who used a cash benefit compared to control group members.[359] There would of course be some problems with poor quality care at the hands of friends or family, but it may prove no worse—and possibly better—than in formal care settings. Further, these next friends are many of the same people providing unpaid care today. Compensating them for their work would be unlikely to reduce the quality of their caregiving.

Finally, any comprehensive solution would be very expensive—a fact which undoubtedly influences many scholars' pragmatic focus on piecemeal solutions. Total paid long-term care was just over $220 billion in 2011, excluding Medicare post-acute care.[360] The aforementioned estimate of replacement cost of family caregiving is $470 billion, which would triple current spending, and is only a partial account of long-term care since it only considers care for adults.[361] This increased cost is a genuine hurdle.

Current policy, however, has simply obscured the fact that individuals shoulder those costs privately, as an invisible copayment, and has enabled political inaction. The United States spends relatively less on long-term care than other developed countries do, even as it spends more on nearly every other category of health care.[362] Accounting for next-friend risk makes it harder to continue down this path. If the Congressional Budget Office were to include the over half-trillion dollars in care provided by informal caregivers as a cost of current policies, it would hamstring these policies that are biased toward informal caregiving.[363] Legal myopia has saved the government an estimated half-trillion dollars a year in direct costs. These costs are not avoided. They are simply borne off budget and disproportionately by people less able to bear them.

---

358 *See* WIENER ET AL., *supra* note 291, at 19-20.

359 Barbara Lepidus Carlson et al., *Effects of Cash and Counseling on Personal Care and Well-Being,* 42 HEALTH SERVS RES. 467, 476-79 (2007).

360 O'Shaughnessy, *supra* note 9, at 3.

361 Reinhard et al., *supra* note 26, at 3.

362 MCKINSEY CTR. FOR U.S. HEALTH SYS. REFORM, *supra* note 262, at 9.

363 Although the Congressional Budget Office generally does not consider opportunity costs, it does consider the macroeconomic second-order or "dynamic" effects of policies in its budgetary analysis. *See* Keith Hall, *Answers to Questions About Dynamic Analysis*, CONG. BUDGET OFF. (July 1, 2015), https://www.cbo.gov/publication/50357.

* * *

In sum, the real costs of our current system and the insecurity and inequities it generates demand recognizing next-friend risk and considering it on par with care-recipient risk. In part, social policies have prioritized care-recipient risk because of the immediacy of the need, the vulnerability of the recipients, and the dire consequences of failing to meet their needs. But next-friend risk is creating deep and long-lasting harm. This harm is easier to ignore but no less important of a target for social policy. Although we should not neglect the short-term needs of the disabled and sick, we should no more neglect the wellbeing and security of their next friends.

Any major social problem seems too big to solve until society recognizes that the costs of not solving it are also untenable. Many other countries—including Japan, Germany, and the Netherlands, as discussed below—have overcome objections and created universal long-term care social insurance systems. These systems are expensive, and these countries certainly revisit the costs on a regular basis. Yet, they each (and others as well) have decided that long-term care is an important social priority and worth an investment of social resources.

IV. A BRIEF SKETCH OF POLICY OPTIONS

The primary goal of this Article is to introduce the concept of next-friend risk and to make the case for considering it as a social policy priority. I leave for later the development of policy details. Nonetheless, this Part offers a brief sketch of several different possible approaches to illustrate how policies—both comprehensive and incremental—can be designed in ways more sensitive to next-friend risk.

One primary goal would be to create financing and institutional structures for long-term care that enable a smoother toggle between paying for care and providing care, as described above. Policies must have a toggle in structure and support processes and institutions that empower next friends to actually choose between options. Section IV.A illustrates how a comprehensive social insurance program could better mitigate next-friend risk. Yet, incremental changes that build on existing social welfare programs could also make a significant difference, as discussed in Section IV.B.

A. Envisioning Next-Friend Social Insurance

1. The Basic Concept

A universal long-term care social insurance program could be designed with the explicit goal of mitigating both next-friend and care-recipient risk. The specific contours could take many forms. The basic idea would be that

someone who has a qualifying disability would designate a next-friend, who would then receive benefits that could be used to pay for or provide care. It could be designed to supplement what Medicaid does now for care recipients or to replace it entirely. It could be created from the ground up or expand the scope and size of existing programs that are sensitive to next-friend risk, such as the Veterans Administration family caregiving program or Cash and Counseling participant-directed programs, discussed below. Others have offered proposals for universal long-term care insurance.[364] Here, I consider specifically what elements such social insurance would need to include to be sensitive to next-friend risk and how it might differ from policies that focus narrowly on care-recipient risk.

Eligibility would be based on both the care recipient and next friend. The first step would be determination of qualifying disability or illness, based on a care recipient's condition, as with Medicaid and Medicare post-acute care now. A second step would be to identify an eligible next friend, which could be based on whom a care-recipient or her legal guardian chooses. Eligibility rules could categorically limit next friends to close relatives, as the Family and Medical Leave Act of 1993 (FMLA) does for its guarantee of twelve weeks of unpaid, job-protected leave for family care.[365] But a more flexible definition would better reflect the existing picture of informal care, as an African saying recognizes: "The one you are left with is your relation."[366]

---

364 Recent proposals for universal long-term care insurance include, for example, JUDY FEDER ET AL., GEORGETOWN UNIV. LONG-TERM CARE FINANCING PROJECT, LONG-TERM CARE FINANCING: POLICY OPTIONS FOR THE FUTURE (2007), https://georgetown.box.com/shared/static/mhdbkd4vtklps9ntkskc.pdf; INST. OF MED. & NAT'L RESEARCH COUNCIL OF THE NAT'L ACADEMIES, FINANCING LONG-TERM SERVICES AND SUPPORTS FOR INDIVIDUALS WITH DISABILITIES AND OLDER ADULTS: WORKSHOP SUMMARY (2013), http://www.nap.edu/read/18538/chapter/1; UNIVERSAL COVERAGE OF LONG-TERM CARE IN THE UNITED STATES: CAN WE GET THERE FROM HERE? (Douglas Wolf & Nancy Folbre, eds., 2012); Laphonza Butler et al., Long-Term Care Comm'n, *A Comprehensive Approach to Long-Term Services and Supports* (Sept. 23, 2013), http://www.medicareadvocacy.org/wp-content/uploads/2013/10/LTCCAlternativeReport.pdf (dissenting report from Commission on Long-Term Care's September 30, 2013 Report to the Congress); Melissa M. Favreault et al., *Financing Long-Term Services and Supports: Options Reflects Trade-Offs for Older Americans and Federal* Spending, 34 HEALTH AFF. 1 (2015); Lee Goldberg & G. Lawrence Atkins, *Social Insurance: A Critical Base for Financing Long-Term Services and Supports*, SCAN FOUND. (2013), http://www.thescanfoundation.org/sites/default/files/ltc_financing.social.insurance.goldberg.3.20.13.pdf; and Anne Tumlinson et al., *Insuring Americans for Long-Term Care: Challenges and Limitations of Voluntary Insurance*, AVALERE HEALTH (2013), http://avalere.com/research/docs/20130320_Avalere_RTI_Scan_LTI.pdf.

365 29 U.S.C. § 2612(a)(1)(C) (2012) (reserving job-protected leave for parents, children, and spouses).

366 WORLD HEALTH ORG., *supra* note 277, at 11; *see also* Nancy Knauer, *LGBT Older Adults: Chosen Family and Caregiving*, 31 J.L. & RELIGION (forthcoming 2016),

Program rules might limit the caregiving any one individual can be paid to do or the number of people for whom she could be paid to coordinate in-kind benefits.

The process of having to designate a next friend offers the collateral benefit of prompting more transparent and deliberate decisions about long-term care. Naming a next friend would make clear who is responsible for helping a care recipient with care management decisions, akin to naming a health care proxy. If benefits were vested in or controlled in part by the next friend, it could encourage a care recipient to initiate explicit conversations about what kind of care he wants with his next friend, before the next friend helps him to operationalize his care.

Any individual who does not want to provide care would have greater ability to opt out. The universality of benefits, and the ability to use them interchangeably to pay for in-kind care, would bolster her bargaining power.[367] Imagine that a mother asks her daughter to care for her in her old age. Without next-friend insurance, she may feel as if she has few options. With it, in contrast, she could accept responsibility and provide care and get paid to do so. She could accept responsibility and hire someone else to provide some or all of the care, using benefits for this in-kind assistance. Or she could decline and suggest another family member or friend instead. Such conversations would undoubtedly still be shaped by family dynamics. But the goal would be for the structure of benefits to create a more neutral baseline for conversation and for real deliberation. As in other countries' social insurance programs for long-term care, case managers could explain options, mediate disputes that arise, and monitor quality on an ongoing basis.[368]

A critique of an approach that empowers next friends in the decision process is that it erodes the autonomy that independent living movement advocates have long worked to wrest back for care recipients, by requiring them to name a next friend who has some control over how benefits are used.[369] Care recipients, however, would retain the ultimate control through the ability to designate the next friend.[370]

---

http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2721451 (exploring the disproportionate reliance on non-relatives for long-term care within the aging LGBT community).

367 *Cf.* RHONA MAHONY, KIDDING OURSELVES: BREADWINNING, BABIES AND BARGAINING POWER (1996) (discussing how women can use bargaining theory to undo sexual division of labor in the home, in part based on having an income-generating position).

368 *See* WIENER ET AL., *supra* note 291, at 8.

369 *See* Batavia et al., *supra* note 48.

370 There could be an option that allows someone who wants to and is able to do so to manage his own care by designating a formal care provider to serve as the next friend. Letting someone choose to bypass friends and family altogether would still serve the ends of protecting friends and family from next-friend risk, while also meeting a care-recipient's needs and honoring his autonomy.

More importantly, the reality is that many people rely on family to help meet their long-term care needs now, and recognizing these caregiving dyads more formally in the law would be beneficial. For example, it could address problems in the Medicaid consumer-directed demonstration programs, in which care recipients can hire and fire their own provider. One criticism of these programs is that they turn care recipients into employers and put them in a position where they might mismanage their personal budgets.[371] The responsibility can be burdensome: "only a fraction of individuals with disabilities have the time, inclination, and skills to search for, hire, and train their own personal assistants. . . . Many people, disabled and nondisabled . . . find that the burdens of becoming an employer are great."[372] Plus, these programs have eroded caregivers' job benefits and labor protections because they treat each care recipient as an individual employer.[373] Taking the care recipient out of the middle so that the state directly pays the next friend or formal caregiver, once selected, avoids these problems. It may be that care recipients find that the ability to influence their care, without having to manage it or to become an employer, is even more autonomy enhancing.

Next-friend insurance could professionalize long-term care services, by more formally recognizing the work friends and family do and creating a structure for formal labor protections and job benefits. The Department of Veterans Affairs (VA) family caregiver program offers a model. It compensates family caregivers at higher rates than other programs and also addresses sources of nonmonetary harm.[374] Family caregivers of seriously injured post-9/11 veterans can receive health insurance, mental health services, comprehensive training by Easter Seals, respite care of thirty days or more a year, and reimbursement for travel expenses when accompanying the veteran for care.[375] These types of protections would benefit all informal and formal caregivers.

The point here is not to flesh out the full details of a new social insurance benefit but rather to highlight the most critical elements. Next friends would be formally appointed and have a voice in decisions. They would be treated as workers, if they provide care, or compensated for their time as case managers if they help to arrange care. The goals of such policies would be two-fold: to get people needed long-term care, and to enable their friends and family to help them do so without taking on excessive risk themselves.

---

371 *See* Crowley, *supra* note 95, at 16.

372 Bagenstos, *supra* note 73, at 79.

373 *See* Smith, *Home Sweet Home*, *supra* note 126.

374 Czapanskiy, *supra* note 123, at 58.

375 *Services for Family Caregivers of Post-9/11 Veterans*, U.S. DEP'T VETERANS AFF. (Aug. 10, 2012), http://www.caregiver.va.gov/support/support_benefits.asp.

2. *Models for Next-Friend Social Insurance*

The idea of creating a social insurance program explicitly intending to benefit next friends might seem utopian, but there are already elements of this type of approach in practice in various small-scale programs, including the VA program, the consumer-directed Medicaid programs, and in the state paid leave programs in California, New Jersey, and Rhode Island, which offer benefits to pay for time spent caregiving for family or friends.[376] Next-friend social insurance could build on these types of efforts.

It could also be based on the models of universal long-term care social insurance implemented in other countries. At the very least, the different models chosen elsewhere provide a window into policy design that is more or less sensitive to next-friend risk.

Lessons from long-term care social insurance in Japan, the Netherlands, and Germany illustrate how long-term care policy can be designed in ways more or less sensitive to next-friend risk. The long-term care policies in these three countries share many characteristics: they are all non-means tested, universal social insurance programs funded primarily by payroll taxes (and secondarily by premiums in Japan and copayments in Germany).[377] The Dutch and German programs are for beneficiaries of all ages,[378] while the Japanese program is for older beneficiaries.[379] They all give beneficiaries some level of control over benefits. Yet, each has had very different results.

The Japanese program strongly discourages family care with the goal of displacing the tradition of reliance on daughters-in-law for elder care.[380] The program was developed to address social changes similar to those in the United States that made this reliance unsustainable: fewer people are living with their children; an increased number of women are working; and people are more willing to accept outside help.[381] This program *only* pays for in-kind care; cash allowances were fought by feminists who wanted dollars to be used

---

376 These paid leave programs (soon to be joined by New York), part of the states' temporary disability insurance, replace a portion of salary for four to six weeks when someone takes leave from a job to care for a family member, in effect compensating someone's FMLA leave. *See Paid Family Leave*, NAT'L CONF. ST. LEGIS., (2016), http://www.ncsl.org/research/labor-and-employment/paid-family-leave-resources.aspx.

377 *See* John Creighton Campbell & Naoki Ikegami, *Japan's Radical Reform of Long-Term Care*, 37 SOC. POL'Y & ADMIN. 21 (2003) (discussing the Japanese reform); Pamela Nadash et al., *European Long-Term Care Programs: Lessons for Community Living Assistance Services and Supports*?, 47 HEALTH SERVS. RES. 309 (2012) (discussing the German and Dutch programs).

378 WIENER ET AL., *supra* note 291, at 3.

379 Campbell & Ikegami, *supra* note 377, at 22.

380 *Id.* at 22.

381 *Id.*

to grow labor supply to meet demand and to liberate daughters-in-law.[382] They believed that an option for cash benefits would reinforce oppressive caregiving patterns. Japan's policy design could serve as a model of a strong counterbalance to existing family care biases—a thick version of neutral policy. In effect, the choice is between paid in-kind care and unpaid informal care, putting a heavy thumb on the scale for formal care but still allowing someone who strongly values providing care (or with an insistent family member) to do so without pay.

The Dutch and German systems are more similar in design, although different in result. The Dutch program illustrates a relatively flexible toggle that has resulted in ninety percent of beneficiaries choosing in-kind home-care.[383] People can choose between in-kind services or a cash "personal budget" worth seventy-five percent of the value of the in-kind benefit (the discount is explained as due to the higher administrative costs of agency-based care but creates a bias toward in-kind care).[384] For people who choose cash, at least ninety percent of the personal budget must be spent on human assistance, paying anyone the "budget holder" chooses, including friends or family.[385] The cash benefits are relatively more valuable than in Germany, yet most Dutch claimants still choose in-kind care.[386]

Germany's program, in contrast to both the Japanese and Dutch systems, has reinforced reliance on informal caregivers. In 1994, Germany created a compulsory, universal social insurance that is available to people with more severe disabilities (defined as in need of assistance with at least two Activities of Daily Living).[387] Like the Dutch system, it has a toggle between in-kind services and cash benefits, but the cash benefits have a face value of only 50% of the in-kind benefit.[388] Despite this significant discount, 80 percent of home care beneficiaries and half of all beneficiaries, including those in nursing homes, have chosen the cash benefit and continue to rely on informal caregivers.[389]

Some of the variability in results may be due to different underlying social expectations or institutions but likely not all. All three countries have long histories of reliance on family for long-term care. The rates of employment of women in the Netherlands is especially low, which, in theory,

382 *Id.* at 26-27.
383 Nadash et al., *supra* note 377, at 317-18.
384 *Id.* at 314 (discussing how benefits are targeted); WIENER ET AL., *supra* note 291, at vi.
385 Nadash et al., *supra* note 377, at 320.
386 *Id.* at 318. Both countries face shortages of formal caregivers. *Id.*
387 Wiener & Cuellar, *supra* note 355, at 421; Nadash et al., *supra* note 377, at 311-12.
388 Nadash et al., *supra* note 377, at 314.
389 *Id.* at 318.

would make the opportunity costs of providing informal care lower than in Germany; yet more people choose in-kind care.[390]

Several elements of the design of the German program have been identified as perpetuating reliance on informal caregivers. The most important is that the cash benefit can be used in any way desired and is vested in the care recipient, not the caregiver; in other words, the care recipient is given cash that the government does not require be spent on human assistance, as in the Dutch program. Experts speculate that high unemployment led some beneficiaries to opt for cash benefits but then to continue to rely on *unpaid* informal care.[391]

In addition, the cash benefits, when paid to a family member, are not counted as income for tax purposes.[392] And although like in the Dutch program, the German family workers are not formally on the state payroll and have no formal worker protections, the German government does pay into pension, health insurance, and unemployment funds for any family caregiver who provides more than fourteen hours of care per week.[393] These benefits plus tax-free income might make caregiving relatively more attractive than other paid work.

Experts surmise the German program was intentionally designed to bias family care, which had been declining as families became smaller and geographically dispersed.[394] Consistent with conservative German "family-first" notions, one expert describes that these policies "enabl[ed] women to withdraw from the workforce."[395] The program has thus institutionalized reliance on family care, reinforced gender roles, and not contributed to the growth of the formal labor force for caregiving. Although the German program has a policy toggle in structure, it does not operate fluidly in practice and is likely not intended to do so.

B. Incremental Reforms

A new social insurance program is not necessary, however, to better mitigate next-friend risk. Especially in the short term, it is possible to build on current policies and demonstration projects to scale them and to make them more sensitive to next-friend risk. Some approaches would require additional funding; others might not.

---

390 *Id.*

391 *Id.* at 318 (describing that 31% of all beneficiaries and 49% at the highest level of disability report using their benefits for their own expenses).

392 *Id.*

393 *Id.*

394 WIENER ET AL., *supra* note 291, at 15.

395 Wiener & Cuellar, *supra* note 355, at 439.

1. Filling in Medicaid's Gaps

One possibility is to fill in Medicaid's gaps so that at least those care recipients who are eligible for Medicaid might rely less on next friends. One monumental, but potentially expensive, step would be to loosen financial eligibility criteria for long-term care benefits.[396] Doing so would increase the number of Medicaid eligible care recipients and enhance the impact of reforms that build on Medicaid as a foundation.[397]

Another incremental step would be to require states to cover more personal care services—such as assistance with bathing, feeding, transferring, or toileting—for the existing beneficiaries who receive long-term care at home, instead of in an institutional setting. As described in Part II, many states do not have personal care services programs for adults at all,[398] or pay for a very limited quantity.[399] Changing these benefits from optional to mandatory in the standard state programs and requiring waiver programs to cover them at sufficient levels would prevent states from shifting long-term care into home settings but then failing to cover needed care. The lack of funding for these services in home settings not only burdens next friends, it also limits choices. When family and friends can fill in the gaps, home care remains a viable option. For others, nursing home care might be the only choice. Thus, even just increasing funding for these services could meaningfully alleviate burdens and stress for next friends, while also preserving options for care recipients (even if it left largely unaltered the current structure of long-term care).

2. Expanding and Designing Policy Toggles in Medicaid Consumer-Directed Care Programs

A more ambitious approach is to adapt, invest in, and build out nascent programs that allow benefits to be used more flexibly. A major trend in long-term care financing is consumer-directed programs that allow beneficiaries the ability to hire, train, supervise, and fire their home-care workers. Many of these programs are designed with a toggle, where the beneficiary can choose either in-kind benefits (formal caregivers or a nursing home) or use a cash benefit to pay a family member or friend for care.

---

396 *See supra* note 70 and accompanying text.

397 These types of incremental expansions of eligibility used to be routine, but following the Supreme Court's decision with regard to the ACA's Medicaid expansion in *NFIB v. Sebelius* they would likely be challenged as beyond Congress' authority. *See* Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566, 2607 (2012).

398 *Medicaid Benefits: Personal Care Services*, *supra* note 115.

399 NG. ET AL., *supra* note 94, at 12-14.

These "participant directed" programs have gained popularity following a successful demonstration called Cash and Counseling, initiated in the mid-1990s by the Robert Wood Johnson Foundation.[400] Six percent of Medicaid long-term care beneficiaries are now in a participant-directed program.[401] The terms of these programs vary considerably state-by-state on important dimensions. For example, the majority of the programs restrict hiring a legally responsible individual (e.g., a spouse, parent, or legal guardian), which can create a bias toward hiring a formal caregiver.[402] These programs will likely continue to grow as a share of Medicaid long-term care funding and can be designed to be more sensitive to next-friend risk if doing so were a core goal.

An example of how even just one design element could create bias in how benefits are used is illustrated by the In-Home Supportive Services (IHSS) program in California. This Medicaid program is the largest program in the United States with a toggle that, in design, allows benefits to pay formal caregivers or close family members.[403] Two-thirds of IHSS recipients receive care from a relative, and in about half of these cases, they live in the same home.[404] To qualify for IHSS funding, as well as Supplemental Security Income cash benefits for the person with a disability, household income must be extremely low.[405] In calculating household income, these programs disregard IHSS benefits paid to a family caregiver.[406] This means the money paid to a wife to care for her husband would not disqualify him from receiving benefits, but wages from her work in a job outside the home likely would. The policy creates a strong incentive for her to provide care directly, rather than keep her job and hire someone to provide the care, even if doing so leaves her insecure in the long run. Treating her IHSS income or outside income the same—either counting both or neither—is necessary to enable the toggle to work.

---

400 *See* ROBERT WOOD JOHNSON FOUND., *supra* note 357.

401 *Facts and Figures: 2013 National Inventory Survey on Participant Direction*, NAT'L RES. CTR. FOR PARTICIPANT-DIRECTED SERVS 5 fig.2 (2014), https://nrcpds.bc.edu/downloadfile.php?filename=1411162479_NRCPDS_Facts_Figures_Final.pdf. Six percent includes over thirty percent of beneficiaries in California, which skews the national average. *Id.*

402 *Id.* at 11 (reporting that 11% of responding programs indicated that a spouse, parent, or legal guardian could be paid as a caregiver).

403 ROBERT MOLLICA & LESLIE HENDRICKSON, HOME AND COMMUNITY-BASED LONG-TERM CARE: RECOMMENDATIONS TO IMPROVE ACCESS FOR CALIFORNIANS 17 (2009), http://www.canhr.org/reports/HomeCommunityBasedCare2009.pdf.

404 *Considering the State Costs and Benefits: In-Home Supportive Services Program*, CAL. LEGIS. ANALYST'S OFF. (2009), http://www.lao.ca.gov/reports/2010/ssrv/ihss/ihss_012110.aspx.

405 *IHSS Eligibility Information*, CAL. DEP'T SOC. SERVS. (2013), http://www.cdss.ca.gov/cdssweb/PG135.htm.

406 20 C.F.R. § 416.1161(a)(16) (2016). Under this rule, "in-kind support and maintenance" is also not deemed income. *Id.*

As participant-directed care grows in the United States, an approach sensitive to next-friend risk would consider how policies should be designed to avoid reinforcing a strong bias toward family care, as in Germany or California. The goal should be, at the very least, policies that aim for a thin version of neutrality.

3. Investments in Infrastructure

Investment in community-based care infrastructure and a formal labor force could enhance options in the gap between nursing home and home-based care. New models show that high-quality care can be provided in community settings, but these existing models exist as isolated experiments and mostly focus on elder care.[407]

One of the first programs, which combines health and personal care needs is called On Lok and was started as a health plan in San Francisco in 1971 to help an aging Asian population age at home.[408] On Lok inspired a Medicare demonstration program known as the Program for All-Inclusive Care for the Elderly (PACE). [409] The most intriguing part of the model is the On Lok Lifeways Centers, which they call the "hub" of the program, where participants go from one to five days a week for medical care, adult day care, and social activities, including exercise and meals.[410] The model has targeted low-income and frail elderly.[411] Participants who are eligible for Medicare, Medicaid, and SSI pay nothing out of pocket; others pay a monthly fee.[412] For example, people eligible only for Medicare can "top off" Medicare benefits, which enables middle-income families to afford these programs and increases

---

407 Some models of innovative care for children with disabilities exist as well, but are less common. For example, the Center for Discovery is a residential center for children, which offers "advanced care and treatment" of young people with "medical complexities" and autism spectrum disorders. *See What We Do*, CTR. FOR DISCOVERY (2013), http://www.thecenterfordiscovery.org/what-we-do.

408 *About On Lok*, ON LOK (2015), https://www.onlok.org/about.

409 INST. OF MED., RETOOLING FOR AN AGING AMERICA: BUILDING THE HEALTH CARE WORKFORCE 84-85 (2008), http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2008/Retooling-for-an-Aging-America-Building-the-Health-Care-Workforce/RetoolingforanAgingAmericaBuildingtheHealthCareWorkforce.pdf.

410 *How PACE Works*, ON LOK LIFEWAYS, https://onloklifeways.org/how-pace-works (last visited Aug. 15, 2016).

411 *Who We Serve: The On Lok Lifeways PACE Program Is the Perfect Alternative to a Nursing Home*, ON LOK LIFEWAYS, https://onloklifeways.org/who-we-serve/#learnmore (last visited Aug. 15, 2016).

412 *Frequently Asked Questions (FAQ)*, ON LOK LIFEWAYS, https://onloklifeways.org/faqs (last visited Aug. 15, 2016). The programs receive a capitated rate from Medicare and Medicaid that in 2008 was $4900 per member, per month. *See* INST. OF MED., *supra* note 409, at 105.

funds available for investment in the programs' growth. On Lok program evaluations show high participant satisfaction, improved health and physical functioning, improved quality of life, and lower mortality.[413] At the same time, they free up informal caregivers for all or part of the work week.

A newer private-sector experiment is the Green House movement. Started by a doctor who wanted a better way to care for frail elderly than in nursing homes and with seed funding by the Robert Wood Johnson Foundation, Green House intends to be a "homelike" community-based care setting.[414] People live in a private room with a bathroom in a small, technology-equipped home for eight to ten residents. They eat communally. Green House accepts both Medicaid and Medicare reimbursement. As of the end of 2014, 167 Green Houses had over 1700 people living in them, and 108 new homes were in development.[415] They have had particular success recruiting and retaining caregivers, whom they call "shahbazim" and pay ten percent more than certified nursing assistants. Green House can afford higher salaries because of extremely low turnover and the shahbazims' responsibility for a broad range of activities, from personal care to cooking to housekeeping.[416]

Early research on Green House also indicates positive outcomes.[417] Anecdotal evidence in a recent *New York Times* article describes one older woman who "needed help eating and rarely spoke" but within a day of moving into a Green House, fed herself and sang Amazing Grace.[418] Even if not all residents are so dramatically altered, this program creates smaller-scale, community-based care options for families who are reticent to "put mom in a nursing home."

An obvious challenge is scaling such models in a way that they retain their quality and remain affordable for more than just the wealthiest families. One intriguing aspect of Green Houses is that community members have donated land and professional services to build facilities, lowering fixed costs.[419] For lower-income residents, On Lok received Department of Housing and Urban Development funds for its residential facilities. The ability to combine public and private funds in both programs creates growth opportunity and access for more people. Yet, even with many of these elements in place,

---

413 INST. OF MED., *supra* note 409, at 85.

414 *Id.* at 81-82.

415 Jane E. Brody, *The Green House Effect: Homes for the Elderly to Thrive,* N.Y. TIMES (Dec. 15, 2014, 10:21 AM), http://well.blogs.nytimes.com/2014/12/15/moving-away-from-nursing-homes.

416 *See* INST. OF MED., *supra* note 409, at 82-83.

417 *Id.*

418 Brody, *supra* note 415.

419 *Id.*

programs have not scaled well.[420] If we understand these kinds of programs as necessary to mitigating next-friend risk, learning how to scale them should be higher priority.

One of the greatest infrastructure challenges is the caregiver labor shortage. By one estimate, 3.5 million additional health providers, including nearly 1.6 million registered nurses and nursing aides, will be needed by 2030 just to maintain already insufficient provider-to-population ratios.[421] Meeting the needs of the elderly will be especially hard because of a gap in geriatric care training.[422]

Higher wages are needed to spur labor growth.[423] That said, higher wages on their own might be insufficient. As one scholar bluntly recognizes: "Helping people to dress, eat, urinate, and defecate simply is not an attractive career. Dealing with individuals in various stages of dementia is trying."[424] He adds that the lack of respect, little room for advancement, and stress of these jobs is not easily defrayed with money.[425] Efforts to overcome the aspects that could be improved are thus even more critical; without high-quality options, many people will be unwilling to outsource care.

4. Reshaping the Social and Institutional Baseline

Finally, addressing the many ways that existing legal and social norms and institutions bias care choices is beyond the scope of this article but nonetheless important for policy development. As one example, FMLA job-leave protections may be insufficient to support efforts to balance caregiving and paid work.[426]

FMLA leave is limited to caregiving for a spouse, child, or parent, leaving out the many people who care for grandparents, siblings, aunts and uncles, or close friends.[427] Furthermore, some of its terms have been interpreted to exclude activities common in long-term caregiving.[428] For example, the term "provide care" has been interpreted to exclude time spent moving a parent into a new living arrangement that better met her health

420 *See* INST. OF MED., *supra* note 409, at 105.

421 *Id.* at 124-25.

422 *Id.* at 128-36.

423 Even with the labor shortage of care professionals, wages have remained stagnant or declined slightly over the past decade. *America's Direct-Care Workforce*, *supra* note 297, at 4-5 (2013).

424 White, *supra* note 226, at 63.

425 *Id.*

426 *See generally* Smith, *Elder Care*, *supra* note 126, at 382 (describing some of the shortfalls of FMLA coverage in cases of elder care).

427 29 U.S.C. § 2612(a)(1)(C) (2012).

428 *See* Smith, *Elder Care*, *supra* note 126, at 393.

needs.[429] The complexity of FMLA makes it difficult for people to understand what is covered.[430] Finally, twelve weeks of leave may be too short in many cases, considering that the average period of informal care lasts 4.6 years.[431] It is unrealistic to expect employers to hold jobs open for years, and this expectation would also be unproductive since such mandates can shift costs to workers. However, something more than twelve weeks is needed in some situations.[432] The point is that there are many ways we could address these broader legal or social factors that exacerbate next-friend risk.

CONCLUSION

Taking next-friend risk seriously fundamentally shifts what it means to solve the long-term care crisis. It is not just a crisis faced by people who suffer from prolonged illness or disability. It is equally a crisis for their children, parents, siblings, grandchildren, aunts and uncles, and closest friends, who sacrifice their own wellbeing to care for them. They are interrupting their careers, their relationships, and their life pursuits. These next friends are invisibly bearing the costs of caring and experiencing disquieting insecurity in their own lives.

By seeing these costs as evidence of an insurable risk and pursing policies that are more sensitive to this risk, we can create a society in which some people, especially women, no longer experience severe harms due to the tragic misfortune of having a loved one become ill or disabled. Better long-term care policy, defined as policy that aims equally to mitigate next-friend risk, can solve a problem that is perpetuating deep social inequities and can provide greater security for all families.

Reimagining risk is an exercise with import beyond long-term care. Most social insurance programs and many regulations are based on implicit definitions of the risks that are worthiest of collective attention. By illustrating one field in which a narrow definition of risk has created an unstable foundation for policy-making, this article invites further examination of the law's role in inscribing obligation for some and security for others by how it imagines risk.

---

429 Pang v. Beverly Hosp., Inc., 94 Cal. Rptr. 2d 643, 649-51 (Ct. App. 2000).

430 *See* Nancy R. Daspit, *The Family and Medical Leave Act of 1993: A Great Idea but a "Rube Goldberg" Solution?*, 43 EMORY L.J. 1351, 1352 (1994).

431 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 19. This average is skewed by certain relationships, such as parents caring for children with disabilities (9.5 years on average). *Id.* at 20.

432 ALSTOTT, NO EXIT, *supra* note 22, at 154-62. But evidence suggests the FMLA has not resulted in such cost shifting so far. *Id.* at 159.