How To Fix Long-Term Care:

The threat to America's middle class and principles for sustainable reform

Robert P. Saldin | August 2021 | NiskanenCenter.org

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Key Takeaways

- Long-term care (LTC) is arguably the biggest hole in the American social safety net. Our expensive, patchwork system weighs down the economy and forces middle-class family members requiring such care to drain their life savings and risk impoverishment.
- Demographic forecasts indicate the number of individuals requiring LTC is set to increase dramatically from its current population of 14 million to 24 million by 2030, raising the urgency of reform.
- Past reform efforts fell victim to policy traps that today's policymakers must seek to avoid, including inadequate financing, underdeveloped strategies for combatting adverse selection, and widespread ignorance about the scale of the problem.
- In the short-term, rather than prioritize costly institutionalized settings, policy can encourage states to expand home-based care settings through Medicaid's home and community-based services (HCBS) program, particularly in states where the option is currently underutilized.
- In the long-term, the U.S. should adopt a national catastrophic insurance program for seniors on the model of the Netherlands or Japan. Whether provided as a public program or through mandatory private insurance, income-based premiums could cover the first three years of elder care needs before making them automatically eligible for Medicaid, thus protecting the elderly and their families from financially ruinous LTC expenses while relieving the fiscal pressure on state budgets.

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Long-term care (LTC) arguably constitutes the biggest hole in the American social safety net. People in the middle class are most vulnerable because LTC is so expensive that its costs can quickly lead to impoverishment. Health policy experts have recognized it as a serious challenge dating back to the debates over Medicare in 1965, and the Biden administration recently proposed $400 billion in new funding to address it. Most other developed countries are facing similar challenges and have responded to them by implementing national programs.[1] Yet in the United States, the mass public has never perceived LTC as a pressing societal issue, nor has it garnered enough supporters on Capitol Hill to rise to the top of the political agenda. This means that many individuals and families are left to fend for themselves in paying for the supports and services they require.

The core problem is that LTC costs far exceed what most Americans can afford. As a result, LTC needs force many senior citizens into poverty. At that point Medicaid — the state-federal health program for individuals with little income or assets — picks up the tab, but that commitment is increasingly putting pressure on state budgets. Given our aging population and smaller, geographically dispersed families, LTC is only going to become more of a challenge for individuals, families, and the states. Reforming the country's LTC system should be one piece of a broader effort to build a system of social insurance that can provide the necessary foundation for a free, dynamic society — what my Niskanen colleague Samuel Hammond calls the "free-market welfare state."[2] While numerous incremental reforms would be welcome, including those proposed by President Biden, the ultimate objective should be a universal national program geared toward mitigating the catastrophic costs that impoverish middle-class Americans and drain state resources.

America's long-term care challenge

Long-term care refers to the services and supports that over 14 million chronically ill or disabled Americans require to complete "activities of daily living," like eating, bathing, and getting dressed.[3] For those requiring this form of assistance, there is considerable variation in the level of need, the

1 For an overview of LTC systems in 10 similarly situated countries, see Ezekiel J. Emanuel, Which Country Has the World's Best Health Care? (New York: Public Affairs, 2020). See also Howard Gleckman, Long-Term Care Financing Reform: Lessons from the U.S. and Abroad, The Commonwealth Fund, February 2010.

2 Samuel Hammond, "The Case for a Free-Market Welfare State," Symposium, 10 May 2021; Hammond, "The Free-Market Welfare State: Preserving Dynamism in a Volatile World," Niskanen Center, May 2018, https://www.niskanencenter.org/the-free-market-welfare-state-preserving-dynamism-in-a-volatile-world/. See also Brink Lindsey and Hammond, "Faster Growth, Fairer Growth: Policies for a High Road, High Performance Economy," Niskanen Center, Fall 2020, https://www.niskanencenter.org/faster-growth-fairer-growth-policies-for-a-high-road-high-performance-economy/.

3 Edem Hado and Harriet Komisar, "Fact Sheet: Long-Term Services and Supports," AARP Public Policy Institute, Aug. 2019.

type of services required, and the location in which this care takes place. At one end of the spectrum are individuals with relatively modest limitations who may only require in-home visits by a family member or an aide for a few hours a week. At the other extreme are individuals residing in nursing homes and requiring 24-hour support.

America's LTC challenge is inextricably connected to what is otherwise a remarkably positive development: we're living longer. Today's youth have a life expectancy of 82, which is roughly a 50 percent increase from a century earlier.[4] Projections indicate that the number of older adults will double between 2015 and 2050 and that the number of people over 85 will triple.[5] Reaching "old age" is the new norm. However, a challenge that comes with this otherwise welcome news is that as one ages, the likelihood of requiring LTC increases. To be sure, LTC is not exclusively an issue for elders. People of any age *may* require LTC. A young adult who is, for instance, paralyzed in an accident will require assistance with activities of daily living. Those cases, however, are relatively rare. The far more common scenario involves older adults who need help in the later stages of life. Nearly 60 percent of those requiring LTC are 65 years old or older, and 80 percent of national long-term care spending is for elderly recipients.[6]

Of course, the challenge of meeting the needs of older people who require assistance in one form or another is not new. What is new and concerning are demographic forecasts that indicate the number of individuals requiring LTC is set to increase dramatically. The latest estimates suggest that by 2030 the current population of 14 million people requiring LTC will grow to 24 million.[7] Perhaps the starkest data points are these: Americans who reach the age of 65 can now expect to live past 85. And for those reaching 65, about 70 percent will need some LTC, with the average man requiring 1.5 years of assistance and the average woman 2.5 years.[8]

The key takeaway here is that we have a rapidly aging society that is going to need far more services and supports in the coming years and decades, and that increased level of need is a challenge because LTC is so costly. Without reform, this situation could impose significant constraints on our society's dynamism and vitality.

The squeeze on the middle class and state budgets

We do a poor job of measuring LTC spending, but it is clearly already one of the biggest drivers of health care expenditures in the U.S. One analysis found that about $235 billion is spent annually on long-term care; another estimated that LTC spending amounts to more than 9 percent of total U.S. health expenditures.[9] Notably, the data on LTC spending lowballs the real cost because so much of

4 Marc A. Cohen and Judith Feder, "Financing Long-Term Services and Supports: Challenges, Goals, and Needed Reforms," Journal of Aging and Social Policy 30, no. 3-4 (2018), 209.

5 Jeff Stein, "'This Will Be Catastrophic': Maine Families Face Elder Boom, Worker Shortage in Preview of Nation's Future," Washington Post, 14 Aug. 2019.

6 Hado and Komisar, "Fact Sheet: Long-Term Services and Supports;" H. Stephen Kaye, Charlene Harrington, and Mitchell P. LaPlante, "Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much?" Health Affairs 29:1 (2010): 18.

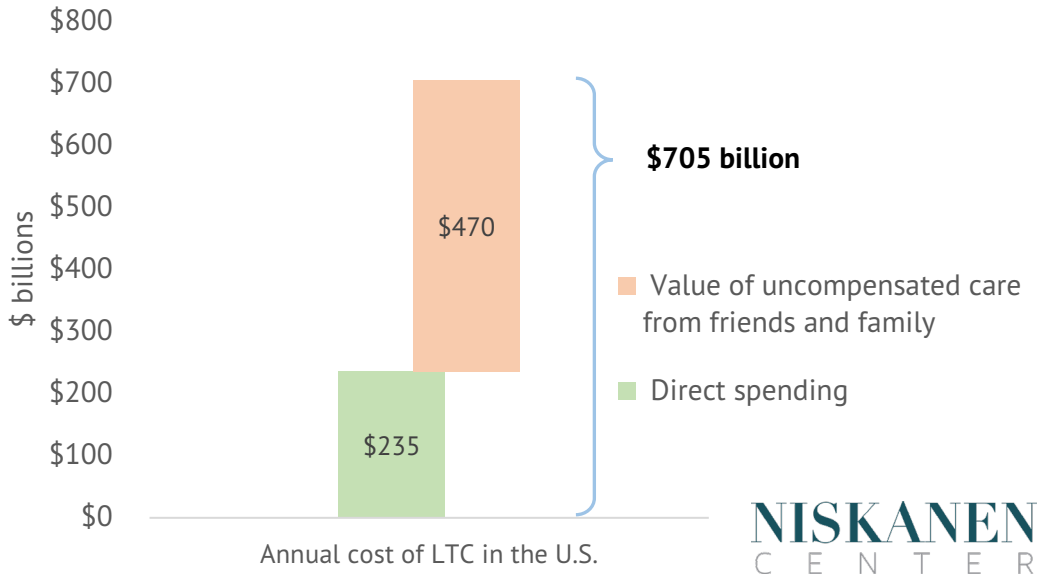
7 Tara O'Neill Hayes and Sara Kurtovic, "The Ballooning Costs of Long-Term Care," American Action Forum, 18 Feb. 2020.

8 Melissa Favreault and Judith Dey, Long-Term Services and Supports for Older Americans: Risks and Financing, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, rev. Feb. 2016.

9 Hado and Komisar, "Fact Sheet: Long-Term Services and Supports;" Carol V. O'Shaughnessy, "National Spending for Long-

the care is provided free of charge, usually by family members. The value of that care is estimated to be $470 billion annually, raising the annual cost of LTC to about $705 billion.[10]

Figure 1: Families shoulder the large majority of long-term care costs



Partly due to those high costs and partly out of preference, the overwhelming majority of long-term care in the U.S. has traditionally been provided informally and without charge by family members. Annually, 41 million unpaid caregivers provide 34 billion hours of care.[11] This form of caregiving can be a source of joy and meaning for both the caregiver and the recipient, but it can be physically and emotionally draining as well. It can also interfere with informal caregivers' ability to hold a job or relocate for better career opportunities, which increases their own financial vulnerability in both the short- and long-term, thereby exacting an economic toll both on them as individuals and on society.[12]

Many individuals also rely on paid care, either because willing family and friends are not available or because their needs exceed what family and friends are capable of providing.[13] Yet for those who aren't wealthy, LTC costs can quickly exhaust personal savings. Individuals requiring paid assistance will need to hire a home health aide at a rate of about $24 per hour, and costs only increase from there. For a family that concludes that an elderly parent can no longer live independently, the figures can quickly become overwhelming. A bed in a nursing home costs about $93,075 for a shared room or $105,850 for a private room annually.[14]

Term Services and Supports (LTSS), 2012," National Health Policy Forum, 27 Mar. 2014, http://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf.

10 Susan C. Reinhard et al., "Valuing the Invaluable: 2019 Update," Insight on the Issues, (AARP Policy Institute: Nov. 2019).

11 Ibid.

12 Among nonworking adults on Medicaid without disabilities, 12 percent cite caregiving responsibilities as their reason for staying out of the labor market. Rachel Garfield et al., "Work Among Medicaid Adults: Implications of Economic Downturn and Work Requirement," Kaiser Family Foundation Issue Brief, 11 Feb. 2021.

13 Sandra R. Levitsky, Caring for Our Own: Why There is No Political Demand for New American Social Welfare Rights (New York: Oxford University Press, 2014).

14 Judith Graham, "Biden Seeks $400 Billion to Buttress Long-Term Care. A Look at What's at Stake," NPR, 12 Apr. 2021; Genworth, "Cost of Care Survey," 2020, https://www.genworth.com/aging-and-you/finances/cost-of-care.html.

To the surprise of many, Medicare does not cover LTC expenses. This means that individuals and families are paying out of pocket unless they are poor enough to qualify for Medicaid or are among the few with private LTC insurance. The average person reaching the age of 65 will require $138,000 in LTC spending, although there is considerable variation. About half will face "significant need" — defined as being unable to perform multiple activities of daily living without assistance. For those, the average lifetime cost will be over $250,000.[15]

This system of LTC provision squeezes the middle class especially hard. Unlike the poor — who have few assets to spend down — and the wealthy — who can finance their own care with relative ease — those in the vast middle have a lot to lose. About half of households aged 55 or over have retirement savings, but the median amount is just $109,000. To many families a sum like that represents a lifetime of responsible saving and gives off the appearance of a healthy nest egg. But LTC expenses can eat through that in short order. Another 23 percent of 55+ households have no funds earmarked for retirement, but do have a defined benefit plan that funds their retirement.[16] Many such households would be well above the poverty line, but would have little to no capacity to pay LTC bills. In other words, the middle-class cohort that is squeezed by our system of LTC provision is remarkably broad, stretching from just above the poverty line all the way up to those who are still sitting on six-figure retirement savings *after* a couple of decades of retirement. Medicaid does provide a safety net, but qualifying for the means-tested program requires being in financial ruin.

And even then, the financial burden doesn't go away: It's merely shifted from the individual to society. Medicaid covers 57 percent of the nation's LTC costs. That spending amounted to $129 billion in 2018, consuming 32 percent of the program's total budget.[17] Medicaid is already the second-largest budget line item for states after K-12 education. With LTC spending projected to keep growing fast, it threatens to pinch already-tight state budgets and crowd out other fiscal priorities.

Long-term care's policy traps

The LTC challenge hasn't caught health policy experts by surprise. There have been many attempts to reform our approach to LTC, dating back to the creation of Medicare in 1965 and including the Medicare Catastrophic Coverage Act of 1988, the Pepper Commission of 1990, the failed Clinton health reform, and most recently the fatally flawed CLASS Act, which became law as part of the Affordable Care Act but was later abandoned by the Obama administration and eventually repealed by Congress.[18]

15 Cohen and Feder, "Financing Long-Term Services and Supports;" Favreault and Dey, "Long-Term Services and Supports for Older Americans."

16 Twenty-nine percent have no retirement savings or defined benefit income. U.S. Government Accountability Office, "Most Households Approaching Retirement Have Low Savings," 2015, www.gao.gov/assets/680/670153.pdf. The GAO notes that "we define household age as the age of the household head" (ftnt. 16, pg. 7).

17 Caitlin Murray, et al., "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018," Centers for Medicare and Medicaid Services, 7 Jan. 2021; Hado and Komisar, "Fact Sheet: Long-Term Services and Supports;" National Association of State Budget Officers, State Expenditure Report 2010, 2011, https://higherlogicdownload.s3.amazonaws.com/NASBO/9d2d2db1-c943-4f1b-b750-0fca152d64c2/UploadedImages/SER%20Archive/2010%20State%20Expenditure%20Report.pdf.

18 For an overview of long-term care's policy history, see Robert P. Saldin, When Bad Policy Makes Good Politics: Running the Numbers on Health Reform (New York: Oxford University Press, 2017), Chapter 3. For more on the MCCA, see Richard Himmelfarb, Catastrophic Politics: The Rise and Fall of the Medicare Catastrophic Coverage Act of 1988 (University Park:

The recent policy history of LTC reveals formidable policy traps that risk plaguing future reform efforts. These include:

Financing

Paying for a national program has always been the main sticking point. The idea behind the Medicare Catastrophic Coverage Act (MCCA), for instance, was to limit older adults' out-of-pocket expenses for catastrophic care. However, a proposed national LTC program was stripped from the package during the legislative process because both the Reagan administration and Democratic leaders in Congress were insisting on a deficit-neutral bill. Including the LTC component made that goal unreachable, but dropping it meant that the legislation failed to do anything about what was, by far, the most catastrophic financial risk facing older adults. The more streamlined package that became law also struck many as underwhelming – or worse – because it merely duplicated health benefits that many seniors already had while leaving many of them on the hook for financing the program. The law was repealed following an uproar among seniors that came to be symbolized by a bizarre incident in which Rep. Dan Rostenkowski (D-IL), chairman of the Ways and Means Committee and the public face of the legislation, was forced to flee an angry band of older adults heckling and chasing him down the streets of Chicago.[19]

"...major attempts at reforming LTC all collapsed due to the staggering realities of financing a national program."

But LTC — and the struggle to finance it — quickly returned to the policy spotlight. Only one year later, in response to the MCAA debacle, a bipartisan congressional panel was tasked with devising a plan "to change the nation's fundamentally flawed approach to long-term care financing." The group recommended a social insurance plan, but failed to reach a consensus on funding it, rendering their report "dead on arrival."[20]

Just a few years after that, however, LTC was back on the agenda as part of the Clinton health care reform effort. A LTC package was crafted by a group of policy experts and was included in legislation from several committees before the health reform process collapsed. Foreshadowing a rift that would reemerge during the Obama reform effort and underscoring LTC's second-tier status in the health policy hierarchy, some came to blame the LTC component's high cost for the demise of the larger Clinton reform effort.[21]

Taken as a whole, these major attempts at reforming LTC all collapsed due to the staggering realities of financing a national program. The MCCA saga also led many to conclude that mandatory participation had to be avoided because it was too politically contentious. Finally, these reform

Pennsylvania State University Press, 1995). On the Pepper Commission, see John D. Rockefeller, IV, "The Pepper Commission Report on Comprehensive Health Care," New England Journal of Medicine 323 (1990): 1005-1007. On the Clinton reform's LTC component, see Joshua M. Wiener et al., "What Happened to Long-Term Care in the Health Reform Debates of 1993-1994? Lessons for the Future," The Milbank Quarterly 79, no. 2 (2001). On the CLASS Act, see Saldin, When Bad Policy Makes Good Politics.

19 The definitive account of the MCCA is Himmelfarb, Catastrophic Politics. See also Julie Rovner, "Congress's 'Catastrophic' Attempt to Fix Medicare," in Intensive Care: How Congress Shapes Health Policy, eds., Thomas E. Mann and Norman Ornstein (Washington: American Enterprise Institute and Brookings Institution, 1995).

20 U.S. Bipartisan Commission on Comprehensive Health Care, A Call for Action, Final Report (Washington: Government Printing Office, 1990); Rockefeller, "The Pepper Commission Report on Comprehensive Health Care."

21 Wiener et al., "What Happened to Long-Term Care in the Health Reform Debate of 1993-1994?"

efforts revealed a split among health reform advocates. For those focused on older Americans and individuals with disabilities, LTC remained a priority. But many others in the health policy community came to see it as a threat to the more central goal of achieving universal health coverage because LTC's price tag had the potential to drag down future health reform efforts. As a result, the advocates who devised the CLASS Act and got it inserted into the Obama reform package were faced with an impossible task. They perceived themselves to be in a situation in which any chance of moving a LTC program required that it have optional participation and either be cost neutral or, ideally, a money maker. Unfortunately, not all good things go together. Those severe constraints on policy design caused the CLASS Act to fall victim to the next three policy traps.[22]

Widespread ignorance

The American public is generally ignorant about LTC and ill-prepared for the financial risk it poses. Among those 40 and older, two-fifths say they are not concerned at all about their potential LTC needs, two-thirds say that they have done little or nothing to plan, and only one-third report having saved money for LTC. Over 40 percent erroneously assume Medicare will cover their nursing home bills should the need arise.[23] In short, the American public is woefully underestimating the likelihood of requiring LTC and doesn't understand how that care is financed. Those misperceptions severely limit reformers' ability to rally the public behind a new program to address the issue.

Adverse selection

America's patchwork system of LTC provision is plagued by a classic case of adverse selection. Because there is relatively little interest in planning for likely LTC needs, the population that *would* be interested in LTC coverage is far more likely to already need care. This situation makes a non-mandatory program untenable because there would be too few healthy people paying into the system to cover its costs. The current private LTC insurance market helps illustrate the situation.

The dysfunctional private LTC insurance market

While private LTC insurance exists, the market is dysfunctional. Insurers and potential purchasers are both constrained by technical problems and the lack of awareness described above. The result is that LTC private insurance policies are expensive. Fewer than 4 percent of Americans hold such plans. A typical private LTC plan has an average monthly premium of about $216. If one has sufficient need, daily benefits are about $128 for five years.[24] Medicaid's existence and structure may reduce uptake of these private plans. As the safety-net "payer of last resort," Medicaid imposes "an implicit tax" on private insurance in so far as having another source of financing suppresses the market for private

22 On the CLASS Act, see, Saldin, When Bad Policy Makes Good Politics.

23 "Long-Term Care in America: Expectations and Reality," The Associated Press-NORC Center for Public Affairs Research, May 2014, https://www.longtermcarepoll.org/project/long-term-care-in-america-expectations-and-reality/; Howard Gleckman, "Denial Ain't Just A River in Egypt: Americans (Still) Unprepared for Care Needs in Old Age," 21 May 2014, http://howardgleckman.com/2014/05/denial-aint-just-river-egypt-americans-still-unprepared-care-needs-old-age/.

24 Alexander Sammon, "The Collapse of Long-Term Care Insurance," The American Prospect, 20 Oct. 2020.

long-term care insurance. Because of these problems in the private market, many insurers have quit offering LTC plans altogether; only 12 companies continue to do so.[25]

The political implausibility of a mandate

Required participation in a LTC program has long been considered even by many advocates as a political nonstarter. One core lesson from the unpleasant MCCA experience was that mandates are unpopular. That insight about what was and wasn't politically viable shaped future legislative proposals, including the Medicare Modernization Act of 2003, which created a voluntary prescription-drug benefit within Medicare, as well as the CLASS Act. CLASS' optional structure, for instance, was based on a calculation of what was politically feasible, not what would make for a sound policy.

This lesson was reinforced by the acrimony over the ACA's individual mandate for health insurance.[26] Health insurance, after all, is widely desired, but the mandate was still a source of major controversy. LTC insurance, by contrast, is not widely desired (due, in no small part, to the ignorance and misunderstanding described above). If a mandate for something desirable like health insurance barely made it through Congress (prior to being effectively repealed years later), it is hard to see how mandatory LTC insurance could survive the lawmaking gauntlet.

"If a mandate for something desirable like health insurance barely made it through Congress, it is hard to see how mandatory LTC insurance could survive the lawmaking gauntlet."

Notably, however, the rationale for requiring long-term care coverage is even stronger than it was for general health insurance during the ACA process. The case for the individual mandate rested on the premise that some mechanism was necessary to prevent healthy people from taking advantage of the system. If the insurance industry was required to offer coverage to everyone regardless of health status, they needed to ensure that everyone carried insurance. Otherwise healthy people would be incentivized to go without coverage, knowing that they could avoid paying for it until they became sick, at which point insurers would still be forced to take them on. At a mass scale, that type of consumer calculation would deny insurers the pool of healthy individuals required to support those filing claims.[27] That same logic applies to LTC coverage, but even more so because of its high cost and the high levels of ignorance and confusion among the American public, which make it even less likely that people with no impending need will buy in to the program.

25 Jeffrey R. Brown and Amy Finkelstein, "Insuring Long-Term Care in the United States," Journal of Economic Perspectives 25:4 (Fall 2011), 129; Benjamin W. Veghte et al., Designing Universal Family Care (Washington: National Academy of Social Insurance, 2019), 167; Sammon, "The Collapse of Long-Term Care Insurance;" Emanuel, Which Country Has the World's Best Health Care?, 29.

26 Saldin, When Bad Policy Makes Good Politics, Chapter 3; Kimberly J. Morgan and Andrea Louise Campbell, The Delegated Welfare State: Medicare, Markets, and the Governance of Social Policy (New York: Oxford University Press, 2011); Thomas R. Oliver et al., "A Political History of Medicare and Prescription Drug Coverage," The Milbank Quarterly 82, no. 2 (2004), 283-354.

27 For more on the history of the individual mandate before and during the ACA's legislative process, see: Jonathan Cohn, The Ten Year War: Obamacare and the Unfinished Crusade for Universal Coverage (New York: St. Martin's Press, 2021); Lawrence R. Jacobs and Theda Skocpol, Health Care Reform and American Politics: What Everyone Needs to Know (New York: Oxford University Press, 2010); Paul Starr, Remedy and Reaction: The Peculiar American Struggle Over Health Care Reform (New Haven: Yale University Press, 2011).

Meeting the diverse needs of seniors and people with disabilities

A final sticking point with LTC is that it involves a diverse range of cases that are different in crucial respects. A key distinction is between seniors and younger individuals with disabilities. Accommodating the needs of both in a single program is difficult. Among the differences are:

1. Disabilities incurred by younger people – ranging from permanent challenges suffered in accidents to disorders such as autism – are relatively uncommon and often difficult to anticipate, whereas we know that there is a strong chance that people living to the age of 65 will encounter challenges as they age;
2. The needs of the latter group pose a far greater cumulative fiscal challenge;
3. Younger people usually have a far longer time horizon for their care needs — often decades;
4. Finally, older and younger clients typically have different goals and priorities. Many younger individuals with disabilities, for instance, are eager to work, and they often have different realities and desires in terms of their family situations than those over the age of 65.

Guiding principles for long-term care reform

Policy experts and lawmakers have spent over 50 years struggling to devise LTC reform in a way that both meaningfully improves the status quo and has a fighting chance to clear the many political hurdles in the lawmaking process. However, with a rapidly aging population, LTC is likely to draw increasing attention. It is therefore worth sketching out a set of guiding principles that could inform future reform efforts ranging from incremental adjustments to a more sweeping overhaul.

Treat LTC reform as part of a broader effort to bolster the safety net

Long-term care should be reconceptualized. The current patchwork system leans heavily on two suboptimal support structures: unpaid family assistance that, among other problems, sharply reduces labor mobility for informal caregivers; and Medicaid's means-tested, payer-of-last-resort backstop.

Reforming the LTC status quo could be a significant pillar of a broader effort to bolster the American social safety net in a way that promotes economic freedom and could even bring some much-needed stability to our democracy by providing the kind of social continuity and certainty that are essential for sustainable economic dynamism. As the Niskanen Center's Samuel Hammond has emphasized, combining free markets with an extensive and universal system of social insurance can facilitate economic freedom and free enterprise. It can also forestall the kinds of bitter polarization and populist demands for government interventions in the economy that have been on full display in recent years.[28]

Combining economic freedom and an expansive, universal welfare state doesn't map cleanly onto our familiar conceptual framework for understanding the American political spectrum (ranging from

28 Hammond, "The Case for a Free-Market Welfare State; "The Free-Market Welfare State: Preserving Dynamism in a Volatile World."

small-government libertarianism on the right to big-government progressivism on the left). Yet other similarly situated, industrialized countries have effectively combined the two, with encouraging results both for those who prioritize an open, dynamic, and innovative economy and for those concerned about the individuals who inevitably fall through the cracks in a free-market system. The experiences of countries such as Sweden and Denmark show that broad social protections actually provide the essential foundation that allows for robust personal and economic freedoms.[29]

Reduce the risk of catastrophic expenses for the middle class

The LTC status quo leaves middle-class Americans the most vulnerable to financial ruin. To become eligible for Medicaid, people must "spend down" their savings until they are impoverished. That means spending one's assets on long-term care; wealth transfers are prohibited, and Medicaid's five-year "look back" period is designed to ensure that applicants haven't, for instance, gifted money to family members.[30] These eligibility requirements hit the middle class hardest. Poor Americans have few assets to burn through before qualifying for Medicaid, while the wealthy are often able to self-finance their care without significantly diluting their wealth. But for middle-class Americans hoping to pass on modest inheritances to family members or support philanthropic endeavors, LTC expenses can rapidly deplete a lifetime of savings. Reform efforts should seek to mitigate that risk while also recognizing that it is reasonable to expect that middle- and upper-class individuals make some provision for the likelihood that they will have LTC needs as they age.

Provide relief to state budgets

Growing LTC outlays have created significant pressure on state budgets. As noted, in most states, Medicaid rivals K-12 education as the biggest line item in the budget, and recent studies have shown that the program is the top concern for budget experts in state legislatures.[31] The LTC needs that are projected for the coming years and decades threaten to overwhelm public resources and capabilities and to crowd out other public priorities at the state level, including other health needs, education, transportation, law enforcement, corrections, and parks and recreation.[32]

Mitigate the burden on informal, unpaid caregivers

Informal, unpaid caregiving from family and friends is an essential component of LTC provision, but it comes with a hidden cost. The decision to take on caregiving responsibility for a loved one

29 Lindsey and Hammond, "Faster Growth, Fairer Growth." See also Andrea Louise Campbell, Trapped in America's Safety Net: One Family's Struggle (Chicago: University of Chicago Press, 2014), 124-5.

30 Mark Eghrari, "The Medicaid Look Back Period Explained," Forbes 1 Aug. 2014.

31 National Association of State Budget Officers, State Expenditure Report 2010, 2011, https://higherlogicdownload.s3.amazonaws.com/NASBO/9d2d2db1-c943-4f1b-b750-0fca152d64c2/UploadedImages/SER%20Archive/2010%20State%20Expenditure%20Report.pdf; National Conference of State Legislatures, "Top Fiscal Issues for 2014 Legislative Sessions," 30 Dec. 2013, http://www.ncsl.org/research/fiscal-policy/top-fiscal-issues-for-2014-legislative-sessions.aspx.

32 U.S. Department of Health and Human Services and U.S. Department of Labor, The Future Supply of Long-Term Care Workers in Relation to the Aging Baby Boom Generation: Report to Congress, 14 May 2003, http://aspe.hhs.gov/daltcp/reports/ltcwork.htm#note1.

involves considerable uncertainty regarding the time horizon for such a commitment and the extent of support that will be needed. Additionally, there are often significant financial implications for the caregiver. In many instances, a potential family caregiver is put in the position of needing to choose between remaining in the workforce in the middle of their prime earning years or helping an elderly loved one. By one estimate, there are about 53 million family members providing an average of 24 hours of care per week and an average of $7,000 out-of-pocket annually.[33]

"The LTC status quo leaves middle-class Americans the most vulnerable to financial ruin."

At the macro level, these tradeoffs constitute a significant constraint on economic freedom in the U.S. Additionally, just as our society's need for care is set to skyrocket, shifts in social trends are eroding the informal care model that the country has relied on. For instance, recent decades have seen women enter the paid workforce in large numbers, an increase in single-parent families, declines in average family size, and more geographically dispersed families (an issue that is exacerbated by Medicaid's state-to-state variations and its lack of interstate portability).[34] As a result of these shifts, the pool of informal caregivers is going to decline relative to those needing care.

A two-step approach to reforming long-term care

Bearing in mind these guiding principles, LTC could be reformed in ways that provide relief and assurance to middle-class individuals and families while easing our reliance on Medicaid and the implications that carries for state budgets. The most significant challenges facing such reforms are political. Given this reality, an incremental approach makes sense. But addressing the real crux of America's LTC challenge will ultimately require a national program with universal coverage for catastrophic LTC expenses.

Short-term objective: Incentivize states to offer home-based care

Prioritizing home- and community-based services (HCBS) over institutionalized settings when possible has gradually become a widely accepted approach. There is, for example, roughly twice as much national spending on HCBS now as there was in 2000. However, there is considerable variation among states because, while Medicaid requires states to offer a nursing-home benefit, it largely leaves HCBS options to their discretion.[35] Oregon, for instance, leads the pack, devoting 82 percent of its Medicaid LTC spending to non-institutionalized settings. At the low end, by contrast, only 31 percent of Mississippi's Medicaid spending on LTC does the same.[36] The rationale for incentivizing and empowering states to expand their HCBS opportunities is compelling. For one thing, studies

33 Graham, "Biden Seeks $400 Billion to Buttress Long-Term Care."

34 Levitsky, Caring for Our Own; Ed Dolan, "The Unintended Consequences of Health Care Decentralization," Niskanen Center, 7 July 2017.

35 Edward Alan Miller et. al, "Stepping into the Breach of Federal Inaction: Reforming the Financing of Long-term Services and Supports in the post-CLASS era," Journal of Health Politics, Policy, and Law 45, no. 5 (2020): 849; Steve Eiken et al., "Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2015," Truven Health Analytics, 14 April 2017, https://www.appliedselfdirection.com/sites/default/files/LTSS%20Expenditures%20FFY%202015.pdf.

36 Eiken et. al, "Medicaid Expenditures for Long-Term Services and Supports."

suggest that prioritizing HCBS over institutional care saves money.[37] Additionally, most people would prefer to stay in their homes than move to a nursing facility.[38]

As part of his administration's American Jobs Plan, President Biden has embraced this approach. Currently, Medicaid's HCBS program suffers from two significant problems: a long waitlist for enrollees eager to utilize this option and relatively low pay ($12 per hour) for the home-care workers providing the services and supports. While the details in Biden's proposal are thin, he would spend $400 billion over eight years and empower states to both expand the availability of HCBS and boost caregiver pay.[39]

Despite the big price tag, however, Biden's proposal is quite limited and doesn't really address the most vexing challenges in America's system of LTC provision. Most notably, it doesn't offer anything to those who haven't already met the means test for Medicaid eligibility, nor does it do much for those who do require assistance in a skilled-nursing facility. Nonetheless, it is a positive step that is politically plausible now. It would help to establish a sustainable caregiver workforce and reorient the setting of LTC in a way that is more cost-effective and more desirable for seniors. In these ways, it would put the country in a better position to meet the anticipated surge of demand for LTC in our aging society, even if it falls far short of confronting the full scope of the challenge.

Long-term objective: National catastrophic coverage for seniors

A national program focused on the catastrophic costs that can impoverish middle-class Americans and that drain state budgets should be the longer-term objective.[40] Unfortunately, such a program is a heavy lift politically. However, there are some encouraging signs for the political viability of LTC reform. Most notably, the Republican Party has shown increasing openness to the idea of using public initiatives to address the challenges facing middle-class families.[41] While extending that framework to LTC is not on the short- to medium-term horizon, it is conceptually consistent.

There is also no shortage of examples for approaching LTC if one looks beyond our shores. Other wealthy, industrialized countries are facing similar demographic-driven LTC forecasts but have been more proactive in taking steps to address the situation, typically under a universal social insurance model with mandatory participation. The Netherlands was first off the block, launching its social insurance program in 1968. The Dutch approach is universal and based on a public-private partnership

37 See, for instance, Micah Segelman et al., "HCBS Spending and Nursing Home Admissions for 1915(c) Waiver Enrollees," Journal of Aging and Social Policy 29, no. 5 (2017), 395-412.

38 Joshua M. Wiener et al., "Findings from the Survey of Long-Term Care Awareness and Planning," Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, July 2015, https://aspe.hhs.gov/pdf-report/findings-survey-long-term-care-awareness-and-planning-research-brief; Cheryl Lampkin and Linda Barrett, "Home and Community Preferences Survey," AARP, June 2015, https://www.aarp.org/research/topics/community/info-2015/Home-and-Community-Preferences-45Plus.html.

39 The White House, Fact Sheet: The American Jobs Plan, 31 Mar. 2021, https://www.whitehouse.gov/briefing-room/statements-releases/2021/03/31/fact-sheet-the-american-jobs-plan/.

40 For a framework on how to structure universal catastrophic coverage, see: Ed Dolan, "Universal Catastrophic Coverage: Principles for Bipartisan Health Care Reform," Niskanen Center, June 25, 2019. https://www.niskanencenter.org/universal-catastrophic-coverage/.

41 The most recent example of this shift is Senator Mitt Romney's embrace of direct cash payments to families with children. Tucker Higgins, "Romney Child-Payment Proposal Would Spend More than Biden Plan – But Also Aims to Cut Welfare Programs," CNBC, 4 Feb. 2021; Samuel Hammond and Robert Orr, "The Conservative Case for a Child Allowance," Niskanen Center, Feb. 2021.

that relies on private insurers to administer the program. About three-quarters of the cost is financed by individuals via payroll taxes and copays, with general funds covering the rest.[42] Other LTC social insurance programs are common, though details vary. Germany, for instance, started its program, which is open to all ages, in 1995 as local governments were struggling to handle an increasing need for nursing home care. Its citizens are offered a choice between a public LTC plan or comparable private offerings, financed with a 1.95 percent payroll tax split evenly by employers and employees. Though the German program has been more costly than originally anticipated, it has sharply curtailed reliance on means-tested public programs and has brought substantial relief to local governments.[43] Meanwhile, Japan – a country with a particularly acute aging-related demographic challenge – largely limits its social insurance LTC program to those 65 and older.[44]

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In the U.S., the objective need not be a comprehensive program that covers every last dollar of LTC spending. Rather, reform should be geared toward the most daunting concerns facing individuals, families, and American society: the risk of catastrophic, impoverishing expenses and the burden on state budgets. A government-sponsored public program or a regulated private insurance program that provided standard coverage for catastrophic LTC expenses would go a long way toward addressing our most serious LTC challenges without expecting the public to provide complete protection for the assets of wealthy and middle-class Americans.

A key distinction between potential LTC reforms is whether participation should be optional or mandatory. In terms of policy design, mandatory participation — as in the programs in Germany, the Netherlands, Japan and elsewhere — is far preferable and perhaps the only viable approach short of a massive and quite unlikely reversal in public awareness and concern about LTC. As the designers of the CLASS Act recognized, passing a mandatory program is, to say the least, politically challenging. However, it is hard to see a way around it. A non-mandatory approach simply offers very little hope of significantly altering our dysfunctional LTC system.

A catastrophic LTC program of this sort should be limited to serving older adults. The aging population is the driver of the nation's fiscal challenge. LTC needs from younger people are relatively uncommon and harder to anticipate. By contrast, there is a good chance that those living to 65 will require LTC assistance. Given that likelihood, it is reasonable to ask that middle-class and upper-class Americans make some provision for their own care in the later years of their lives. A separate set of reforms could be targeted to the specific needs of younger individuals with disabilities.[45]

The resulting program would be targeted toward addressing the high cost of institutionalized care. As noted above, shifting as much LTC as possible from institutionalized settings to home- and community-based settings is certainly desirable, but nursing homes will always be necessary, too. And it is in that location that costs are highest and the burden on the middle class and Medicaid

42 Emanuel, Which Country Has the World's Best Health Care?, Chapter 7.

43 Andrea Louise Campbell and Kimberly J. Morgan, "Federalism and the Politics of Old-Age Care in Germany and the United States," Comparative Political Studies 38, no. 8 (Oct. 2005): 887-914; Gleckman, Long-Term Care Financing Reform, 6-8.

44 Gleckman, Long-Term Care Financing Reform, 11-14.

45 For more on the challenges facing younger individuals with disabilities, see Campbell, Trapped in America's Safety Net.

is greatest. Such a program based on the social insurance model could be financed through a new payroll tax, as in the German model. Such a program could be public, like Medicare (or a new program within Medicare), or it could rely on private insurers, as the Dutch program does and like the ACA does for health coverage.

Alternatively, individuals could be required to carry private, government-approved catastrophic long-term care coverage.[46] Subsidies would be needed to assist those with few assets, but this formulation would make certain that the wealthy and middle class would be funding at least some of their own LTC needs. Income-based premiums – already a feature of Medicare parts B and D – could further ensure that the middle class and especially the wealthy are contributing to their own LTC needs rather than simply leaving taxpayers to pick up the tab. The coverage could be based on the private LTC insurance plans that are already available.

Again, the mandated coverage should be geared toward the kind of catastrophic expenses that lead to impoverishment. Because the average nursing home stay is about three years, individuals could be required to carry a plan covering that length of time. As noted earlier, a shared room in a nursing home costs about $93,000 per year, which could be covered with a daily benefit of about $250. Those living beyond the covered three years could become eligible for Medicaid immediately. This scenario would retain Medicaid as a key player in LTC spending, but it would dramatically reduce its obligations, thereby easing budgetary pressure on state governments. If participation was mandatory, premiums would be far more reasonable than those currently available from private insurers.

Conclusion: An urgent need — and opportunity

For decades, any serious proposal for addressing America's long-term care problem has been widely dismissed as a black hole for public resources that the country could never realistically afford to take on. Yet other similarly situated countries have managed to pull it off without courting fiscal catastrophe. To be sure, following suit with a national program in the U.S. would represent a significant expansion of our social welfare state – one that the American populace is less accustomed to than are those of most other industrialized countries. Yet we will need to grapple with our LTC situation at some point.

More importantly, addressing LTC does not need to be viewed as an inevitably grim, sacrificial exercise of eating one's peas. Nor should it be understood as a lurch toward socialist dystopia. On the contrary, the old, reflexive narrative that LTC and other social protections cost too much fails to appreciate a key factor for promoting economic freedom in a healthy liberal democracy. Such protections have the potential to not only address problems the free market is poorly-suited to handle, but to simultaneously provide the kind of social protections, stability, and confidence that a free and dynamic society needs to truly flourish.

46 For variations on this approach, see, for example: Howard Gleckman, Caring for Our Parents (New York: St. Martin's Press, 2009); William A. Galston, "Old, Gray and Here to Stay," The American Interest, Sept.-Oct. 2011.

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