LONG-TERM CARE: THE FORGOTTEN HEALTH CARE CHALLENGE

Leading the Way to Broader Reform

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ABSTRACT

American families are increasingly learning that they cannot have income security without health care security, particularly if a family member is older or disabled. The demographic inevitability of the aging of the baby-boom population, and the resultant health cost burdens that such aging will increasingly impose on families and the government, will create substantial economic and political pressures to take action on long-term care. However, policy efforts to respond to this pressure will likely fail in today's polarized environment, unless these efforts build on policies that are attractive to both parties. One such policy consensus appears to be an agreement that (1) the federal government should, at a minimum, help underwrite the costs of catastrophic health care expenditures; (2) the private sector should finance the indisputable coverage voids that limited federal dollars leave behind; and (3) special protections should be made available to low-income Americans. Applied to long-term care, such an approach can help ensure that Americans are not impoverished by care costs, produce more affordability and predictability in the private insurance market, and deliver much needed budgetary relief to invest in under-funded Medicaid populations. This paper proposes a new private-public policy collaboration that integrates these consensus positions into a long-term care initiative for chronically ill Americans of all ages; in so doing, it would make a necessary contribution to stabilizing the weakening retirement security system for older Americans.

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INTRODUCTION

The weakening of the so-called "three-legged stool" of retirement security—Social Security, private pensions, and retirement savings—has already created great anxiety amongst older Americans and their younger family members. To understand this, one only needs to look at the concerns the public conveyed during the Social Security debates or the reaction to decisions by companies like United Airlines to downsize their pension protection. However, even in the face of disconcerting developments in these areas, the public is increasingly recognizing that the most unpredictable and the greatest financial, emotional, and physical threat it may confront is the prospect of needing long-term care.

In short, the lack of a comprehensive and affordable long-term care system is burdening individuals, families, and governments to the point of crisis. Retirees fear as much as anything else that their need for long-term care will ultimately leave them bankrupt, with little of their life's savings (or even their family home) left to bequeath to the next generation. Moreover, they fear that they will be a physical, emotional, and financial burden on their families, who in the absence of a rational support system, provide significant levels of informal care.

State governments, meanwhile, find more of their tax dollars dedicated to health care, especially for the provision of long-term care. While cost inflation is historically recognized as the fundamental health care challenge (and rightly so), there is a growing recognition that rising health care spending is largely driven by the relatively small population of patients incurring a relatively massive amount of cost. As a consequence, states increasingly understand that managing the high-cost, catastrophic cases (especially those associated with long-term care) in a clinically defensible yet cost-efficient manner is the key to containing cost growth.

The challenge facing the entities in the private sector interested in filling the long-term care void is no less daunting. For a myriad of reasons (later described in detail), private long-term care insurance providers have been unsuccessful in marketing an affordable, reliable product to a substantial number of Americans.

Despite the undeniable void in public coverage and a multi-year campaign by private plans to expand access to long-term care insurance, policymakers have been unable to develop policy approaches that are sufficiently effective and pragmatic—as well as politically attractive enough—to make progress on this issue. It has, therefore, become clear that any legitimate retirement security debate must confront the divide between public and private stakeholders and progressive and conservative policymakers, a divide that has produced a fundamentally flawed long-term care financing and delivery system.

Notably, and perhaps even accidentally, both sides are inadvertently driving toward consensus on at least one aspect of a potential policy solution: federal support for a basic level of catastrophic health care cost protection.

Witness the catastrophic protection provisions included in the 2003 Medicare Modernization Act.[1] While policymakers on each side of the aisle vehemently disagreed on the cost and administration of the new benefit, all agreed that Medicare beneficiaries should at least be shielded from the type of extraordinary financial pharmaceutical costs that push some retirees into poverty. Likewise, Democratic proposals, such as John Kerry's call for catastrophic-cost assistance through reinsurance, represented other examples of the emerging consensus that the costs created by the sickest Americans should be shared—not just by people in each insurance plan, but also by the government.

In addition to this growing policy agreement, the political environment surrounding the long-term care crisis is becoming more receptive to action. One factor driving the evolving politics of retirement security is the substantial fear among beneficiaries and their families that uninsured long-term care liability poses immense financial risk.[2] Coupled with a strong recognition of the limitations of private long-term care insurance, the public has begun to call for an increased governmental role in paying for the costs of long-term care.[3] This new political reality is also spurred by states that are increasingly vocal in their desire for a lesser role in long-term care and by private insurers that continue to want a more central role. Mixing in the powerful ramifications of the retirement of the baby boomer, an opportunity for a policy and political coalition begins to emerge.

What policy can capture this momentum for change? A policy founded on the collaboration of the federal government and the private sector to reform the current long-term care delivery system and fund a new model. This policy is based on catastrophic cost protection that is both efficiently targeted and comprehensive in scope.

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1. Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Pub. L. No. 108-173, 117 Stat. 2066 (2003).

2. A June 2005 poll conducted by the Kaiser Family Foundation found that 53% of respondents were "worried" about not being able to afford long-term care services, and nearly a third of those surveyed said they were "very worried." KAISER FAMILY FOUND., THE PUBLIC'S VIEWS ON LONG-TERM CARE 4 (2005), http://www.kff.org/spotlight/longterm/upload/Spotlight_Jun2005_LTC.pdf.

3. The same Kaiser poll also asked respondents about their views on the roles of the private and public sectors in long-term care. Just 21% reported that they held a private long-term care insurance plan. KAISER FAMILY FOUND., *supra* note 2, at 2. Of those that did not hold a policy, nearly 60% cited cost as a prohibitive factor, while another 30% cited the policies' lack of adequate coverage of the costs they expected to incur. *Id.* at 13. Additionally, when asked if nursing homes received enough funds from the government and other insurers, 48% said no; just 26% said the homes received sufficient funding from these sources. *Id.* at 15.

The Helping Expand Access to Long Term Health (HEALTH) initiative would fund catastrophic long-term care costs and, by doing so, substantially reduce the risk and liability exposure of private insurers, enabling them to offer more affordable, reliable, and preferable care. Equally important, this proposed program would provide states with the resources to invest in more home- and community-based services for their low-income citizens as well as in responding to broader health reform challenges such as providing coverage to the uninsured. Solving the long-term care crisis is the necessary first step in bringing renewed stability to the so-called "retirement stool" on which generations of Americans have come to rely for security in their retirement years.

I. A CHALLENGED SYSTEM

Today's patchwork long-term care delivery and financing system is neither affordable nor accessible. As most anyone with a family member or loved one who is considering long-term services or support has experienced, the price of care is extraordinarily expensive and often cost prohibitive. In 2002, a year of institutional care cost approximately $52,000.[4] As one might expect, home-based care is generally less expensive, though hardly a bargain at an annual cost of $26,000.[5] Additionally, the need for long-term care is highly unpredictable: 31% of those turning sixty-five will likely never need long-term care; 17% will likely need a year or less; and 20% will likely need more than five years of care.[6]

With high costs and variable demand, long-term care is a seemingly opportune private insurance market. Yet private long-term insurance coverage remains sporadic at best and wholly inadequate at worst. While policy sales have grown slightly in the past decade, just six million remained active as of 2001,[7] a fraction of the needed coverage for a retiree population that is expected to more than double from just over thirty-five million today to more than eighty million by 2040.[8]

4. GEORGETOWN UNIV., LONG-TERM CARE FINANCING PROJECT, WHO PAYS FOR LONG-TERM CARE? 1 (July 2004), http://ltc.georgetown.edu/pdfs/whopays2004.pdf (citations omitted).

5. *Id.*

6. JUDITH FEDER, CTR. FOR AM. PROGRESS, LONG-TERM CARE AND MEDICAID: THE CRITICAL ROLE OF PUBLIC FINANCING 3 (June 2005), http://www.americanprogress.org/atf/cf/%7BE9245FE4-9A2B-43C7-A521-5D6FF2E06E03%7D/long-term_care_and_medicaid.pdf (citations omitted).

7. HEALTH INS. ASS'N OF AM., LONG-TERM CARE INSURANCE IN 2000-2001 3 (2003), http://membership.hiaa.org/pdfs/policy/030130LTCExecutiveStudy.pdf.

8. U.S. CENSUS BUREAU, U.S. INTERIM PROJECTIONS BY AGE, SEX, RACE, AND HISPANIC ORIGIN, tbl.2a (2003), http://www.census.gov/ipc/www/usinterimproj/natprojtab02a.pdf.

Much has been made of the potential for private solutions to the long-term care crisis, yet despite years of education about the limitations of Medicare and ongoing attempts by the federal government to provide tax clarifications that encourage the purchase of these products, there has been a relatively low take-up rate. There are numerous explanations for this phenomenon, but the primary factor underlying this dynamic relates to the inability of the market to provide an affordable, reliable option that is attractive to a broad range of the public. As currently structured, the market protects itself from the open-ended and expensive liability associated with long-term care costs. Private plans achieve this objective by providing relatively limited benefits with no required inflation or nonforfeiture protections and low lifetime limits.[9] Conversely, when such protections are provided, the cost of the product becomes prohibitive to many purchasers. On top of all these challenges is the fact that younger, healthier populations either prioritize other investment opportunities ahead of long-term care insurance or simply refuse to believe that they will ever need this type of protection.

Because long-term care is now too expensive for the vast majority of individuals and families, and it is inadequately covered by private insurance, the only remaining option is the Medicaid program. Medicare, the traditional federal health care entitlement for retirees and the disabled, pays only 17% of all long-term care spending (see Figure 1). This is due to current Medicare law, which offers extremely limited coverage for acute or postacute, noncustodial skilled nursing; it does not provide coverage of nursing home and home- and community-based care for the chronically ill.

Thus Medicaid, originally designed as the health care safety net for low-income Americans, has emerged as the predominant purchaser of long-term care services. Medicaid's long-term care expenditures have been steadily increasing. Since the enactment of Medicaid in 1965, the allocation of Medicaid spending devoted to long-term care has risen from the single digits to nearly 40% in 2002. The net rise in spending may be attributed to both the relatively high cost of care for the elderly and disabled and to the growing number of enrollees entering the program specifically for its long-term care services. Indeed, Medicaid spends roughly seven times as much per recipient on the elderly and disabled population as it does on children and adults, resulting in just 27% of Medicaid enrollees accounting for nearly 70% of spending.[10]

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9. Nonforfeiture standards prevent a participant from losing benefits based on one or a few missed payments, many of which occur at the time of disability.

10. John Holahan & Arunabh Ghosh, *Understanding the Recent Growth in Medicaid Spending, 2000-2003*, HEALTH AFF., Jan. 26, 2005, at W5-52, W5-59 tbl.6, http://content.healthaffairs.org/cgi/content/abstract/hlthaff.w5.52v1. For more discussion on the topic, see NAT'L GOVERNORS ASS'N, DUAL ELIGIBLES: MAKING THE CASE FOR FEDERALIZATION (2005), http://preview.nga.org/Files/pdf/0505Dual.pdf.

Moreover, in the absence of viable private insurance opportunities, enrollment will continue to increase as many in the working and lower-middle classes are spending the vast majority of their private resources on expensive long-term care services and thus qualifying for Medicaid. This increased cost burden on the states for long-term care is unsustainable. Indeed, as the bipartisan National Governor's Association recently emphasized, the lack of a meaningful Medicare or private long-term care insurance role has shifted the burden of the vast majority of long-term care expenditures to Medicaid and thus to the states.[11]

Amidst such heavy expenditures, Medicaid's ability to invest in the type of program enhancements that improve quality, contain costs, and satisfy beneficiaries has been limited. Though much progress has been made, including a doubling of Medicaid expenditures dedicated to home- and community-based care, the program retains an institutional bias that tends to favor relatively undesirable and expensive nursing home care, and that frequently restricts consumer choice.[12] Furthermore, Medicaid has been relatively slow to adopt cost-containing, quality-improving protocols, such as chronic care management programs, health information technology enhancements, and investments in training and workforce expansions. Finally, to compensate for the gaps in private and public coverage, unpaid care is commonly provided by family members and loved ones. Typically, these informal caregivers are women in their mid to late forties.[13] Providing such care consumes time and imposes great emotional and physical strain.

Adding to these challenges, demographics dictate that the retirement of the baby boomers will produce an increased demand for long-term care. Even assuming a declining disability rate, the sheer rise in the number of elderly people will most likely result in increased long-term care needs: the population over the age of eighty-five, whose demand for long-term care is likely to be the greatest, is estimated to double by 2030 and quadruple by 2050.[14] Additionally, the number of elderly living alone and without siblings or children is expected to rise sharply in the coming years. By 2020, it is estimated that nearly 1.2 million older individuals will be without any family support for their long-term care needs, almost twice the number without support in 1990.[15] Finally, the

11. NAT'L GOVERNORS ASS'N, *supra* note 10, at 6-8.

12. WILLIAM G. GALE ET AL., RET. SEC. PROJECT, RETIREMENT SAVING AND LONG-TERM CARE NEEDS: AN OVERVIEW 16 (2004), http://www.retirementsecurityproject.org/pubs/File/Publication_Retirement_Savings.pdf.

13. SHEEL PANDYA & BARBARA COLEMAN, AARP PUB. POLICY INST., CAREGIVING AND LONG-TERM CARE FACT SHEET (Dec. 2000), http://www.aarp.org/research/housing-mobility/caregiving/aresearch-import-685-FS82.html.

14. FEDER, *supra* note 6, at 3.

15. JACOB SIEGEL, U.S. DEP'T OF HEALTH & HUMAN SERVS., ADMIN. ON AGING, AGING INTO THE 21ST CENTURY, tbl. 9 (1996), http://www.aoa.gov/prof/Statistics/future_growth/aging21/table9.asp.

rising level of medical cost inflation, due among other reasons to the rising prevalence and diagnosis of chronic disease, will push the costs of long-term care ever higher. Ominously, the nonpartisan Congressional Budget Office has forecasted that Medicaid spending on long-term care for the elderly alone will nearly double by 2020.[16]

II. A NEW DIRECTION FOR LONG-TERM CARE

A reformed and improved long-term care delivery and financing system would not only provide higher quality care more efficiently and equitably, but also would free valuable resources for cash-strapped states and bring financial predictability and security to disabled and retired citizens. The salient characteristics of any reformed long-term care system should include the following: a new federally financed long-term care catastrophic cost protection benefit, a revitalized private long-term care insurance market with appropriate consumer protections, a modernized delivery system that improves care and empowers beneficiaries, and financing relief for an already overburdened Medicaid system to allow for targeted and overdue investments.

HEALTH is a new federal mandatory program that aims to strike the appropriate policy balance between the private and public sectors and to achieve the goal of shared responsibility. It would create a new, fully federally subsidized $100,000 catastrophic protection benefit, but limit eligibility to only those Medicare beneficiaries who purchase a qualified private long-term care insurance plan. This contrasts with purely federal and purely private mechanisms, which ignore the inherent symbiotic relationship between the two sectors in the American health care system. It also provides a specific acknowledgement that both sectors have important and necessary contributions to make to achieve a more rational, affordable, and responsive long-term care system.

How would HEALTH work? Purchase of the necessary qualified private insurance plan by nondisabled beneficiaries must occur during the following open enrollment periods: 1) at the legislation's inception; 2) during the first six months of official eligibility for Medicare; and 3) for those between the ages of sixty-five and seventy. Plans may increase premiums for those that delay to counter the effects of age and adverse selection.

As mentioned above, to be eligible for the $100,000 catastrophic protection, beneficiaries must first invest in a qualified private long-term care policy. To qualify as such, these plans must adhere to moderate benefit standards, including nonforfeiture and renewability guarantees, indexing of per diem payments to inflation, and a minimum benefit package. Additionally,

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16. CONG. BUDGET OFFICE, PROJECTIONS OF EXPENDITURES FOR LONG-TERM CARE SERVICES FOR THE ELDERLY 5 (Mar. 1999), http://www.cbo.gov/ftpdocs/11xx/doc1123/ltcare.pdf.

private plans would be required to offer home care benefits at parity with nursing home services, offer a minimum set of cost and quality systems, including (but not limited to) chronic care management protocols and drug management programs, and make adult day-care and respite services available as a supplement to the vitally important and comforting work of informal caregivers. Because qualified plans would be required to insure all nondisabled Medicare enrollees who chose to participate, carriers would be permitted to implement reasonable cost sharing practices. Finally, for those who are consuming long-term care services, HEALTH would provide insurers with some additional assistance (e.g., risk-corridor payments) to help subsidize the cost of care.

In addition to purchasing private insurance, enrollees and plans would be required to exhaust a catastrophic sum of long-term care expenses before being eligible for federal relief. In its first year, the HEALTH catastrophic level would be set at $100,000 of lifetime incurred costs, which would include a combination of privately insured expenses and their associated co-payments. To contain future costs, the catastrophic level would be indexed over time to a variable rate such as GDP inflation, the Consumer Price Index (CPI), or the Consumer Price Index-Medical (CPI-M). Finally, enrollees would not be required to forego the home-health benefits already provided through Medicare. Rather, HEALTH's design essentially wraps the new benefit around the more acute care-related provisions in current Medicare law.

Once a beneficiary reaches the $100,000 catastrophic threshold, HEALTH would reimburse qualified plans, with the goal being a federal payment rate of 90%. This payment would not equal 100%, so as to incentivize private plans to continue to effectively manage the care of those who have reached the catastrophic amount. Plans would also be allowed to require beneficiaries to pay nominal co-payments. Such a combination of federal match and moderate co-pays would serve as incentives to provide cost-effective, quality care that remains affordable for beneficiaries.

For the "dual-eligible" population (those enrolled in both Medicare and Medicaid), the states would continue to provide payment of long-term care services for Medicaid beneficiaries during the precatastrophic phase. Upon reaching the catastrophic level (as measured by total state and Medicaid beneficiary contributions to long-term care that exceeded $100,000), states would also be eligible for the 90% HEALTH match. States would be required to cover the cost-sharing above the catastrophic level for this population and to reinvest savings to either enhance the Medicaid home and community-based benefit or expand coverage to the uninsured.

The combination of a federal commitment to catastrophic coverage and a substantially modernized and affordable private long-term care market would, at last, fill the niche of a stable and responsive long-term care system for chronically ill Americans. Leveraging the investment to accelerate a much

more aggressive use of chronic care management and information technology will ensure efficiencies and improve care. This, combined with the financial relief it would provide to the Medicaid program, would provide states with the ability to reinvest savings to improve compensation, staffing levels, and accompanying quality improvements, thus enhancing the long-term and acute care health system for low-income Americans.

III. FINANCING THE NEW LONG-TERM CARE VISION: A NECESSARY PRECONDITION FOR PROGRESS

The absence of viable financing options for major health reform initiatives is the major albatross for any effort to make serious improvements in the nation's health care system. It is therefore imperative that realistic and thoughtfully designed financing sources be tapped to fully and fairly underwrite the cost of expansions. To have any chance in succeeding, such financing mechanisms must have a logical correlation to the intended policy proposal.

As this paper has made clear, retirement security is as much about health care as it is about income. The three-legged stool of retirement security must be redesigned. Consistent with this vision, dedicating a portion of the increased revenue from an increase in the Social Security income eligibility cap is a logical and completely defensible course of action. For example, raising the cap in $10,000 increments from its current level of $90,000 would likely produce hundreds of billions of dollars in additional revenue over ten years. Most of this amount could and should be dedicated to strengthening Social Security, but a portion of it, perhaps a quarter, should be allocated to long-term health care reform because of its importance in maintaining retirement security.

Likewise, slightly limiting the estate tax exemption—which by 2006 will likely be permanently set at $3.5 million or more—to a still extremely high $2.5 million, would achieve substantial revenue and affect less than 10,000 additional individuals per year. Such a policy would provide a couple with a complete exemption from any federal tax on fully $5 million worth of estate value, and only make an assessment on the value of the estate *in excess* of the exemption level. This rational reform could produce nearly $7 billion in additional savings per year and upwards of $75 billion over ten years. Since the new catastrophic protection benefit would have the effect of making a substantial contribution to preserving family savings and assets, such a fair, progressive tax reform policy makes logical sense.

IV. OPPORTUNITY FOR CONSENSUS

Long-term care reform is most certainly not a newcomer to the health care debate. Indeed, the facts and versions of some of the concepts highlighted in

this paper have been thoughtfully presented in previous forums.[17]

Yet solutions to long-term care, and even the debate itself, have been historically put aside for three major reasons. First, the long-term care debate—like many of the larger health care and macroeconomic policy fights of the past several decades—has traditionally been dominated by fierce ideological divisions based on the roles of the private and public sectors. Second, proposals that promote major health reform, in particular long-term care reform, are rarely partnered with specific, viable financing mechanisms that would adequately fund the reform vision. And finally, all too often, everyone's second best choice on the long-term care policy debates is to maintain the status quo.

Unlike other proposals, however, by embracing a public-private approach for catastrophic cost coverage, HEALTH successfully bridges the different reform visions of both ideological perspectives, while still being responsive to the very real long-term care coverage shortcomings burdening chronically ill Americans, families, and public budgets. It also suggests explicit and defensible financing sources for the policy, a policy that aims to fund important services and provide financial and health security. Moreover, precisely because there is broadly based acceptance that the current situation is unsustainable, stakeholders' second best choice can no longer be to do nothing.

No health reform initiative of any consequence is without failings. The long-term care initiative in this paper is no exception. HEALTH does not fill all the gaps or address all the obvious inequities of our currently flawed health care financing and delivery system. However, it offers real hope for long overdue progress in this area by merging conflicting ideological visions in a manner that addresses the multifaceted long-term care and retirement security challenges confronting this nation.

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17. *See, e.g.*, *Medicaid, Costs, and Health System Reform: Hearing On The Future of Medicaid: Strategies for Strengthening American's Vital Safety Net Before the S. Comm. on Finance*, 109th Cong. (2005) (statement of Jeanne M. Lambrew, Senior Fellow, Center for American Progress).