

**UNIVERSAL COVERAGE OF LONG-TERM CARE IN THE
UNITED STATES: CAN WE GET THERE FROM HERE?**

DOUGLAS WOLF AND NANCY FOLBRE
EDITORS

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CHAPTER 1

INTRODUCTION

DOUGLAS WOLF

Among the many problem areas addressed by social policy in the U.S., long-term care (LTC)—generally characterized as the provision of services, supports, and assistance to people limited in their ability to address their own everyday needs such as mobility, dressing, and personal hygiene—continues to be one of the least developed. The U.S. does spend billions on nursing home care, and some on in-home services, mainly through the Federal-state Medicaid program. A variety of other programs assist those who need care, and those who care for them. However, taken together these constitute, at best, a “fragmented” system (Harrington Meyer and Hausauer forthcoming).

Long term care has generally been relegated to the “policy wilderness” (Gleckman, chapter 3). There are several reasons for our collective failure to move long term care policy closer to the scope and coverage of universal and mandatory programs such as Social Security and Medicare. One may be an unconscious view that for most people, at least, there is no need for government programs to do what most people, for most of their lives, do for themselves: get dressed, clean up, use the bathroom, and otherwise go about the tasks of daily life. Many of these are not “skilled” tasks that require professional guidance, and when health or functional change makes those tasks difficult, we are content—and may even prefer—to get help from those closest to or best known by us: our family, friends, and neighbors. Many of us are already engaged in providing just this sort of assistance to others in our families, or are prepared to do so should the need arise—however unpleasant or unwelcome the prospect of that need arising may be (for an extended discussion of motivations to be a caregiver, see England, Folbre, and Leana 2012). Indeed, in Carol Levine’s characterization (chapter 2) of the world of long term care, family caregivers provide “... near-universal long term care coverage, with Medicaid as a ‘safety net’ with gaping holes.”

Yet in 2010 a rather surprising policy development occurred: on March 23, President Obama signed into law the Patient Protection and Affordable Care Act (PPACA), a legislative package that included, as a separate provision, the Community Living Assistance Service and Supports (or CLASS) Act, a bill that called for the creation of a Federally-operated voluntary long term care insurance program. While neither universal in coverage, nor comprehensive in its provision of benefits, the CLASS Act had the potential to greatly alter the long term care landscape. Although the larger and more sweeping PPACA contains some provisions that are expected to improve parts

of the long term care system, for example some changes to Medicaid (Kaiser Family Foundation 2010; Reinhard, Kassner and Houser 2011), the long term care community focused mainly on the CLASS Act (see, for example, several articles in *Public Policy & Aging Report's* Spring/Summer 2010 edition; Munnell and Hurwitz 2011; and Shugarman 2011).

October 2011 brought another unprecedented development in U.S. LTC policy: on the 14th, Department of Health and Human Services (DHHS) Secretary Kathleen Sebelius announced that "... despite [the Department's] best analytical efforts, [she did] not see a viable forward for CLASS implementation at this time."¹ As later chapters in this book (especially Gleckman's and Burman's chapters) discuss in more detail, the CLASS Act's legislatively mandated provisions—voluntary enrollment, coverage of disabled workers after a short vesting period, a minimum daily cash benefit, and a requirement that the plan be sustained entirely by the premiums charged—implied an unsustainably high premium. Those in the program's key intended target group, healthy working-age individuals facing the uncertain prospects of LTC needs later in life, would be unlikely to pay the resulting high premium, leading to a "death spiral" that would eventually shrink the program out of existence. As of mid-2012, the CLASS Act occupies an unusual place in the policy arena: it remains on the books, although vulnerable to repeal (Gleckman 2012); it almost certainly will not be revived; and, the prospects for new legislation that would pass the "viability" test are exceedingly remote.

This book was originally conceived as a vehicle for contrasting the distinctly flawed programmatic world of long term care in the contemporary U.S. to an ideal of "universal coverage" of long term care needs through some public program, and for laying out possible paths from the imperfect "here" to a superior "there." The overlapping chronologies of the CLASS legislation and the production of this book have created some unusual coincidences, and have necessitated a few mid-course corrections. The book's chapters were originally presented at a workshop held at Syracuse University in June, 2010. At the time that planning for the workshop began—in June, 2009—intense public and Congressional debate about the administration's key policy initiative—universal health insurance coverage, ultimately embodied in PPACA—was ongoing, with considerable doubt about whether the reform would pass, and with little attention paid to the role of long term care in the health insurance arena. The demise of the "public option" for expanding health insurance coverage had not yet occurred (Noah 2009). Nevertheless, the proposal that ultimately became the CLASS Act had been introduced, and had in fact been introduced several times during the preceding years, at the initiative of then-Senator

Edward Kennedy. At that point in the debate over universal health care, few thought that the CLASS legislation would pass (for a more detailed history of these policy initiatives see Gleckman's discussion in chapter 3). Yet by the time that the 2010 workshop was held, both PPACA and CLASS had been passed, substantially altering the point of departure for any dialogue about the pathway to universal coverage of long term care needs in the future. The original drafts of the following chapters addressed this policy terrain, while reflecting the many ways that CLASS was expected to change it.

However, before the book could be published, CLASS was "suspended," making irrelevant some of the book's contents. Accordingly, the issue of whether CLASS represented a step along a possible pathway towards universal coverage of LTC service needs has been supplanted by discussions of what has been learned from the experience of the CLASS Act. Although CLASS has not been repealed, we refer to it in the past tense.

The early chapters of this book focus on the contemporary long term care policy context in the U.S. Carol Levine, in chapter 2, identifies problems with the current long term care system from the perspective of the family caregiver. Levine's portrayal of the problematic features of the system focuses on the interactions between the family member and various actors in the formal care system: doctors, nurses, discharge planners, program officials, and so on. Conspicuously absent from Levine's list of complaints, however, is any complaint about being a caregiver; indeed, Levine assumes that family members will willingly continue to serve as the de facto "universal coverage" program for long term care services.

If we accept Levine's premise about the centrality of family caregiver services in the overall long term care system, then improvements to the system might seem to have less to do with broadening coverage of, or access to, public programs such as Medicaid, and more to do with care coordination and the involvement of family caregivers in lines of communication and in care decision making. Yet demographic trends, such as growing childlessness (U.S. Census 2010), high levels of divorce, which have been shown to undermine parent-child relationships especially for fathers (Amato, Rezac, and Booth 1995; Furstenberg, Hoffman, and Shrestha 1995; Lin 2008), and greater longevity, which increases care demands at the oldest ages (at which those needing care are less likely to have a living spouse), all suggest that the family's capacity to remain the centerpiece of our hodgepodge long term care system may be reduced in coming years; pressures for programmatic reform are likely to grow.

Chapter 3, by Howard Gleckman, reviews the legislative history of the CLASS Act, and highlights its novel features, but also explains many of its limitations and its built-in flaws. Chief among those flaws is the potential for adverse selection—i.e., the process whereby those in greatest need of the insured services are most likely to participate, while those least likely to need them opt out—because participation is voluntary rather than mandatory. A curious feature of CLASS is that many of its details were left to the discretion of the DHHS Secretary, including the very important detail of how the premiums for this voluntary long term care insurance program would be priced. Indeed, the apparent inability to determine a price consistent with the goals of adequate participation and self-sustaining funding was the main reason DHHS abandoned its efforts to implement the Act.

Robert Hudson places contemporary depictions of the long term care problem, and its policy solutions, into historical, institutional, and programmatic context, in chapter 4. He emphasizes the long-time “residual” status of long term care in the policy arena, and discusses the question whether CLASS would have represented an important step towards the institutionalization of a collective approach to the long term care problem.

We then shift attention to the long term care programs of other countries—in all cases, countries whose programs go well beyond those of the U.S. with respect to universality, comprehensiveness, and integration into a broader social safety net—with a view towards extracting lessons for the U.S. from those other countries’ experiences. Comparative studies of long term care policy have appeared with some regularity for many years (Brodsky Habib, and Mizrahi 2000, Daatland 2001, Rostgaard 2002, Glaser, Tomassini, and Grundy 2004), and U.S. readers scarcely need to be reminded that there are several countries with more generous and inclusive social policies than ours.

For three reasons, however, another look at comparative long term care policy seems in order: first, as these chapters point out, many European countries, as well as Japan, are to varying degrees farther along the trajectory of demographic change—population aging—than is the U.S., but those same demographic forces are underway in the U.S., and may create irresistible pressures for policy change. Second, while the countries discussed in these chapters have adopted long term care policies that are, in the aggregate, more generous and inclusive than their counterparts in the U.S., there are surprisingly many ways in which the details of policy are similar across countries. Finally, even if the U.S. is unlikely to adopt radically more comprehensive and universal policies, the behavioral responses of individuals in those other countries to the policy changes to which they have been exposed offer important lessons to the policy community in the U.S.

In chapter 5 David Bell and Alison Bowes discuss a policy innovation that many Americans, despite their familiarity with “free” roads and highways, or “free” public education (the quotation marks serving as a reminder that any publicly provided service must somehow be paid for) will find quite fanciful. Free (publicly financed) personal care services have been offered in Scotland since July 2002. Of course, in the absence of prices to serve as a rationing device, some other means of allocating services must be adopted, and Bell and Bowes acknowledge the importance of assessments, and the definitions those assessments embody, in deciding who gets the free services. Two likely responses to the introduction of free services come immediately to mind: we would expect family members to withdraw their supports in favor of the freely-provided public services, and we would expect a rapid and possibly catastrophic growth in public costs. But Bell and Bowes point out that while family members do seem to have reduced their provision of personal care, they have substituted other forms of care, and therefore almost certainly improved the overall quality of life of their older and needy family members as a consequence. Importantly, even in the presence of free government services, the family and the state remain “partners” in the provision of long term care. And, while there has indeed been a rapid growth in the number of recipients of free personal care services (since 2003, when the data series begins), that growth was accompanied by reduction in the numbers occupying expensive geriatric long stay beds, or supported in care homes (which may or may not provide on-site nursing services). Bell and Bowes conclude that overall, costs have been reduced, while efficiency has improved and more care recipients are receiving care in their preferred setting.

Svein Olav Daatland addresses the long term care policy regimes found in Europe, with particular emphasis on Scandinavia (chapter 6). These countries are widely known to have much more comprehensive social sectors than in the U.S. Yet even in Scandinavia, where an explicit goal of policy is to “... protect citizens’ autonomy vis-à-vis the family...”—a sentiment that would appear to have little appeal in the U.S.—the state and the family continue to act as “partners” in long term care. Daatland emphasizes the role of demographic change as a source of pressure to grow the welfare state. There is considerable irony in the discovery that several countries with a strong tradition of familism—for example Italy and Spain—are facing the most dramatic increases in population aging as a consequence of low birthrates. These countries offer comparatively little in the way of publicly funded long term care services, and may despite their familistic traditions experience increased pressure to develop a public presence in the provision of long term care. In contrast, Scandinavian countries, characterized by family-friendly policies, have higher birthrates but correspondingly less pressure to grow their elder care sectors.

In chapter 7, Mary Jo Gibson reviews and draws lessons for the U.S. from the experiences of two countries with recent and dramatic changes in their long term care policy: Germany and Japan. Noteworthy is the fact that Germany, after a protracted period of policy debate, adopted a dramatically new, yet explicitly partial, long term care policy, one intended to cover only a portion of the costs of long term care, whatever the setting in which it is provided. Moreover, Germany's new long term care insurance program makes explicit provision for the use of family members as caregivers. Eligible beneficiaries can choose between direct service receipt or a cash benefit—which can be used to pay family caregivers—equivalent to only about half the value of the in-home direct service package. Despite this large discount for those opting for family care, the cash option has been popular.

In contrast to Germany, Japan's newly adopted long term care program includes no cash benefit. This difference underscores the importance of context: Japanese feminists argued against the inclusion of a cash benefit, fearing that it would simply vanish into the household budget while women continued to serve as the principal source of care; the program ultimately adopted responded to a desire on the part of family caregivers for, as Gibson (citing Eto, 2001) puts it, "... liberation, not recognition." In contrast, in the U.S. cash payments to family caregivers have been advocated as a means to compensate the largely female family caregiver workforce, however minimally, for what by default is unpaid care that can render its providers economically vulnerable. Another important lesson for the U.S.—although "reminder" is possibly a better word for this—is that in neither Germany nor in Japan did it turn out that the original legislation, which in both cases ushered in dramatic policy changes, "get it right." In both cases, one or more rounds of less sweeping, more incremental, changes have been necessary to correct what have been revealed as flaws in the original programs, and to deal with changing features of the larger context in which policies must operate.

The final set of chapters assess the prospects for moving towards a truly universal—whether entirely public, or mixed private and public, as at present—long term care system for the U.S. Several issues identified in these chapters would have demanded attention whether or not the CLASS Act had passed, and surely demand attention given that it will not be implemented. Robyn Stone's chapter deals with the problem of staffing the paid workforce needs of a growing formal care sector (chapter 8). Encompassing both the institutional and the in-home care sectors, Stone describes the credentials and duties of 8 different professional categories of producers of long term care. The tasks carried out by the professionals in these different categories all have some sort of counterpart in the activities carried out by "informal"—i.e., family—

caregivers, illustrating the inadequacy of any attempt to view family caregivers as a homogeneous and unitary whole (and underscores a similar point made by Carol Levine in chapter 2). As Stone points out, impending demographic change will increase aggregate demand for paid care services; had CLASS gone forward, its infusion of more cash into the hands of those needing care would have only increased that demand. At the same time, there seems to be little on the horizon in the way of efforts to grow the supply of such workers. One avenue of improvement could be to increase the supply of immigrant laborers, itself a policy option with little support at present.

There seems to be little difficulty identifying what we *want*—better and more equitable access to the services presently in place, in the form of less restrictive Medicaid assets tests, for example, or more supports for family caregivers to reduce both emotional and financial hardship. We also know what we will *need*—more resources devoted to growing and raising the quality of the paid care workforce. More challenging is the problem of *financing*: improvements will entail either more taxes (for public programs) or greater private expenditures (on private insurance, to purchase the services that would otherwise be provided through public programs). These financing issues are the subject of chapters 9 (by Leonard Burman) and 10 (by David Stevenson, Marc A. Cohen, Brian Burwell and Eileen J. Tell).

Burman focuses on public finances and their role in a move towards universal long term care coverage. He uses economic analysis to show why thanks to the Medicaid program, a rational consumer has little to gain from buying private long term care insurance; the sub-rational person (probably a better approximation to the population of actual people) has even less reason to do so. In fact, under current policies—Medicaid’s eligibility criteria, in particular—the more likely one is to need long term care services, the less incentive one has to either save for it, or insure oneself against its costs. These disincentives are greatest for those in the middle of the income and wealth distributions. Burman’s preferred solution is to adopt a policy that achieves full pre-funding of long term care costs, and the policy proposals offered to achieve this situation rely on major changes in taxation (i.e., more taxes), or interventions in the private insurance industry (i.e., more regulation), or both; the recent experience with the political process that led to (and followed after) the passage of PPACA is not encouraging in either dimension. Given this reality, Burman suggests a number of incremental steps, starting from the initial step represented by CLASS itself.

Stevenson et al.’s chapter reminds us that the CLASS Act’s benefits were inadequate to cover the costs of care for those with more severe care needs, especially for care received in a nursing facility. This leaves a substantial scope for the role to be played

by private insurance, analogous to private “Medigap” insurance that covers acute health care costs not covered by Medicare. Their chapter includes a number of concrete suggestions for encouraging the expansion of private coverage in this way.

In the book’s final chapter, Nancy Folbre and Douglas Wolf draw together and expand on earlier chapters, discussing both the problems and the possibilities facing more comprehensive reform. A key theme of that chapter—indeed, a recurring theme throughout this book—is the importance of family care not only in the current “system” of long term care, but also in an imaginary world, one in which there is (in Folbre and Wolf’s words) “an equitable, efficient and universal system of publicly-funded long-term care insurance...” The CLASS Act, however successful it might have proven to be, left much room for the continued role of family care in the overall system of long term care, for two reasons. First, its cash benefit could have been used to pay family caregivers for the services they are otherwise provide without compensation. Second, and more important, due to the CLASS Act’s modest cash benefit, for many beneficiaries it would have been inadequate to purchase a sufficient volume of services, leaving a possibly large hole for family members to continue to fill.

Folbre and Wolf’s chapter, like those of Gleckman, Gibson, and Burman, includes a number of concrete suggestions intended to improve on, and extend the reach of, the CLASS Act. Some of these ideas represent incremental steps—for example, requiring Federal contractors to include CLASS among their fringe-benefit offerings. Others represent larger steps, such as the idea of allowing taxpayers to divert some of their tax liability into payment of CLASS premiums. However effective the various inducements might turn out to be, as long as the program remained voluntary they would leave us far short of universal coverage. Accordingly, Folbre and Wolf go farther, recognizing that even a fully pre-funded insurance program (as advocated by Burman) will leave many of society’s vulnerable members unprotected; the universal-coverage world for which they would have us reach recognizes, and will attempt to overcome, inequalities of access both within and between generations.

DHHS Secretary Sebelius’s October 2011 announcement suspending work on the implementation of CLASS was, for many observers, unsurprising. The Secretary had already acknowledged, during a February 2011 Senate hearing, that the Act was “totally unsustainable” as written; with 2 to 3 percent participation it would be “barely sustainable” and with 5 to 6 percent participation it would become “much more sustainable”.² Following her announcement, many commentators have pointed out that the problems CLASS was intended to help address will only worsen, and have reiterated their calls for various policy initiatives ranging from the modest (e.g., fixing

some of the technical provisions of CLASS so as to improve its sustainability) to sweeping (a mandatory program); see, for example, Van de Water (2011), Span (2011), Monheit (2011) or Gleckman (2012).

Although the CLASS Act proposed a modest program, it seemed important as a first step towards something more comprehensive, more universal, and therefore better able to meet those future care needs. Further aging of the population, itself an indicator of success in extending lives well past the ages once thought possible, will maintain pressures to set off on a path towards improved social policy towards long term care. Successful experiences in other countries, countries that find themselves further along that path, will encourage further progress towards a better policy future. The process should prove to be an interesting, if contentious, exercise in the evolution of policy.

Notes

¹ See "[Secretary Sebelius' Letter to Congress about CLASS](#)" (online document).

² See "[Sebelius: CLASS Act "Totally Unsustainable" As Written](#)" (internet posting).

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CHAPTER 2

LONG-TERM CARE AND LONG-TERM FAMILY CAREGIVERS: OUTDATED ASSUMPTIONS, FUTURE OPPORTUNITIES

CAROL LEVINE

I am having an identity crisis. When my husband Howard suffered a severe traumatic brain injury in 1990, I was his wife. Not a “good” wife, as I was repeatedly told by nurses and social workers at a rehab facility, but a “bad” wife who was unable to control her quadriplegic brain-damaged husband’s rages, refused to take him home without some assurance of help, and failed to take professionals’ advice to quit her job and spend down to make him eligible for Medicaid.

Five years later, after I had created a fragile, private-pay arrangement at home, I finally realized that I was not a bad wife but a beleaguered one dealing with a dysfunctional system. Without any orientation or guidance, I had been transported, like Alice through the looking glass, into the bewildering world of “custodial” or long-term care. In my discussions with various agents of bureaucracies, I gained a new appreciation for Humpty Dumpty’s maxim, “When I use a word, it means just what I choose it to mean—neither more nor less” (Carroll 1872). For example, a “two-person” transfer in rehab meant two nurses or aides had to be present to move my husband from bed to wheelchair. At home, however, only one person was needed for a two-person transfer. That would be me.

This chapter differs from the others in this volume in its blend of my personal experience as a caregiver and my professional experience as a health policy and medical ethics researcher, editor, and writer. From my perspective, this book’s question: “Universal Coverage of LTC in the U.S.: Can We Get There from Here?” has been answered. We already have near-universal long-term care coverage: it is family care, with Medicaid as a “safety net” with gaping holes. This chapter looks at a slightly different question: How can public policy best support long-term family care? Based on the realities of an aging population, financial shortfalls, and workforce shortages, all described in detail in other chapters, I assume that family care will continue to be at the heart of any form of universal or near-universal long-term care coverage. This dependence on families is rarely explicit in policy proposals for home- and community-based care, although it is surely implicit. More important, in my view, removing family care from the long-term care equation would not be good for older people, their families, or society. Families want to and will continue to provide care; but they should not be expected to do it alone.

“Health statistics represent people with the tears wiped off.” This statement, attributed to the British epidemiologist Sir Austin Bradford Hill, is particularly apt when applied to family caregivers. Sometimes the tears hidden in caregiver statistics are tears of grief, loss, and isolation; sometimes, though, they are tears of anger and frustration brought on by the indifference, lack of information, and even hostility they experience in their encounters with the health care and long-term care systems.

Family caregivers today are ill-served by entrenched health and long-term care systems developed in the 1970s and 1980s. The language, policies, and programs of these systems do not reflect the realities today’s caregivers face. There are new opportunities for change, but they require rethinking some basic policy assumptions and professional practices. This is culture change of a major magnitude.

This chapter first describes the family caregiving population today, which is large and diverse, and suggests some research limitations that have impeded a full understanding of the experience. Second, it looks at family caregiving through a policy lens. Efforts to control health care costs, as well as changes in medical practice and technology, have resulted in more responsibility and more complex tasks being offloaded to untrained and unprepared family caregivers. Yet family caregivers do not generally see themselves as part of the workforce. Finally, the current emphasis on reducing hospital readmissions has created an opportunity for bringing long-term and health care together through a belated recognition that safe and effective transitions in care settings depend in large part on prepared and supported family caregivers.

From Care to Supports and Services

In 1996, frustrated with my inability to navigate the shoals of long-term care in the “community” (an ill-defined concept in its own right), and perceiving an opportunity for research and advocacy, I changed the focus of my professional work from AIDS policy and ethics to the challenges facing families caring for aging or disabled relatives. I soon learned from the literature that I was not a wife but an “informal” or “spousal” caregiver, a research and policy designation that distinguished unpaid caregivers from paid professionals and aides. “Spousal” typically meant an older, unemployed or never-employed, always-on-call woman. Since “informal” clearly did not describe the demanding challenges and responsibilities I had taken on in addition to a full-time job, I opted for the alternate designation of “family caregiver.”

Now I find that after all those years (my husband passed away in 2007), I should have had a different title. I was not providing long-term care, as I thought, but long-term services and supports, now the preferred, albeit not universally accepted, terminology. Should I have been calling myself a “family long-term service and support provider”?

I understand the reasons behind this change as a way to establish the primacy of independence and self-management for (mostly) younger, competent disabled people who don't want "care" but do want control and prefer to keep their families out of their daily routines.

Many older adults also want and should have the power to direct the most intimate aspects of their lives. But the most vulnerable and most in need of assistance—my late husband, say, or an 85-year-old woman with dementia and multiple chronic conditions—need care, not control. Certainly services and supports are part of care but substituting this impersonal and bureaucratic language diminishes this primary human need.

In the widely accepted view that long-term care is personal care, medical care is seen as episodic, related to acute, treatable illness or trauma, and provided and controlled by doctors, nurses, other medical professionals, and insurance payers. Chronic medical care is part of long-term care except when it isn't. Medicare's definition is illustrative. "Long-term care is a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom (Medicare.gov 2010). Yet, this separation of medical from other kinds of care is not what most ordinary people think of as long-term care, especially for someone with multiple chronic conditions that require multiple daily medications, frequent doctor visits and tests, and other medical interventions. Humpty Dumpty strikes again.

Family Caregivers: The Big Picture

In one way or another, every article on long-term care has some statement like these: "Family members are far and away the principal providers of assistance to the long-term care population living in households" (Kaye, Harrington, and LaPlante 2010) or..."reliance on informal care remains very much the backbone of the U.S. system of long-term care for older Americans with chronic functional disabilities" (Doty 2010).

Yet the perception that Americans have abandoned their elderly relatives en masse remains entrenched in the public's mind and to some extent in uninformed policy makers' considerations as well. In a conversation with Ramraj Gautam after the meeting on which this book is based, I learned that he routinely asks his introductory gerontology class in the school of nursing at the University of Massachusetts-Lowell to estimate how many older Americans live in nursing homes. The initial estimates range as high as 80 percent. When he asks them to estimate the lowest percentage they

feel is reasonable, it is still around 25 percent. Comments on blogs about aging and family caregiving routinely decry families' supposed rush to put Grandma in a nursing home and forget about her. For example, one anonymous blogger wrote (October 8, 2008) to "The New Old Age," a *New York Times* blog, "North American Indians did not discard their aging family members like disposable products or no longer wanted pets." Another wrote: "We live in an age of barbarism towards the old."

Yet a relatively small percentage of older adults actually reside in nursing homes, and some of them provide high-quality care. According to 2009 estimates of the U.S. Census Bureau, 12.9 percent of the population, or 36.9 million people, are 65 years or older. That number is predicted to increase to 86.7 million, or 21 percent, by 2050. Currently, 1.5 million to 1.8 million people, or about 4 percent, live in nursing homes at any given time. The likelihood of spending some time in a nursing home increases with age.

Nursing home residents are typically the oldest old and also the frailest old. There has been an increase in the residents aged 31 to 64, from 10 percent in 2000 to 14.2 percent in 2010, largely due to cuts in state Medicaid payments for home attendants and mental illness in this population (Shapiro 2010). Two thirds are female with a median age of 82. Notably, 92.8 percent have mobility impairments, 75.8 percent cognitive impairments, and 37.2 percent sensory impairments (Kaye, Harrington, and LaPlante 2010). Long-stay nursing home occupancy has actually been declining, as states have tried to close beds and increase community services and as nursing home operators have marketed their short-term rehab services for financial reasons. A portion of the healthiest and wealthiest elderly population, estimated at 900,000, reside in assisted living facilities (National Center for Assisted Living 2012).

Even when their family members live in nursing home, many family caregivers are still actively involved. Although they do not provide as much hands-on care, they have important roles as advocates and care monitors. Because there are so many variables, measuring the frequency of contact between nursing home residents and their family and friends presents a methodological challenge (Port et al. 2003). One five-year longitudinal study found that the majority of caregivers maintained the frequency and length of their visits for extended periods of time (Yamamoto-Mitani, Aneshensel, and Levy-Storms 2002). Another study found that spouses visited more frequently, and that those who perceived that their social network respected and supported the choice to institutionalize their family member were more likely to visit (Gaugler, Zarit, and Pearlin 2003). Yamamoto-Mitani et al. (2002) concluded that "To a large extent, family visits to nursing home residents with dementia become established in the period immediately after relocation, which means that efforts to

enhance continued family involvement should commence at the time of admission” (p. S234). This is consistent with a report on family involvement which concluded that “[f]amily members are a crucial part of a team approach to resident and patient care... The intensely busy schedules of staff in long-term and post-acute facilities make it even more important to work collaboratively with family members” (Gerzon 2010: 41).

While public policy focuses on nursing homes, most older people live in their own homes or with family. They have not been abandoned. Those who need assistance receive all or most of the help they get from family members and may never need nursing home placement. Despite the oft-proclaimed wish to die at home, most people still die in hospitals.

Prevalence and characteristics of family caregivers

How many family caregivers are there? The estimates range widely, depending on the definition of caregiving, the population surveyed, and the methodology, for example, whether caregivers were identified by people with disabilities or by people who identified themselves as caregivers (Giovannetti and Wolff 2010). The most recent estimate—62.5 million—comes from the 2009 National Alliance on Caregiving/AARP telephone survey, which found that about 28.5 percent of the respondents reported being caregivers, similar to its 2004 survey results (National Alliance for Caregiving 2009). This total includes caregivers of people of all ages, including children with disabilities; about 43.5 million caregivers take care of someone over the age of 50. One third of these caregivers take care of two or more people. An earlier survey of children aged 8-18 estimated that 1.4 million minors were engaged in caregiving, often doing the same things adults do (Hunt, Levine, and Naiditch 2005). Other survey methods obtain different, generally lower results. Although somewhat outdated in terms of survey results, a side-by-side comparison of methodologies prepared by the Family Caregiver Alliance is a useful reference (caregiver.org 2001). This unpaid care is currently valued at \$375 billion a year (Houser and Gibson 2008), an increase from the \$196 billion estimated in 1999 in the first use of this methodology (Arno, Levine, and Memmott 1999).

The surveys agree that the majority (two-thirds) of family caregivers are women in their middle years taking care of older women. In the 2009 National Alliance on Caregiving survey, the average age of caregivers taking care of people of all ages was 48, and the average age of the care recipient was 61. In the same survey analysis of caregivers of people over the age of 50, the average age of the caregiver was 50, and the average care recipient was 77. But the composite making up the picture of an average caregiver should not conceal the picture’s diverse elements. Caregivers are

men as well as women, spouses and partners, adult children, minor children, friends and neighbors, people of all religious, economic, and ethnic backgrounds.

On average, family caregivers spend about 20 hours a week assisting their family member. Like the composite description, this average is made up of caregivers who spend eight to ten hours a week as well as those who have to be available all day, every day (and what is even harder, all night, every night). The big picture also includes caregivers whose responsibilities are fairly simple, such as shopping and making meals and just checking in, to complex medication management and operation of medical equipment like feeding tubes, ventilators, and IV infusions, or keeping a person with advanced dementia safe and comfortable.

Impact of caregiving on mental, physical, and financial health

Substantial research has documented that the stresses of caregiving take a toll emotionally, physically, and financially. Not all caregivers experience problems but the longer one is a caregiver, the more likely it is that there will be serious consequences. Some of the stress results from seeing the family member decline as well as the specific stresses of caregiving over time. I know of no time parameters for “long-term.” I meet caregivers who are desperate after a few months of caregiving and others who are doing well after five or more years. Most caregivers underestimate the length of time their family member will need care, and weeks turn into months and months into years. The average length of stay in a nursing home is about 2.4 years, suggesting that many years of care have likely preceded this stage. Many family caregivers agonize over the decision to place a family member in a nursing home and make it only when the situation become untenable at home or when the relative is hospitalized and is discharged to a nursing home.

Here are some representative statistics. Between 40 and 70 percent of family caregivers have clinically significant symptoms of depression (Zarit 2006). These symptoms increase as the care recipients’ condition declines. Placing the family member in a nursing home does not necessarily lessen anxiety and depression because of guilt, loss of control, and worries about the quality of care. Caregivers who provide 36 or more hours a week of care have the highest level of depression.

Many caregivers suffer from high levels of stress. The Evercare study of “Caregivers in Decline” found that “when caregivers talk about their worsened health, stress seems to be the most pervasive health problem in their lives...Caregivers believe that the stress takes physical form as some of the other health problems they report, including increased blood pressure, heart attack scares, arthritis flare-ups, acid reflux, headaches, and other conditions”(National Alliance for Caregiving 2006: 5). One of

the most common topics at caregiver workshops is “stress reduction,” which usually involves breathing exercises and meditation techniques. Caregivers feel angry, drained, guilty, helpless, and isolated. Most studies focus on stress related to the demands of caregiving, balancing different roles and responsibilities, or the dynamics of the relationship with the care recipient or other family members.

Unfortunately, few studies ask whether the difficulty of dealing with health care or social service professionals or the bureaucracies in which they work is a significant source of stress. One of the few studies to ask about this aspect of caregiving is the 2008 study of employed current and former caregivers conducted by the Work and Family Institute (Aumann et al. 2010). Over a third (36 percent) of former caregivers reported that professionals had made medical errors in the care of their relatives. In some cases the mistakes were so serious that the caregivers believed that they contributed to their relative’s death. There was no independent verification of these beliefs; what is important is the lack of trust in the health care system that they reveal. When asked about their top wishes for the way in which doctors, nurses, and other in the health care system could support family caregivers, they reported: “more frequent and better quality two-way communication; less overworked, more compassionate staff at medical and nursing facilities with the skills to listen and learn from the caregivers and the elders; and a more user-friendly easier-to-navigate and less costly health care system” (Aumann et al. 2010: 3).

Caregivers’ physical health suffers as well as their mental health. They are generally in worse health than their non-caregiving peers. They are at increased risk of heart disease, stroke, and dementia. Immune system deficiencies have been well documented; if a caregiver actually finds time to get a flu shot (as frequently advised), its protection is not as strong because of the lowered immune response. Joint and muscle problems are common, often exacerbated by the lifting, moving, and pushing needed to take care of someone who has mobility problems or is in a wheelchair. Sleep deprivation is very common. Increased mortality is the ultimate caregiver sacrifice. In one study older caregivers who reported strain were 63 percent more likely to die than their noncaregiving peers (Schulz and Beach 1999).

Most caregivers do not like to dwell on the financial sacrifices they make or even to tally them. Only 15 percent of the respondents to the 2009 National Alliance for Caregiving reported serious financial hardship, with the highest percentage (22 percent) among the lowest income group. Perhaps it seems wrong to worry about money when your family member needs your help. But the financial impact of caregiving does take a toll. Out-of-pocket expenses can be a constant drain, especially travel for long-distance caregivers. Expenditures for all the things not covered by

Medicare and commercial insurance—copays, disposable items, extra help, assistive devices, home modifications, or a customized wheelchair—add up. In an era of widespread unemployment, when two incomes are needed to meet basic family needs, this financial drain can be severe.

If caregivers do not think a lot about the short-term drain on their finances, they are largely oblivious to the long-term impact on their retirement and their own long-term care needs. People in their 40s and 50s often cannot or will not think about saving for their own future needs when their parents' and children's immediate needs are more pressing (see Chapter 10 on long-term care insurance).

Half of all caregivers are employed full- or part-time. In the 2009 National Alliance on Caregiving/AARP study, 70 percent of workers reported that caregiving had an impact on employment. Two thirds went to their jobs late, left early, or took time off. Twenty percent took a leave of absence. Some caregivers turn down promotions or opportunities for enhancing their skills because it will interfere with caregiving. Some large employers have established flexible policies for family caregivers, but most have not. Some businesses are totally supportive or generally tolerant. Others do not make any adjustments for caregivers. For their part caregiving employees are reluctant to acknowledge their dual responsibilities in their workplaces lest this be seen as shirking their workload and perhaps jeopardizing their job.

The Families and Work Institute's study of employed caregivers adds depth to this picture (Aumann et al. 2010). The study found that 42 percent of individuals in the workforce—an estimated 56 million--had provided elder care over the past five years. Unlike other surveys, this study found that employed women and men provide care in roughly equal numbers. However, women are more likely (44 percent) than men (38 percent) to provide care on a regular basis rather than intermittently. Despite their caregiving responsibilities, family caregivers work at their jobs as many hours on average (45 hours) as those who are not caregivers. Family caregivers were asked for their top wishes for the way in which workplaces could better support them. Their answers were: "greater flexibility, more options for managing time; time off for elder care, especially time off without having to use up vacation time; and more understanding of their situation from management" (Aumann et al. 2010: 3).

Despite this litany of problems, it is important to remember that not all caregivers are equally vulnerable. Older caregivers are particularly at risk, as are poor caregivers and those with chronic health problems. Caregivers with language or health literacy difficulties have a hard time navigating the various systems. Caregivers taking care of more than one person are obviously doubly challenged. But all caregivers may be at risk in different ways, such as financially and emotionally.

For many caregivers, there are rewards as well as stresses and strains. This is an area that is less studied than the problems caregivers face, and a fertile ground for research. Is it entirely a matter of financial resources and family support, prior relationships with the older person, and perhaps personal temperament? Or are there ways to encourage the rewards while lessening the strains? Many caregivers learn new skills. They may enjoy the extended time spent with their family member, and gain a new perspective on that person's life. Some feel satisfaction, a sense of a duty fulfilled, even if they do not have a particularly loving relationship with their family member. Prayer is the most commonly cited coping technique, and many caregivers report spiritual growth.

Interestingly, one of the findings of the Families and Work Institute study was that only 14 percent of current caregivers reported that caregiving has improved their relationship with the person they care for. That percentage rose dramatically—to 60 percent—when caregivers whose relative had died were interviewed. The authors suggest that “Quite possibly, caregivers do not have enough time or mental resources to reflect on the caregiving experience and the relationship with the care recipient until after [it] is over” (Aumann et al. 2010, underline in original). It is hard to search for meaning and transcendence in an earthquake when the walls are shaking around you. Bereavement services should allow for individuals to search for their own meaning, a healing process that cannot be rushed.

Research Gaps and the Limitations of ADLs and IADLs

This is only the barest summary of what is known about family caregivers. Despite the numerous studies conducted in the past forty years, there are serious gaps in knowledge. More studies have looked at certain groups, for example, caregivers of people with Alzheimer's disease or other dementias, more than others, such as people with disabling arthritis or diabetes. In contrast, children and young adults who do the same tasks as older caregivers are hardly studied at all, at least in the U.S., and are rarely even considered to be caregivers. There is a considerable body of research from the UK, where all carers (as they are called), including children, are counted in the census (Aldridge and Becker 2003; Dearden and Becker 2004). The tyranny of the average—the middle-aged woman caring for her elderly mother—dominates most media portrayals and other discussions as well.

Another problem is the nearly universal reliance on the ADL-IADL scheme to describe what caregivers do. These measures date from the 1960s; the original ADLs were developed to measure how well older adults were recovering from hip fractures and could go home. IADLs were added to take account of the individual's ability to manage at home. As Susan Reinhard points out in her analysis of these measures,

“When family caregiver research began in earnest in the 1980s, researchers applied the ADL and IADL scales to caregivers, on the assumption that what caregivers provided was the mirror image of the functional limitations of the care recipient. While this approach has intuitive appeal, it fails to consider many aspects of caregiving” (Reinhard 2004: 37). Furthermore, she asserts that there is so much measurement error in ADLs even for their intended purpose that using them as a proxy measure for caregiving was flawed from the outset. Nevertheless, the use of ADL-IADL measures in public policy began in 1982, with the first informal caregiver supplement to the National Long-Term Care Survey of Medicare Beneficiaries, and has continued ever since. This inadequate structure is the basis for policy decisions and eligibility for publicly funded services and many long-term care insurance benefits.

Consistent with the definition of long-term care as personal care, neither ADLs nor IADLs pay much attention to the medical tasks (medication management, wound care, symptom monitoring, communication with medical professionals, and the like) that typically are family caregiver responsibilities. The only national survey that specifically identified medical tasks found that 54 percent of the respondents reported that the person they cared for was hospitalized overnight in the year prior to the interview, and 74 percent said that this person had a serious or chronic illness. The survey included several measures that are not typically asked: wound care, pumps and machines at the bedside, and medication administration. Over 40 percent performed at least one of these tasks, and 26 percent helped to give five or more medications. Most received little or no training from professionals (Donelan et al. 2002).

Among its several flaws, the ADL-IADL scheme fails to take account of the variations in degree of difficulty. Help in bathing can mean anything from making sure that the water isn't too hot or cold and that the towels are easily reached to managing to get a demented patient into the shower when she does not remember what a shower is and is sure the caregiver intends to drown her. Nor do these measures even begin to acknowledge the skills required to manage the insurance and financial or legal needs of the care recipient.

Steven Albert says that the ADL-IADL measures “will always be an imperfect guide” to describe caregiving because they are “both too gross and too narrow.” They are too gross, he says, because they “do not specify fully what it means to help with ADLs and IADLs” and too narrow in that they “do not cover the full range of tasks caregivers typically do” (Albert 2004: 99). He goes on to propose a new formulation that would incorporate four features of the context in which caregiving takes place:

- Timing—whether care is required rarely, frequently but in predictable ways, or frequently in unpredictable, unexpected ways.
- Caregiving proximity—whether it is enough that the caregiver is in the house while someone eats a meal or bathes or must the caregiver be in the same room standing by or providing hands-on help.
- Effort—the level of effort required, from coaxing to complex guidance and control.
- Participation of the care receiver—whether it is active, passive, or resistant.

A new generation of research is needed to develop new measures, new approaches, and new ways to describe the varied and complex roles caregivers play.

We also need more information on how the care receiver perceives the care provided by family members, particularly personal care and medical tasks. Well-meaning professionals and friends say, “What’s the big deal? Your mother changed your diapers. You can do the same for her.” But what does Mother think about this? Does she accept this as a quid pro quo for services performed in a totally different situation fifty years ago or does she feel humiliated and angry? Do care recipients trust the family caregiver to monitor the machinery and give the right pills when their experience has been that this person is irresponsible in other aspects of his or her life? Does accepting care inevitably mean loss of independence? The respondents in the Work and Family Institute survey named as their top challenge in their relationship with their family member “striking a balance between dependence and independence, getting the elderly relative to accept help and embrace a positive or cooperative attitude” (Aumann et al. 2010). Culture plays a large role in this role shift, and attitudes may vary considerably about what is proper behavior between a father and daughter, for example.

Through the Looking Glass: LTC Policies and Family Caregivers

Long-term care and health care systems have been separated by their cultures, disciplines, funding, and power. Anything that looks like a “medical model” is often distrusted by social service staff; anything that looks like “social care” is similarly handed off by medical staff. The family caregiver is left to negotiate the boundaries. Furthermore, advocacy for family caregivers has largely been part of the less-powerful, less well-funded aging and social service network. Medical champions of family caregivers are rare, although their numbers are increasing; often physicians and nurses see the family as “intrusive,” “dysfunctional,” and a hindrance to doing their jobs (Levine and Zuckerman 1999).

Policy makers have been ambivalent about family caregivers, fearing that public funding will replace free family care, although multiple studies have shown that it does not. They also worry that without some support family caregivers will not be able to sustain this role and will place their relative in a nursing home at even greater public expense. They have generally resolved their ambivalence by extolling family caregivers in public, supporting some measures designed primarily to control costs, and failing to fund adequately significant initiatives that do not promise an economic payoff.

The artificial separation of long-term care from medical care has long historical roots but was given its current incarnation in 1965 with the advent of Medicare, which was designed to pay for the acute care needs of individuals over 65. Medicaid was added at the last minute to replace the state-run Old Age Assistance models that in turn had replaced poorhouses and indoor relief. As David Barton Smith and Zhanlian Feng put it, “Long-term care [in the period 1910-1930] was, in essence, the last holdover of the Elizabethan poor-law approach.” They observe that Medicaid emerged as the default payer for long-term care, partly because of its late addition to the Medicare legislation and “a lack of attention to long-term care in the overall reform package, and the historical tradition of states’ assuming the responsibility of welfare programs. The ultimate effect was to relegate long-term care to a welfare system largely segregated from the mainstream of medical services” (Smith and Feng 2010) and, one might add, still bearing a taint of its historical stigma.

Medicare is a form of social insurance, a program to which employees contribute in anticipation of benefits when they reach 65; Medicaid is a social welfare, means-tested system. We have been living with both the benefits and unanticipated consequences of these distinctions ever since. Because Medicare does not pay for long-term care, long-term care policies and programs are essentially shaped by Medicaid, or for those dually eligible, by Medicaid and Medicare.

Family caregiver support services generally follow the services to which their family member is eligible. There are a few federal programs with eligibility not based on Medicaid, but these are inadequately funded. The National Family Caregiver Support Program (NFCSP) was established in 2000 under Title III E of the Older Americans Act. It is administered by the U.S. Office of Aging and provides grants to states, which disburse funds to local Area Agencies on Aging. The NFCSP provides information and referral, counseling, respite, and other services. Its budget in fiscal year 2008 was \$153.4 million, including set-asides for Native Americans and grandparents caring for grandchildren (Administration on Aging 2010). The Lifespan Respite Program (PL 109-442) was enacted in 2006 but funded only in 2009, with an

initial \$2.5 million to be awarded to states through a competitive grants process (Family Caregiver Alliance 2010).

Using Medicaid and their own resources, states have developed their own programs in the effort to “rebalance” services from institution to community. A review of home- and community-based services across the states found that there are five major revenue streams: Medicaid waivers, programs and grants funded by the Centers for Medicare and Medicaid Services, state-funded programs, Medicaid State Plans, and Title III of the Older Americans Act (Rose et al. 2010). While the many variations across states can be seen as tailoring programs to local needs, Terence Ng and colleagues assert that:

“Home and community-based services programs often have different administrative structures, financial eligibility criteria, screening and assessment procedures, provider recruitment and management, reimbursement structures, and quality oversight procedures. The many state home- and community-based services programs are administratively costly and confusing to consumers [including family caregivers] and providers” (Ng, Harrington, and Kitchener 2010: 26).

A listing of programs does not tell much about whether the services are actually available and their quality. Moreover, these programs have waiting lists and are particularly vulnerable to state budget cuts (Leland 2010).

Many services available to family caregivers are provided by nonprofit organizations, dedicated to specific diseases or communities. Finding appropriate services, particularly for a long-term family caregiver whose family member is not eligible for Medicaid, remains a challenging and frequently unsuccessful task.

Caregivers as Part of the Workforce

In its 2008 report *Retooling for an Aging America: Building the Health Care Workforce*, the Institute of Medicine called for a new perspective on family caregivers: “The definition of the health care workforce must be expanded to include everyone involved in a patient’s care: health care professionals, direct-care workers, informal caregivers, and patients themselves. All of these individuals must have the essential data, knowledge, and tools to provide high-quality care (Institute of Medicine 2008: 1). However, health care professionals do not see family caregivers as part of their workforce, nor do family caregivers see themselves in that role. Often they do not even see themselves as caregivers, but as spouses, daughters, sons, or friends. Organizing these disparate individuals with little in common except their caregiving role is hard enough; gaining enough political power to counter entrenched economic and professional interests is even harder. Only when there is a compelling

case—such as the caregivers of “Wounded Warriors” (service personnel injured in Iraq and Afghanistan)—does caregiver advocacy rise above political and economic barriers (see <http://www.woundedwarriorproject.org/>).

One policy initiative does see family caregivers as part of the workforce and even pays them. This is consumer- or participant-directed home care. The most well-known program, Cash and Counseling, has been introduced in twelve states beyond the original pilot projects in Florida, Arkansas, and New Jersey. These programs are intended to give people receiving Medicaid personal care services more control over their care by allowing them to use a monthly budget to hire and pay their own workers, including family members and friends (Simon-Rusinowitz et al. 2010b). Another impetus has been the difficulty of finding direct-care workers, particularly in rural areas.

A panel of experts in long-term care recently recommended an expansion of these programs as a way to recruit and retain family caregivers. The panel noted that this approach benefits family caregivers as well as consumers because it “also provides family caregivers with much needed financial compensation, especially when their earnings in the paid workforce are diminished because of caregiving responsibilities or there are financial expenditures related to the care recipient’s needs” (Noelker et al. 2010: 22).

Similarly, a review of Cash and Counseling programs suggests that family caregivers “could be targeted for recruitment as professional caregivers and that family caregiving has the potential to increase significantly the direct care workforce” (Simon-Rusinowitz et al. 2010a). Some former family caregivers do go on to paid jobs as home health aides. However, it is doubtful that former family caregivers make up a large pool of potential direct care workers. As some members of the expert panel on long-term care pointed out, “former caregivers are often burned out and, if they are looking for employment, are likely to be looking for more lucrative opportunities” (Noelker et al. 2010). At a meeting a few years ago I heard a well-known female physician offer her solution to the need for caregiving workers: “Just pay all these working women to stay home!” No one dared to ask her whether she included herself in that group.

Respondents to the 2009 National Alliance for Caregiving/AARP survey identified tax credits and vouchers by which their relative would pay them a minimum wage for some of the hours of care they provide (the Cash and Counseling model) as top policy preferences. None of the survey choices was explained so it is not clear that the respondents understood the difference between tax refunds and tax credits, which would be subject to specific requirements. Nor was it clear that for a family caregiver

to be paid, the relative would have to be on Medicaid and that this arrangement would be in lieu of agency help, not a supplement to it. Nor would the payment come with benefits like health insurance. Clearly, money was important to these respondents, even though only 15 percent reported financial hardship. The third most desired option was respite services; other choices were: assessment of their capabilities and needs with referrals to services, partially paid leaves of absence, and outside transportation services.

DRGs and Cost Containment

Since their inception, Medicare and Medicaid have gone through cycles of expansion and retrenchment. Prospective payment in the form of Diagnosis-Related Groups (DRGs), introduced in hospitals in 1983, was the first major cost-containment measure. Instead of paying hospitals “reasonable costs” for treating Medicare and Medicaid patients, which gave hospitals and physicians control over spending, prospective payment sets predetermined payment rates based on diagnosis. In the DRG system a patient who can be discharged home before the standard number of days for that diagnosis is an economic benefit to the hospital, just as the longer-stay patient results in a financial burden. Whether patients have been discharged “sicker,” there is no doubt that they have been discharged “quicker.”

Even patients with complex illnesses requiring technological support like ventilators, IV infusions, and total parenteral nutrition can be sent home with equipment and a modicum of formal home care support. As hospital length of stay decreased under DRGs, home care agencies grew rapidly until the Balanced Budget Act of 1997 reduced their ranks and Congress introduced prospective payment systems for home care and nursing homes. The medical technology industry grew as well, meeting the demand for high-tech equipment for home use. The pharmaceutical industry flooded the market and television screens with expensive medications for chronic conditions, many with benefits but also risks. Families provided the bulk of care, as they always had, but now it was not just to the frail older person who needed a little help managing around the house, but a patient with hospital-level care needs (Arras 1995). This trend is not limited to the U.S.; Australian authors have called it the “invisible contract” with family members (Dow and MacDonald 2007).

Starting with DRGs but growing in fervor in the past decade, cost-containment has been the mantra of policy makers, providers, and the public. Yet the perfect storm that took medical care out of hospitals and professionals and put it into the home and the hands of untrained family caregivers is still raging. With rising insurance deductibles and copays, home care and rehab service limitations, and other cost-shifting practices,

families are left not only to provide more demanding care but also to pay for a greater percentage of it.

Transitions in Care: The New Frontier for Family Caregivers

The high-tech/low-tech, social/medical distinctions that have governed long-term care for the past fifty years are outdated. The reality that medical and long-term care is part of a spectrum of individual needs is a truism that has yet to be incorporated into policy and practice. As Robyn Stone points out, “The boundaries among primary, acute, and long-term have been blurred. Instead of concentrating on acute care in hospitals as before, our health system is increasingly devoted to chronic care by various providers in various settings” (Stone 2000: 2). The frequent moves from skilled nursing facilities to hospitals and back again has been called a “revolving door” by Vincent Mor and colleagues. They found that a quarter of Medicare beneficiaries discharged from a hospital to a SNF was readmitted to the hospital within 30 days at an annual cost of \$4 billion (Mor et al. 2010).

Some of the reasons behind this trend toward more diversity in postacute care are financial. Between 1999 and 2007 Medicare postacute spending grew more than the number of new users. Nursing homes have expanded their short-term rehabilitation programs, preferring the higher Medicare reimbursement for postacute services than Medicaid’s reimbursement for long-term care. Ng and colleagues assert that “Although Medicare postacute and Medicaid long-term care services are intricately related, they are poorly coordinated and have competing incentives. Medicare focuses on reducing hospital and postacute use and costs, resulting in shifts to the Medicaid long-term care program. That program, in turn, has little incentive to reduce Medicare hospital and emergency room use (Ng et. al. 2010: 27-28). Caught in the middle is the family caregiver, whose family member is moved from one setting to another because financial incentives may compete with good patient care and patient and family preferences.

The moves to and from these different settings—each with different staff, rules, culture, and expectations of patient and family caregiver—is the new normal in health care. Transitions in care settings can occur within the hospital from ER to ICU to regular floor, from hospital to home or to short-term rehabilitation program in a skilled nursing facility or inpatient rehab hospital, from rehab to home or to a long-stay unit in the same or different nursing home, and from the opening to closing a home care case. Often these transitions are abrupt and inadequately planned. As Mor and colleagues point out, “Especially in an elderly population, cycling into and out of hospitals can be emotionally upsetting and can increase the likelihood of medical errors related to care coordination” (Mor et al. 2010: 57). Coleman and colleagues

studied the patterns of post-hospital care transitions and found 46 distinct types of care patterns experienced by Medicare patients over a 30-day period (Coleman et al. 2004). Between 13.4 and 25 percent of these transitions were described as “complicated,” i.e., the patient did not go directly home but moved once, twice, or three times between settings (8.1 percent died with the study period). A systematic review of studies of the determinants of preventable hospital readmissions found significant variation in index conditions, readmitting conditions, timeframe, and terminology (Vest et al. 2010).

Given this complexity, there is no typical pattern of transitions. But the following hypothetical example, based on Coleman’s work and the Institute for Healthcare Improvement’s list of typical failures in transitions (Institute for Healthcare Improvement 2009) brings this profusion of factors to a concrete level. This is neither a worst-case nor a best-case scenario; it is simply a common-enough scenario (for a geriatrician’s view of a multiple-transition case, see Gillick 2010).

Mrs. Jones, an 81-year-old widow who lives alone and manages fairly independently, although recently she has begun to have memory lapses. Her daughter, Louise, lives nearby and helps her mother manage her medications for her heart condition and hypertension and pays her bills. One day on her way to the store Mrs. Jones falls and breaks her hip. She also hits her head on the sidewalk and is confused and disoriented. A passerby calls 911, and an ambulance takes her to the nearest Emergency Department (not the hospital where her doctor has admitting privileges). She is admitted to the hospital and has surgery to repair her hip. She spends several days in the ICU where she develops delirium and is given a psychotropic drug before being moved to the regular floor. All this time Louise has been standing by, getting bits of information from different doctors but without a clear understanding of her mother’s condition or what is going to happen next. Mrs. Jones is recovering reasonably well from surgery but her confusion and disorientation persist.

After only a day on the hospital floor, Louise is told on Friday morning that her mother is being transferred that afternoon to a nursing home for rehab. Louise protests that she wasn’t consulted on this move and does not want her mother to go to a nursing home. She is told (incorrectly) that if she does not accept this transfer, she will have to pay for the additional hospital care. No one explains her right to appeal. Mrs. Jones is transported again by ambulance to a nursing home. By then it is late evening and the nursing home is short-staffed and not ready to receive a new patient. No medications have been sent with Mrs. Jones, although she needs regular doses of pain and heart medications. The medication list, when it does arrive, does not contain all the changes made in the hospital.

After a weekend when nothing happens, Mrs. Jones begins therapy on Monday. She complains of dizziness and nausea, which turn out to be related to the psychotropic drug. After a week she develops an infection near the surgical site and is sent back to the ED and then readmitted to the hospital. Louise finds out about the transfer only when she goes to visit her mother at the nursing home. After the infection is treated with IV antibiotics (which might have been done in the nursing home), she is discharged, this time to a different nursing home because there is no bed available at the first one, and Louise declined to pay for a bed hold. After two weeks of therapy, Mrs. Jones has reached a plateau and is not improving. Louise is told, again incorrectly “Medicare won’t pay” (Levine 2010). Her mother is sent home with a referral for home care services, which Medicare will cover in part. Home care services consist of a weekly nurse visit and a physical therapist twice a week. A home health aide comes three days a week for four hours a day. Louise takes time off from her job because her mother cannot be left alone.

In three weeks, the home care services end because Mrs. Jones no longer needs a skilled service. There are two possible future scenarios: Mrs. Jones has recovered well enough to resume her life, more or less as before, with perhaps a little more help from Louise in terms of shopping and transportation. Or, the whole cycle may be repeated, with more falls and hospitalizations, leading to further cognitive and physical decline. After one or more downward cycles, Louise will realize that her mother cannot live independently anymore, nor can she devote her full-time efforts to her care. So Mrs. Jones will enter the long-term care system through admission to a nursing home in worse shape than she was before all the interventions designed to help her. Her private resources soon run out, and she becomes eligible for Medicaid. The first fall was the precipitating event, but the subsequent revolving door was a major factor in her decline.

Health care reform has emphasized the importance of reducing avoidable rehospitalizations as a cost-containment measure. Even before the Patient Protection and Affordable Care Act was passed in 2010, with provisions to penalize providers with high readmission rates, efforts were underway to counter this trend. The June 2008 MedPAC Report to Congress recommended that “to encourage providers to collaborate and better coordinate care, the Congress should direct the Secretary to reduce payments to hospitals with relatively high readmission rates for select conditions and also allow shared accountability between physicians and hospitals” (MedPAC 2008: 100).

This directive was given a substantial push by the publication in April 2009 of a study that found that one in five Medicare beneficiaries was readmitted to the hospital

within 30 days at a national cost of \$17 billion a year. Half of the readmitted patients had no contact with a physician after discharge (Jencks, Williams, and Coleman 2009). The Centers for Medicare and Medicaid Services (CMS) are currently writing regulations to determine what counts as an avoidable rehospitalization; states also are establishing their own standards for Medicaid. It is not just rehospitalizations that are the problem; about 10 percent of the nearly 40 million initial hospitalizations in 2008 were potentially preventable. Patients aged 65 and older accounted for 60 percent of these hospitalizations, which were primarily for conditions such as diabetes, dehydration, heart conditions, and infections (Stranges and Stocks 2010).

Improving transitions in care has now moved to the top of health care providers' agendas. Several programs have been developed to achieve this goal; most focus on assessing patients at risk of rehospitalization, providing education about self-management, providing some care coordination after discharge. Only a few explicitly recognize the role of family caregivers (Levine et al. 2010). The United Hospital Fund's 15-month Transitions in Care—Quality Improvement Collaborative (TC-QuIC) is unique in several ways: first, its 28 participant teams from hospitals, nursing homes, and home care agencies work in partnerships across settings, whereas most transition programs focus on hospital to home. Second, recognizing the pivotal role of family caregivers in transitions, it places them at the center of teams' activities. Finally, its goal is to have good transition practices become routine for all staff, not the sole province of a specially hired person. Different aspects of the transition may be managed by different people but they should all be aware of and responsive to the family caregivers' needs in the process. There is no specific goal to reduce rehospitalizations by a certain percentage because so many other elements are involved, although many teams are monitoring this trend.

The teams use elements of the United Hospital Fund's Next Step in Care materials on its website (www.nextstepincare.org), as well as other tools. The methodology is the basic Model for Improvement popularized by the Institute for Healthcare Improvement. TC-QuIC's aims are: to identify and assess the needs of the family caregiver; to integrate the family caregiver into the care plan through processes of medication reconciliation and management and discussion of discharge planning options; to improve the handoff on the day of discharge; and to close the loop with the receiving agency and family caregiver.

Launched in March 2010, TC-QuIC is still a work in progress. Some interesting points have emerged, however, during monthly reports, biweekly collaborative calls and webinars, as well as coaching sessions and onsite visits. First, it is clear that organizations that routinely share patients have never collaborated in a systematic way

to improve transitions. Meeting their counterparts and “walking in their shoes” is something staff see as a major benefit. Second, staff find that talking to family caregivers and assessing their needs is providing important information and insights. One hospital team reported delaying an unsafe discharge because they learned that the elderly caregiver could not manage the care. Third, they are finding that the distinction between health care and long-term care breaks down in practice. One social worker at a rehab facility reported that staff felt a transition had gone smoothly until they learned that the family caregiver had no idea how to get her disabled father into a taxicab when leaving the facility. That essential skill had not been part of the clinical teaching. And a home care nurse found that a husband who had confidently asserted in the hospital that he had no worries about taking care of his wife at home was lost when it came to ordinary household chores like operating a clothes dryer. Simple things, to be sure, but for a caregiver they make the difference between coping and not coping, and for a patient the difference between a successful transition and a return to a facility.

Transitional care initiatives are an important step in closing the gaps created by a fragmented system and bridging the worlds of medical and long-term care. To succeed, however, these initiatives must include family caregivers in designing and implementing change.

Future Directions

Advocates for family caregivers have claimed that health reform will bring many benefits to family caregivers (caregiver.org 2010). Nevertheless, very little help will be available in the immediate future. Many of the programs they cite are pilot projects (Independence at Home Medical Practice and Community Care Transitions Program) or still untried (Accountable Care Organizations). Some adjustments to Medicaid do offer benefits to family caregivers, such as the provision that protects recipients of Medicaid home and community-based services from spousal impoverishment on an equal basis with institutionalized spouses; this provision begins in 2014 and lasts for five years.

From a more skeptical viewpoint, always a prudent place to stand, much depends on how the pilot projects and financial reforms are implemented and whether they involve family caregivers in a meaningful way. To ensure that this occurs, program development and pay-for-performance and bundling schemes, as well as care coordination requirements, should include attention to patient and family caregivers’ needs (Levine, Coleman, and Naylor 2010). The development of a strong cadre of well-trained direct care workers, who could be paid through various insurance schemes, is essential.

More training is needed and not just for family caregivers. The ability to work in a collaborative way with family caregivers should be a core competency for all health care professionals, and it is not now widely taught or mentored. The experience and techniques of skilled physicians, nurses, social workers, and therapists should be used to help their colleagues learn how to communicate, educate, and train family caregivers.

As already noted, we need better research and survey tools that capture the full experience and needs of family caregivers. We also need dissemination of already existing tools like the Centers for Disease Control's optional Caregiver Module of the Behavioral Risk Factor Surveillance System. Important information is now being collected but is rarely available beyond the state offices that conduct the surveys.

Outside the direct health care and social service realm, public policy can do much more to encourage employers to develop caregiver-friendly policies and programs. Creating flexible work arrangements and openness in the workplace about caregiver responsibilities has potential benefits to employers as well as caregivers. Full implementation of the Equal Employment Opportunity Commission's (EEOC) guide to preventing discrimination against employed caregivers would be helpful (U.S. EEOC 2009).

Finally, we need better ways to help caregivers coalesce into a strong and united movement. Family caregivers generally have not been successful advocates for themselves, though they may be vigorous proponents for research for their family member's condition or for better care. Overwhelmed with the tasks of caregiving and often failing to see the policy connections to their situation, they have not been effective lobbyists or organizers. They may tell their powerful stories to legislators, but without a policy initiative they want legislators to sponsor or support. There have been exceptions, of course: advocates for people with Alzheimer's disease or other dementias, returning service men and women, and those who marshaled support for the Lifespan Respite Act. The National Partnership for Women and Families, in its Campaign for Better Care, is attempting to rally supporters for comprehensive change. Its efforts so far have focused on the various programs in the health care reform legislation.

Building a national movement to bring long-term and medical care into a coherent whole and meet the diverse needs of individuals and their family caregivers will take time and a strong political champion. Baroness Jill Pitkeathly, a former social worker and now a lifetime peer in the House of Lords, played this role in the U.K., bringing carers onto the national agenda in a way that has not yet been accomplished in the U.S. despite the tireless efforts of many advocates.

Tentative steps have been taken to break down the silos, but they were built to last and do not give way easily. As anyone who has survived a construction project knows, building a sound structure takes time and incremental, carefully calibrated steps.

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CHAPTER 3

THE RISE AND FALL OF THE CLASS ACT: WHAT LESSONS CAN WE LEARN?

HOWARD GLECKMAN

The Patient Protection and Affordable Care Act (ACA) of 2010 (HR 3590/ PL 111-148)¹ included the Community Living Assistance Service and Supports (CLASS) Act, a voluntary national long-term care insurance program. The CLASS Act had the potential to begin to shift long-term care financing in the U.S. from a structure that relies heavily on the means-tested Medicaid program to a more financially sustainable and consumer-oriented insurance-based system. However, as designed, CLASS attempted to accomplish two disparate goals: It was both a benefit program for working people who already have a disability and voluntary insurance for those seeking to hedge against the cost of future disability. As a result, in a phenomenon known as adverse selection, large numbers of high-risk buyers could drive up premiums and threaten the program's viability. Because of these and other problems the Obama Administration concluded the program was not viable and abandoned it in October, 2011.

What were the flaws in CLASS, how can it be improved, and what are possible next steps to build on this controversial idea?

Background

In contrast to acute medical care, long-term care helps those with chronic illnesses manage their daily lives in relative comfort and security. Such care is provided to both the frail elderly and younger people with disabilities, and may include assistance such as eating, bathing or toileting, cooking, or eating. It may be provided at home, in a nursing facility, or in other settings such as assisted living facilities or group homes.

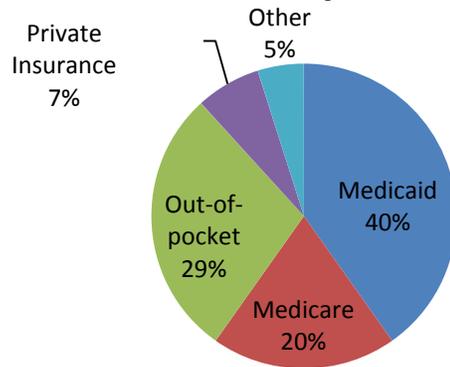
About two-thirds of those who turned 65 in 2005 will need some long-term services in their lives. They will require assistance for an average of three years over their remaining lifetimes (Kemper, Komisar, and Alexih 2005).² Currently 10 million Americans need some form of long-term care. Sixty percent are 65 or older.

Long-term care can be extremely expensive. The "private pay" rate for a single room in a nursing home averages \$75,000 per year. Home health aides cost an average of \$20 per hour (Metlife 2011). A person would have to put away nearly \$50,000 at age 65 to cover the average lifetime cost of long-term care (Kemper, Komisar and Alexih 2005).³ Overall the U.S. spent about \$230 billion in 2008 on long-term services.

In the United States, 40 percent of paid long-term care is funded by Medicaid, the joint federal-state health program for the poor.⁴ Less than 10 percent is financed by private long-term care insurance. Much of the remainder is paid out-of-pocket by those receiving care or by their families (Komisar and Thompson 2007). However, it is important to note that well over half of all long-term care is informal unpaid assistance provided by friends or relatives, usually spouses or daughters (Johnson, Toohey, and Weiner 2007). AARP calculates the economic value of this care was \$375 billion in 2007 (Houser, Fox-Grage and Gibson 2009).

Figure 1: Long-Term Care Spending in the U.S.

Share of Total Spending 2008



Source: SCAN Foundation/Avalere Health (2010)

While the existing Medicaid-based system offers relatively comprehensive coverage for the poor, it is problematic for the middle class. To become eligible, people face severe income and asset limitations and must effectively impoverish themselves. In most states, an unmarried individual must “spend down” financial assets to \$2,000 to qualify.

Although the United States makes limited consumer-directed care available through Medicaid, most payments are still made directly to highly-regulated and licensed providers, such as nursing homes or home care agencies. In addition, Medicaid provides a federal entitlement for institutional services only. As a result many frail elderly and younger adults with disabilities receive benefits only if they reside in a nursing facility, despite consumers’ preferences to remain at home as long as possible. In recent years, Medicaid has taken steps to rebalance its benefits through multiple state waiver programs. However, in 2007, nearly three-quarters of the program’s long-

term care benefits for adults with disabilities and the frail elderly were paid to nursing facilities (AARP 2009).

At the same time, growth in long-term care costs for both the elderly and disabled is driving substantial increases in government health expenditures, especially for Medicaid, which spent more than \$100 billion—or one-third of its budget—on such assistance in 2007 (Burwell, Sredl, and Eiken 2008). This cost growth may become especially problematic as 77 million Baby Boomers reach old age over the next three decades. By 2050, total Medicaid spending could exceed 6.5 percent of Gross Domestic Product (Kronick and Rousseau 2007), the equivalent of \$900 billion today.

Consumers seeking to hedge against their risk of needing costly long-term services may purchase private insurance (Stevenson, Cohen, Burwell, and Tell, this volume). However, to date the demand for such insurance has been modest due to the price and complexity of policies and the reluctance of consumers to confront the costs of potential disability in old age. In addition, in a process known as medical underwriting, private insurers may deny coverage or charge higher premiums to applicants with pre-existing conditions.

The existence of Medicaid may be a further disincentive to the purchase of private insurance (Brown and Finkelstein 2004). There are roughly 7 million policies in force, covering only about 10 percent of adults.⁵

History of the Class Act

Its supporters intended the CLASS Act to be the most significant reform in the financing of long-term care since the creation of Medicaid in 1965. However, CLASS may be seen as only one step—albeit a noteworthy one—in a decades-long process aimed at addressing structural flaws in the initial Medicaid design.

The Pepper Commission

In 1990, the U.S. Bipartisan Commission on Comprehensive Health Care [chaired by Representative Claude Pepper (D-FL) and commonly known as the Pepper Commission] identified the flaws in Medicaid long-term care. It noted the development of private long-term care insurance—at the time a relatively new product. But the panel questioned whether such a product could provide comprehensive coverage to sufficient numbers of elderly and disabled (U.S. Bipartisan Commission on Comprehensive Health Care 1990).

The commission explicitly rejected a “two-tier” system of Medicaid for the poor and private insurance for the well-off. It also chose only limited public insurance. It gave two reasons. First, echoing concerns first raised in the 1965 Medicaid debate, the

panel concluded that costs for nursing home care would “require substantial public resources.” Second, it feared social insurance would allow the wealthy to preserve assets without having to buy private insurance.

Under the Commission’s design, government would provide benefits for all those with severe disabilities, regardless of age. It would pay for most home care, but individuals would be responsible for a modest co-payment. The program would also pay for the first three months of nursing home care for all, regardless of income. Longer-stay nursing home residents would also be eligible for benefits, but only after they had “spent-down” to the program’s new asset limits. However, protected assets would be significantly higher than in Medicaid. The Commission would have allowed individuals to preserve up to \$30,000 (\$60,000 for couples) in financial assets. Even today, Medicaid only permits individuals to retain no more than \$2,000. The Commission also recognized that some consumers would want to buy long-term care insurance to supplement the new government benefit. As a result, it recommended these purchasers receive the same tax benefits as buyers of health insurance.

The Pepper Commission recognized this new program would be expensive—it estimated \$70 billion annually in 1990 dollars. It did not recommend a specific new tax to fund the benefit, but urged that any financing mechanism be progressive, sufficient to keep up with benefit growth, and imposed on people of all ages.

While none of the major Pepper Commission recommendations were adopted, many of its concepts were embraced three years later by the Clinton Administration as part of The Health Security Act--its ambitious, but ultimately ill-fated, health reform plan.

Long-Term Care Reform in the Clinton Health Bill

The Health Security Act would have created a new state-administered, but nearly entirely federally financed, Home and Community-Based Services (HCBS) program for severely physically, developmentally, mentally, and cognitively impaired individuals, regardless of age (Office of Disability, Aging and Long-Term Care Policy 1994). And, in a key change from Medicaid, all medically-eligible individuals could receive home care benefits, regardless of income. However, institutional care, as well as assistance for those with less severe disabilities, would remain in the welfare-based Medicaid program. In addition, users would pay co-insurance tied to their income levels.

While these long-term care provisions eventually died with the rest of Clinton health bill, other reforms surfaced during Congressional debate. One, especially, would play a key role in future reform efforts. In June, 1994, the health reform bill approved by the Senate Labor and Human Resources Committee included The Life Care Act,

introduced by Senator Edward Kennedy (D-MA).⁶ That proposal would have created a voluntary, fully-funded public insurance program to cover extended nursing home stays (Weiner et al. 2001).

Other Reform Efforts

For more than a decade after the demise of the Clinton health bill, much of the focus on long-term care shifted to improving the delivery mechanisms under Medicaid. The federal government and the states took modest steps to shift Medicaid from a nursing home benefit to one that also assists those receiving care at home. This was done principally through the use of limited demonstration projects, as well as the more widespread use of state waivers. These exceptions allowed states to offer home care benefits under certain federal strictures.

This shift has occurred steadily, but slowly. Today nursing home residents continue to be the only enrollees entitled to Medicaid long-term care benefits. State home care programs remain optional, vary widely in scope and quality, and are often underfunded. As a result recipients continue to face either limited benefits or long waiting lists.

While some modest changes were being made in Medicaid, long-term care financing reform in the U.S. largely languished in the policy wilderness. Congress adopted only two significant initiatives—both aimed at enhancing consumer demand for private long-term care insurance. In the Health Insurance Portability and Accountability Act of 1996, Congress approved modest tax incentives to encourage the purchase of private policies. These were scaled-back versions of ideas developed in the Health Security Act. At the same time, more than 30 states enacted tax incentives to encourage purchase of private policies, although there is little evidence these subsidies significantly increased participation rates (Stevenson, Frank, and Tau 2009).

In 1988, the Robert Wood Johnson Foundation funded an experiment known as the Long-Term Care Partnership Program. Originally adopted by four states, the Partnership allowed consumers who purchased long-term care policies to qualify for Medicaid without first having to impoverish themselves. Initially, it produced only modest increases in purchases of long-term care insurance. Congress expanded the Partnership program significantly in 2005, and, as of May, 2010, 37 states were participating. To date, about 120,000 new policies have been sold under the expanded program.⁷ There is not yet evidence of the effects of this expansion on state Medicaid costs.

Even as the U.S. moved to enhance the use of private long-term care insurance to partially substitute for Medicaid, other major developed nations were moving in a

very different direction.⁸ In the 1990s, they too had recognized their means-tested long-term care financing systems were placing severe financial strains on government finances even as the care they funded was less than satisfactory. However, their solution was the one explicitly rejected in the U.S.—universal government long-term care insurance (Gleckman 2010).

Table 1: International Models for Long-Term Care Financing

	Financing	Benefit	Eligibility	Coverage by Private Insurance
U.S. (Medicaid)	General Revenue	Service/ Limited cash	Means-tested	<10%
France	General Revenue	Cash only	Universal for 60+ /Steep income-related coinsurance	25% of those 60+
Germany	Payroll Tax	Cash or Service	Universal	<10%, Optional for high-earners
Japan	Payroll Tax/ General Revenue/ Income-related Premium	Service only	Universal for 65+	None
CLASS	Voluntary premium	Cash	Universal	<10%

In 1995, Germany created a system that provides either a cash or service benefit to adults of any age with limited functional ability. The German system is funded by a payroll tax—currently about 2 percent—and aims to finance about 50 percent of the cost of home care. Institutional benefits are also provided, but for nursing care only. Room and board are excluded. In Germany, some buyers may purchase private insurance in lieu of government policies, though fewer than 10 percent do so.

In 2000, Japan designed a system of national insurance that aimed to pay 90 percent of the cost of home care for those 65 and older or those 40-64 with age-related disabilities. Japan provides a service benefit only. Much like Medicare, the Japanese system is funded by a mix of payroll taxes, general revenues, and income-related premiums.

In 2002, France created a long-term insurance benefit as part of its national pension system. French insurance is funded through general tax revenues. Benefits are

available to those who are age 60+, and are paid in cash only. All those who meet a functional test are eligible for assistance. However, benefits are steeply means-tested. As a result, middle- and upper-middle class people have begun to purchase private long-term care insurance to supplement their government coverage. Private insurance, which was unknown in France prior to creation of the national benefit, now covers about 25 percent of those age 65 or older, and pays about 30 percent of all long-term care costs.

The CLASS Act

In 2003, with little fanfare, Senator Edward M. Kennedy (D-MA) began to develop a long-term care insurance model that was dramatically different from both the proposals of the Pepper Commission and the Clinton Administration on one hand, and the social insurance model adopted by much of the developed world on the other.⁹ The initial focus of this new initiative was working adults with disabilities as well as the frail elderly. Unlike the Life Care Act, it was aimed at people receiving care at home, rather than in nursing facilities.

Since the 1970's, Senator Kennedy had been deeply involved in expanding opportunities for people with disabilities. In 1999, for example, he cosponsored the Ticket to Work and Work Incentives Improvement Act. This legislation made it possible for adults with disabilities to retain Medicaid benefits while employed. But by 2003, Kennedy was looking to break the link between personal care needs and means-tested Medicaid program. His intent was to provide a maximally flexible benefit outside of Medicaid that could help a working person with disabilities with activities of daily living. His solution was insurance.

From the first drafts in 2003, Kennedy insisted on several elements aimed at assisting the working disabled. Benefits would be in cash. They would be available for life or as long as care was required. In addition, no one could be denied coverage due to pre-existing health conditions, so even those who already had functional limitations could become eligible for benefits.

However, Kennedy also recognized the need to keep premium costs relatively low. The 2005 version of the bill proposed an average monthly premium of just \$30. His 2009 version estimated premiums would average \$65. To keep premiums low, the daily benefit would be relatively modest—\$50 for someone who required assistance with two activities of daily living or \$100 for a person who needed help with four ADLs. Kennedy also included two provisions intended to substitute for traditional underwriting: People would have to be actively working to participate in the program, and they would have to be enrolled in CLASS for five years before claiming benefits.

Kennedy made one other critical decision. While the insurance industry and many independent analysts urged him to make the program mandatory, he never seriously considered this option, either for individuals or employers. While Kennedy recognized the potential economic benefits of a mandatory program, he felt such a system would not be approved by Congress. However, while CLASS was not mandatory, workers would be automatically enrolled in the program by those employers that chose to participate. Employees could reject coverage, but to do so they would have to make an affirmative choice to opt-out of the program.

All of these elements were included in Kennedy's first CLASS bill, introduced as S. 1951 on November 2, 2005. Kennedy's cosponsor on that version was a conservative Republican, Senator Michael DeWine of Ohio. Later versions, including the 2009 measure that became the basis for the legislation included in the ACA, were remarkably similar to the 2005 proposal. However, several key changes were made before the final bill was passed. While earlier versions included both premium and daily benefit amounts, the final bill gave the Secretary of the Health and Human Services substantial discretion to design CLASS insurance policies. The projected premium costs were dropped, and the two-tier benefit structure was replaced with a design that allows for between two and six benefit levels. In addition, while some early versions allowed unemployed spouses of eligible workers to enroll, this provision also was dropped in the final measure.

In sum, CLASS became a hybrid aimed at achieving several goals at once. It took on some characteristics of national government insurance, but was voluntary. It represented the first steps away from means-tested Medicaid long-term care benefits, but also maintained Medicaid as a key component of long-term care financing. It was both insurance for those who seek to protect themselves should they age into disability, and effectively a guaranteed benefit program for those with pre-existing disabilities who work.

Because CLASS enrollment was explicitly tied to work, current retirees were not eligible. While relatively young seniors could continue—or resume—work to take advantage of the program, CLASS was principally aimed at creating an insurance program for younger people.

It should be noted that social insurance is not necessarily mandatory. For instance, participation in Medicare parts B, C and D is optional. However, successful social insurance programs must approach universal participation, whether through mandates or incentives for participation sufficiently strong to make enrollment nearly universal (Van de Water 2008). For instance, 95 percent of seniors are enrolled in either Medicare Part B or C. Although participation is optional, the combination of public

subsidies and late enrollment penalties, as well as the immediate need for services, has generated extremely high take-up.

How Did CLASS Pass?

Until the summer of 2009, few expected CLASS would be added to the health bill. Advocates were divided over whether to try to include long-term care in a broader health measure and CLASS itself had little political support. Kennedy's cosponsor, Senator DeWine, was defeated for reelection in 2006 and no other Republican stepped forward to support the bill. Kennedy himself fell ill in May 2008 and was limited in his ability to advocate for either broad health reform or the CLASS Act. Senate Finance Committee Chair Max Baucus (D-MT), who was a key player in the health reform effort, did not support CLASS. While Barack Obama had co-sponsored CLASS as a senator, he said little about long-term care during his presidential campaign and did not publicly endorse the bill until late in the health reform debate.

The long-term care insurance industry was divided on the bill, although major carriers were strongly opposed since they feared it would discourage consumers from purchasing private coverage.

Despite these problems, CLASS had important support. Though ill, Kennedy remained enormously influential in the health debate and was deeply committed to CLASS. In the House, the bill was introduced by senior Democrats John Dingell (D-MI) and Frank Pallone (D-N.J.). At the grassroots level, Kennedy succeeded in building a broad coalition of advocates from both the disability and the aging communities, as well as some long-term-care providers—groups that rarely worked together. In addition, while CLASS had few congressional supporters, it also attracted relatively little criticism since most opponents were devoting their energies to other provisions of the broader health bill.

However, CLASS probably passed in large part due to the Congressional Budget Office, the official scorekeeper of the cost of legislation. In June and July of 2009, CBO estimated that CLASS would generate \$58 billion in revenues from 2010-2019 (Elmendorf 2009a). Due to the bill's five-year vesting period, it would produce premium income during its early years but pay no claims. This windfall, the congressional Democratic leadership claimed, would help reduce the budget deficit, blunting Republican objections that the ACA would increase fiscal shortfalls (Gleckman 2009). While the initial Democratic interpretation raised serious questions about the insurance nature of the bill and its ability to build up reserves, CBO's budget accounting turned CLASS from something of a sideshow into an integral part of the Affordable Care Act.

The final version of CLASS included provisions intended to protect the integrity of both premiums and reserve fund investment earnings. However, due to CBO conventions, CLASS still was scored as reducing the deficit by \$70.2 billion over 10 years (Elmendorf 2009b).

It should be noted that while some critics of CLASS claimed five-year vesting was included expressly to help finance health reform, this argument is implausible. The waiting period was included in CLASS as early as 2005, four years before the health reform debate. In addition, CLASS would likely have produced a similar temporary build-up of revenues had it relied upon traditional underwriting since very few policyholder would go to claim within five years of purchase.

A Brief Description of CLASS

The CLASS Act was designed as a national voluntary long-term care insurance program. Coverage was to be provided by the federal government although CLASS was to be fully funded by premiums without additional taxpayer support.

There was no underwriting, thus coverage was guaranteed and premiums could not be adjusted to reflect pre-existing conditions. Those 18 and older who worked, even part-time, were eligible to participate. Very low-income workers and students would pay a monthly premium of \$5. For others, premiums were age-rated and level. Thus, a participant would pay an initial premium based upon age at enrollment that would not increase over the enrollee's life. However, premiums could be raised for all to maintain solvency for a 75-year period.

Participation was voluntary. In an effort to increase take-up, some workers would be automatically enrolled in CLASS insurance, though they would have the option to opt-out. However, this auto-enrollment feature applied only to employees at firms that chose to participate in the program. The law included neither requirements nor incentives for such employer participation. Other workers could voluntary enroll through an undefined mechanism.

Participants were eligible for benefits after a five-year vesting period. Daily benefits were to be paid in cash, average a minimum of \$50 and increase with an enrollee's need for personal assistance, and would be paid for life. The cash benefit could be used for a wide range of purposes, including paying family members for assistance, hiring home health aides or nurses, adult day care, assisted living, or skilled nursing facilities. Benefits could also be used to make a home accessible to someone with disabilities. Expenses for marketing, counseling, and other administrative costs would be limited to 3 percent of premium revenues.

This overall design would have resulted in extremely high premiums. HHS staff concluded that monthly premiums for basic CLASS insurance as defined in the statute would have averaged as much as \$391. At such a level, few healthy people would buy, and participation rates would have been only 2 percent.

Many details of CLASS insurance design were left to the discretion of the Secretary of Health and Human Services (HHS). The Secretary had until October, 2012 to develop a specific insurance design. However, on October 14, 2011, the Secretary declared that CLASS insurance was unsustainable and ordered her department to cease implementation of the program.

Well-Intentioned But Poorly Designed: Why CLASS Failed

CLASS had the potential to become a critical bridge from the current means-tested Medicaid system to a more sustainable insurance-based design. Such a reform promised benefits for both government and recipients of long-term care and their families. It would make it possible for both federal and state governments, which face a long period of deep financial stress, to transfer some risk of long-term care to households. This would allow them to target increasingly scarce Medicaid resources to those who need them most.

Middle-class families would insure themselves against part of the risk of long-term care (Medicaid would remain a safety net). While individuals who chose to enroll would be responsible for pre-funding a share of their future long-term care costs, these buyers would benefit since CLASS would provide both an additional financial resource and broad flexibility to tailor care to their individual needs. In addition, it may have somewhat reduced the caregiving burden now borne by family members.

The steady and predictable revenue source provided by CLASS would likely have driven changes in the provider market as well. For instance, it may have created new incentives for innovation in delivery designs, such as new forms of community-based assisted living.

However, after her staff spent nineteen months analyzing the law, HHS Secretary Kathleen Sebelius concluded that it would be impossible for her department to design a sustainable insurance program. What went wrong? Why did she abandon the program and what could be done to improve it?

CLASS was killed long before policies were ever offered for three reasons: political, legal, and financial. In 2010 and 2011, the Obama Administration faced strong opposition to many elements of the ACA. While many objections to the overall health law were partisan in nature, criticism of CLASS was bipartisan, with many key

Democrats, as well as Republicans, expressing strong reservations. Much of this concern was focused on the fear that the program would be unable to sustain itself and eventually require significant taxpayer support to remain solvent. In addition, because CLASS addressed long-term care, it was easily separated from the rest of the ACA, which was principally focused on health care. In such a political environment, it was not surprising that the Administration chose to avoid yet one more draining battle over health reform.

The legal concerns were more ambiguous. Even before the ACA was passed, the White House recognized flaws in CLASS and attempted to amend the law to repair some major problems. Immediately after passage, it once again considered offering a package of amendments but never did so. Even had the Administration proposed changes, there was no chance a deeply-divided Congress would have passed them.

As a result, the Administration was left on uncertain legal ground. It could have attempted to change the CLASS design administratively. But its legal authority to do so was unclear and would have relied on vague and sometimes contradictory language in the statute. HHS attorneys were themselves uncertain about the degree of the Secretary's legal authority to revise the program, arguing that some changes may have stood up in court while others probably would not (U.S. Department of Health and Human Services, 2011).

Ultimately, however, CLASS failed as a result of its substantive flaws. Despite its good intentions, independent and government analysis concluded that CLASS's imperfect design would generate premiums that would have been prohibitive for most buyers. As a result, participation rates would likely have remained below 5 percent. This would have created serious adverse selection problems, and risked throwing the program into a classic insurance death spiral.

CLASS suffered from three major design flaws: it was voluntary; it required no underwriting; and it attempted to serve two incompatible purposes by creating both a new benefit program for working people with disabilities and an insurance system for those looking to hedge against the risk of long-term care in old age.

Combined, these three elements doomed the program. The voluntary nature of CLASS and lack of underwriting increased the likelihood that those who chose to enroll would eventually go to claim. This was especially true given CLASS's explicit attempt to provide new, non-Medicaid benefits for working people with disabilities.

Delinking this population from Medicaid (which has strict income eligibility rules) would make it possible for more people with disabilities to work—an outcome many feel is beneficial. However, as with any insurance, if participants are more likely than

average to receive benefits (known as adverse selection), premiums must rise to support those additional claims costs. As premiums increase, healthy consumers are less likely to buy, increasing the share of those in the risk pool who will eventually claim benefits. This phenomenon is known as a death spiral.

CLASS attempted to increase participation by young, healthy workers through its negative opt-out design. However, this would have applied only where employers chose to offer CLASS coverage, and employer participation was fully voluntary. Thus, it was unlikely the opt-out design would have materially improved CLASS's anti-selection problems.

However, making CLASS broadly available to working people with disabilities meant that large numbers of people who were certain to go to claim would enroll. In effect, this would create a new national benefit program for millions of working people with disabilities. However, instead of this new program being funded through tax revenues or another broad-based funding source, only those seeking to purchase insurance for care in old age would finance the program. This would inevitably drive premium costs to unaffordable levels.

What Next?

Given the design flaws of CLASS, policymakers have several options. They are: maintain the basic design of CLASS but attempt to repair its flaws; create a structure that includes private insurance and strong positive and negative incentives for enrollment; or adopt a universal, mandatory long-term care insurance system

Repair CLASS

The most obvious option is to build on CLASS and try to create a revised voluntary public program. Doing so would require addressing CLASS's strong anti-selection bias. Ideally such changes would reduce average monthly premiums to \$100 or less. At this level, the program might enjoy sufficiently broad participation to become a policy alternative to Medicaid for all but the poorest workers. However, these reforms would require changes in eligibility, enrollment, benefits, and premium structure.

The HHS staff itself proposed several significant changes to the CLASS design (U.S. Department of Health and Human Services, 2011). However, while these proposals were quite creative, they were constrained by the limitations of the law itself. In this brief section, I will suggest ways to improve a voluntary, government program in ways that go well beyond the CLASS statute. Thus, these changes would require new legislation.

Eligibility. The first reform addresses eligibility. This may require two solutions to two separate problems: financing care for working people with disabilities and providing insurance for healthy people seeking to protect against the uncertain risk of needing long-term care in the future, especially in old age.

Providing care for working people with disabilities is a major challenge but beyond the scope of this chapter. In 2010 about five million working people had some disability (Bureau of Labor Statistics 2010). In 2007, about half, including 700,000 of those with a “self-care” disability, worked full-time (Rehabilitation Research and Training Center 2009). The rest worked part-time or were self-employed and may satisfy the minimal work requirement needed to enroll in CLASS (Schur 2003). Other research suggests about one million people, or one-quarter of working adults who need help with at least one activity of daily living or one instrumental activity of daily living¹⁰ would have been eligible to enroll in CLASS.¹¹

Unfortunately, coverage of this population was a major reason why CLASS insurance would have been unaffordable. Thus, voluntary public insurance for those seeking to hedge against a future risk would almost certainly exclude this group.

Private insurance addresses the selection issues created by this population by denying them coverage through underwriting. While underwriting is inappropriate for public insurance, premiums can be controlled through the use of an at-work requirement. For instance, working age people might be eligible to enroll in a public insurance program if they work a minimum of 20 or 25 hours per week.

Enrollment. A second concern relates to the auto-enrollment mechanism of CLASS. Behavioral economics suggests that properly designed, such a mechanism could significantly increase enrollment. For instance, evidence of auto-enrollment/opt-out with 401(k) plans suggests that participation nearly doubles, especially for young workers (Madrian and Shea 2001).

The incentive effects of an auto-enrollment model for long-term care insurance are unknown. However, insurance industry actuaries suggest it may have some positive effect on participation rates, though far more modest than the 401(k) experience (Schmitz 2009).

A successful negative opt-out requires broad employer participation. Currently, few employers offer long-term care insurance and participation rates are quite low, even where underwriting is limited.¹² An employer mandate, similar to the requirements of the medical insurance provisions of the ACA, would increase enrollment. Short of a mandate, modest incentives, such as support for administrative costs, may increase

participation somewhat. Similarly, including long-term care insurance in a pre-tax employee benefit package may also increase take-up, though only modestly.

The most critical element of any voluntary system may be the proper set of incentives to encourage enrollment at a relatively young age. Absent either positive or negative incentives, a voluntary long-term care insurance program is likely to fail due to adverse selection issues discussed above.

Medicare Part B is an example of how properly designed incentives can drive participation. Thanks to a mix of subsidies, severe late enrollment penalties, and the recognition that it is difficult, if not impossible, for those 65+ to purchase insurance in the private market at an affordable price, more than 95 percent of those eligible are enrolled in either Medicare Part B or Medicare Advantage. By contrast, private long-term care insurance, where there are few incentives to participation and significant disincentives (including price and the availability of Medicaid) is an example of a market failure.

What incentives could drive the purchase of optional public insurance? Inflation-adjusted premiums would reduce costs for young enrollees (see discussion below). Negative incentives could include penalties for delayed enrollment beyond normal age-rating; a temporary exclusion of benefits for pre-existing conditions at the time of enrollment; or inclusion of home equity when calculating Medicaid eligibility for those who do not purchase insurance.

Benefits. The third concern is the benefit structure. Benefit design must address three issues: daily benefit, duration of benefit, and payment mechanism. The CLASS design was significantly different from private insurance in all three. Its daily benefit was relatively low—an average minimum of \$50. Its duration was quite long—for life. And its payment mechanism was quite generous—cash. By contrast, the private market has evolved away from this model. In contrast to the “long and skinny” design of CLASS, most private insurance policies are “short and fat.” In other words, they provide a more generous daily benefit for a shorter duration—typically \$125 for 3-5 years.

Lifetime benefits were once popular with private insurers but have been largely abandoned in new policies due to the “tail” risk of infrequent but very costly multi-year claims. These long claim periods are often driven by dementia, which represents about half of long-term care insurance claims. Lifetime benefits generally add 40 percent to the cost of an otherwise identical five-year policy.¹³

At the same time, with only a few exceptions private insurance pays on a reimbursement model, rather than cash. While cash benefits offer a significant

potential advantage to consumers, this design is rarely sold by private carriers without limitations such as lower payments or higher disability thresholds. Premiums for private policies that offer cash benefits can be as much as twice the cost of reimbursement policies.

Government insurance could address this set of challenges by offering a limited package of optional products. For example, buyers could choose between a CLASS-like policy, a typical private insurance policy of \$125-a-day for 3-years, or a high-end policy of, say, \$200-a-day for 5 years. Segmenting buyers in this way does create its own selection issues, but it may also create a more attractive product, which is critical in a voluntary market.

Premiums. The key to a successful insurance program is affordable premium. This challenge continues to vex the private market, where the average monthly premium now exceeds \$200 (LIMRA, 2011). One study concluded that after purchasing life and health insurance and assuring for adequate retirement savings, only about one-third of couples age 35-59 could afford mid-price long-term care insurance (Merlis 2003).

Table 2: CLASS Act versus Private Insurance Benefits

	CLASS	Private Insurance ^a
Underwriting	None; work requirement/vesting	Yes
Benefit	Cash	Reimbursement/ rarely cash
Benefit Amount	Minimum \$50 (inflation-adjusted)	\$125 (inflation- adjusted)
Benefit period	Lifetime	3-5 Years
Time before receiving benefit	5 Years after enrollment	90 days after meeting functional limitation test

^aPrivate insurance design is based on a typical policy. Private carriers offer a wide range of benefits.

In addition, potential buyers appear to be very sensitive to price. One industry-funded survey finds that only 20 percent of consumers would opt-out of a CLASS like program with a \$35 monthly premium, while 83 percent would opt out of coverage with a \$110 premium (Greenwald 2009). As private insurers have found, keeping premiums low often requires scaling back benefits. For instance, many private carriers have been reducing inflation protection in newly-issued policies—a poor choice for many buyers.

Low premiums are likely to be a key to participation among young workers. One way to reduce their monthly costs may be to shift from a level-premium design to an inflation-adjusted premium. This idea, which was considered by the Administration, would keep monthly costs very low for young workers and gradually rise with age (and wages). However, when offered by private carriers this design has been criticized by state regulators who suggest it could lead to inadequate coverage or high lapse rates.

Long-Term Financial Stability. In any public system, policymakers should create a separate quasi-government insurance fund that would have the flexibility to invest premiums in a diversified portfolio. This would allow CLASS to collect and invest reserves just as a private carrier might. Such a design may both allow for a more prudent investment portfolio than Treasuries-only and reduce public skepticism about the program's solvency.

The Role of Private Insurance in a Public Program

A critical issue is whether private insurers would write coverage that supplements a public program or whether they would attempt to compete with government insurance. Private insurers that have the ability to underwrite could “cherry pick” low-risk customers, leaving government with the highest-risk, most costly pool, exacerbating its already challenging adverse selection problems.

Another challenge to building a successful partnership with private carriers is determining which coverage is “first-payer.” This has been the subject of much disagreement among private insurers, although the most likely solution would designate this role to private insurance, leaving government with the uncertain “tail risk” of catastrophic insurance. This issue is especially important when considering the budgetary effects for Medicaid. If it remains primary payer, Medicaid would likely save relatively little. By contrast, savings may be quite substantial if Medicaid becomes the secondary payer to private insurance. However, the amount of savings would still vary significantly, depending on the benefit design.

A Full Public/Private Insurance Partnership

Policymakers may want to consider going beyond a fully public model and instead adopting a full partnership with private insurance. Such a model could be built on the Medicare Part D drug benefit or in the health insurance design of the ACA. In this model, insurance is sold by private carriers (with or without a “public option”) through an insurance exchange that is operated by government. Insurers are uniformly regulated, and prices and benefits are fully transparent and easily compared.

In this model, insurance could be mandatory or voluntary. A mandatory system would be based upon guaranteed issue so no buyer could be rejected for coverage. Voluntary insurance would still have to address all of the anti-selection issues of pure government insurance. In this design, underwriting could be based upon a moderately strict at-work requirement (20 or 25 hours per week) or could include short-form underwriting that is similar to private group insurance today.

Buyers above a certain income would purchase at market rates. Low-income buyers would receive a subsidy scaled to their income. Public insurance, such as Medicaid, would continue to be available for those who are unable to work or otherwise uninsurable.

Because long-term care insurance, unlike health insurance, requires the long-term viability of private carriers, government would be required to guarantee policies, perhaps through a system of reinsurance.

Genetic Testing

Any voluntary long-term care insurance—whether government or private—must take into account the likelihood that accurate genetic testing for diseases such as dementia will become widely available. If private insurers have access to those results, they will inevitably deny coverage to those who test positive. If carriers are barred by law from seeing the results (or, in a government model, do not underwrite) they will adjust premium prices upward to reflect the likelihood that many buyers (who would have access to this information) carry genetic markers for these diseases. Either way, such tests will drive major changes in the design of private insurance where underwriting is permitted and have profound negative effects on guaranteed, but voluntary, public coverage.

A Universal Public Program

Economists and actuaries generally agree that the ideal long-term care insurance system would be mandatory. This change would address all of the adverse selection issues that plague voluntary insurance (both public and private). It would also make

coverage available for an extremely modest premium. An insurance model created by the SCAN Foundation and the consulting firm Avalere Health finds consumers could purchase mandatory CLASS-like coverage for less than half the premium price of the voluntary version (SCAN Foundation/Avalere Health 2010).¹⁴

However, a universal system must overcome two substantial hurdles: political resistance and financing. The political obstacles were apparent in the debate over the ACA, where a Democratic Congress was unwilling to accept even a “public option” to private health insurance. While universal long-term care insurance has been adopted by most major developed nations, the likelihood that the U.S. will embrace such a model in the current political environment is vanishingly small. The second key to designing such a plan is financing, particularly given public resistance to higher taxes. Leonard Burman (this volume) describes a model of expanded Medicare funded by higher taxes. In another model, Yung-Ping Chen has proposed embedding long-term care insurance into Social Security. In effect, retirees would forego a small piece of the annuity portion of their Social Security benefit in exchange for long-term care insurance. Such a design could also add long-term care insurance to existing benefits (funded with an additional payroll tax). Either way, private insurance would supplement basic long-term care coverage (Chen 2007).

Conclusion

The CLASS Act had the potential to fundamentally redesign the way long-term care is financed in the U.S. Its cash benefit and the possibility that it would have encouraged some to shift from reliance on Medicaid to self-funded insurance were powerful reforms. However, the design of CLASS undermined its many potential benefits.

Policymakers now have two options. They can try to redesign a voluntary system that avoids the pitfalls of CLASS. This would require building a model that boasts both affordable premiums and a sufficiently attractive benefit structure. Such a design has, so far, eluded carriers of private insurance. It is possible, however, that the right mix of policy carrots and sticks might encourage enough young, healthy consumers to enroll that the program could become self-sustaining. Under this option, insurance could be provided by government, private carriers, or some combination of both. Their second option is to attempt to build a mandatory program. This is the choice already made by most of the developed world. However, in the current political environment there seems little interest in such a design in the U.S.

The most likely course, however, is that Congress will do nothing. After its experience with CLASS, and given the policy and political challenges of reopening

the issue of long-term care financing, it is unlikely that lawmakers will soon attempt to address this serious national problem.

Notes

- ¹ The ACA [[H.R. 3590](#)] is available at online; the CLASS provisions are Title VIII, beginning on page 710
- ² Of those who need care, 17 percent will receive assistance for a year or less while one of five will require assistance for five years or longer.
- ³ This estimate is in 2005 dollars, and represents present discounted value of average lifetime out-of-pocket costs. This is in addition to costs covered by Medicaid or private insurance.
- ⁴ There is little agreement among analysts on the share of long-term care funded by Medicare. This program is explicitly designed to provide health care, and not long-term care. However, while Medicare by law provides only limited post-acute personal and nursing care, it is likely that it also funds some long-term care. In new estimates of long-term care financing in 2008, Carol O'Shaughnessy includes no Medicare funding, but calculates the Medicaid share at 62 percent (see National Health Policy Forum 2012).
- ⁵ Data on long-term care policies are uncertain. However, LIMRA International estimates that 4.8 million individual policies were in force at the end of 2008 and about 2.1 million lives were covered under group policies through 2007. LifePlans Inc. estimates between 6.75 and 7.75 million policies are in force in 2009.
- ⁶ S. 1757; the bill was reintroduced by Kennedy in 1995 as part of [S. 168](#).
- ⁷ Partnership data are available on Thomson-Reuter's [Long-Term Care Partnership Program Website](#).
- ⁸ For more information on the experience in Scotland, see David Bell and Alison Bowles (this volume). For more on the Scandinavian experience, see Svein Olav Daatland (this volume).
- ⁹ This brief history of the CLASS Act is based on author interviews with several participants in the legislative process including Constance Garner of the Senate Health, Education, Labor, and Pensions Committee who was Sen. Kennedy's chief aide on disability issues, and others who asked to not be identified.
- ¹⁰ The law defines ADLs as eating, toileting, transferring, bathing, dressing, and continence. IADLs are activities such as shopping, cooking, traveling, or managing finances. Requiring assistance with IADLs does not qualify a CLASS enrollee for benefits.
- ¹¹ Unpublished tabulations prepared by Melissa Favreault of the Urban Institute, based on 2001 and 2004 Survey of Income and Program Participation (SIPP) data.
- ¹² Large employers often offer insurance with limited underwriting sometimes referred to as "short-form" underwriting. Participation rates, however, remain low, only about 6 percent. The federal government has offered long-term care insurance to its employees for several

years. Enrollment in the government plan, even with limited underwriting, is also about 6 percent.

¹³ See the [U.S. Office of Personnel Management LTC insurance calculator](#). The monthly premium for a typical lifetime policy for a 60-year old is \$251 while an otherwise identical five year policy costs \$183.

¹⁴This projection was based on the HELP Committee's version of CLASS which was amended in some respects in the final law.

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CHAPTER 4

THE CLASS PROMISE IN THE CONTEXT OF AMERICAN LONG-TERM CARE POLICY

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Long-term care (LTC) has long been a stepchild in the social policy family in the United States. Even in the broader context where America has been seen—as a “laggard” (Orloff 1988), as “exceptional” (Lipset and Marks 2001), and as “reluctant” (Wilensky and Lebeaux 1958), long-term care has occupied an especially residual place. Against this backdrop, enactment of the CLASS Act as part of the Affordable Care Act (ACA) in 2010 was seen as a remarkable achievement on at least three counts. Politically, enactment of the CLASS Act as a part of a far-reaching health care reform package, itself historic, was doubly unexpected. Programmatically, the inclusion of the CLASS Act and other provisions pertaining to chronic illness and disability gave a new prominence to long-term care concerns within the much more highly institutionalized world of health and medical care. And conceptually, having CLASS predicated on the principles of social insurance added a third leg—however shaky it proved to be—to the firmly institutionalized income and health care protections for the old and people with disabilities represented by Old Age Survivors and Disability Insurance and by Medicare.

In light of these historical breakthroughs in the long-term care policy arena, the CLASS Act’s being “suspended” in 2011 (Sibeliuss 2011) or “abandoned” (Gleckman this volume) represents a major setback to the LTC community. The provision of non-means-tested cash benefits for disability and chronic illness would have opened a new social policy front for the United States, joining—however haltingly—several other nations which have added public LTC benefits to their social policy offerings in recent years. In particular, the great hope and guarded expectation of advocates and policymakers who brought the CLASS Act to fruition was that it could propel long-term care from the “residual” to the “institutional” policy arena. The purpose of this chapter is to suggest what that transformation looked like at the time and how important it could be seen to be in both conceptual and programmatic terms.

The Residual Place of Long-Term Care: The Populations and the Problem

The distinction between residual and institutional problems and policies is useful for putting the evolving world of long-term care in perspective. As a problem statement, residual refers to that which is only marginally acknowledged and addressed, whereas the institutional refers to problems which have attained a higher level of legitimacy

and which are deserving of a more mainstream response. As an approach to policy, in Wilensky and Lebeaux's classic phrasing, "[The residual] holds that social welfare institutions should come into play only when the normal structures of supply, the family and the market, break down. [The institutional], in contrast, sees the welfare services as normal, 'first line' functions of modern industrial society" (1958: 138). Until passage of the CLASS Act long-term care had been a residual arena on at least three counts: the populations addressed; the social and political construction of the problem; and the policy response.

The Residual Populations of Long-Term Care

First, the populations that stand to benefit from CLASS have been historically vulnerable, barely visible, and politically weak. As old age and its decrements came to be understood as an illness (Haber 1983) and the disabled were slotted into a "sickness" role (Erkulwater 2006) for which there was essentially no cure, there was minimal interest in providing aid, either through institutional or community-based charity care. As for mental impairments among the old, "public officials saw no obvious solution to the dilemmas presented by aged senile persons. Some proposed that counties or family assume fiscal responsibility; others urged the construction of separate building at mental hospitals, and yet others insisted that sons and daughters be forced by law to meet their responsibilities toward parents" (Grob 1986: 40). In Rosenberg's (1986) reckoning, it was the combination of illness and dependence of these individuals, which left them under-attended: "Almshouses and their historical successors, municipal hospitals, often contained 'old folks' wards, demonstrating in practice their administrators' inability to distinguish categorically between sickness and dependence" (p. 236).

The passage of time brought little added enlightenment. Within the older population, individuals in need of long-term care services were understood, by definition, to be some combination of frail, ill, poor, and isolated. Beset by a mix of chronic and acute health care conditions, their ability to function independently was clearly compromised. Often widowed, divorced, or never married, not only were their family and social networks highly circumscribed, but their economic means were wholly inadequate. Periodic and episodic health-related needs could make any given locus of care inappropriate at any point in time. In the event of cognitive deficits, their sense of place and presence may be highly compromised. Their labor force presence was marginal at best, rendering the notion of "retirement income" remote at best.

For their part, historically, people with disabilities had in many ways a tougher row to hoe. Whereas in Haber's (1983) words, "the aged were consciously omitted from 'the redeemable,' i.e., those who should be expected to earn their own support," the

disabled have long been a more suspect group. As framed by Stone (1984), the social welfare question is one of distributive justice, specifically weighing the work-based system against the needs-based system. Not only were children and the old given something of a pass in gaining entrance to the needs-based system, as a matter of *administration*, their entry was straightforward, aka, evidence of a birth date “if not simply visual observation” (p. 23); proof of widowhood was nearly as straightforwardly ascertained. However, as Stone goes on to observe: “Disability however, has always been more problematic, both because no single condition of ‘disability’ is universally recognized, and because physical disability and mental incapacity are conditions that can be feigned for secondary gain” (p. 23). Erkuwaller (2006) echos this sentiment in noting that “[p]eople in wheelchairs are regarded as the deserving disabled by most Americans, but mental disabilities... and chronic pain are poorly understood impairments that elicit as much skepticism as they do empathy” (p. 16).

The Residual Problem of Long-Term Care

The second residual feature that the CLASS Act potentially addresses is the problem of long-term care itself or, more precisely, where to locate it. At what point do long-term disabling conditions move beyond being a trying situation for individuals and families and attain the status of a social problem warranting a formal and bureaucratized response? Beyond that juncture lies determining the balance between private and public sector actors for that formal response. Finally, should these responses remain localized and “closer to the problem” or be organized centrally and subject to more universal standards of intervention and assessment? These distinctions for locating problems and tailoring responses—informal and formal, private, and public, and local and national—are useful here in positioning the long-term care issue in the broader context of American social policy. More specifically, they illuminate the conceptual breakthrough that the CLASS Act represented in comparison to virtually all earlier efforts to locate both the long-term care problem and the responsibility for addressing it.

Over the course of a century or more, what we label today the long-term care problem has moved both slowly and unevenly along each of these dimensions, from what can be seen as the residual constellation of the informal, private, and local toward the more institutionalized one of the formal, public, and national. Once largely the province of families, communities, and local officials charged with care of the poor and helpless, the problem of long-term care came to be seen as something that required a broader and more sustained response. Importantly, what that “something”

was and to whom that response fell became subject to unending conflict and avoidance.

Focused on the old, the problem could be seen as one inadequate income, poor health, physical frailty, mental impairments, or lack of shelter. Yet for the old, the problems of inadequate income and acute health care needs were addressed— first during New Deal and later during the Kennedy/Johnson years. Indeed, centering policy initiatives on the income and acute health care needs of the aged became an overt strategy used by reformers to establish the larger policy principle that could be later extended to additional populations (Hudson 1978). Old Age Assistance and Old Age Insurance stood as Titles I and II of the original Social Security Act, Franklin Roosevelt stating that “poverty in old age should not be regarded either as a disgrace or necessarily as a lack of thrift or energy . . . it is a mere byproduct of modern industrial life” (quoted in Rimlinger 1971: 212). In the case of Medicare, Marmor (1970) quotes Wilber Cohen that “the subsequent massing of data to prove the aged were sicker, poorer, and less insured than other adult groups was like using a steamroller to crush an ant of opposition” (p. 17).

However, “locating” the problem of chronic illness was not nearly so straightforward as was the long-established need for adequate income or hospital and physician care. Because chronic illness involved myriad vulnerabilities and different attitudes about its origins and severity, it was central to none of the sectors that might respond. For the elderly, sustenance and shelter centered initially on “indoor relief,” later replaced by modest cash grants, and later yet by a range of services. The world of health was dominated by physicians and hospitals, neither of which had great interest in long-lasting conditions not lending themselves to fairly immediate remedy. The frail old, in need of a combination of income, health, and social supports, was left ill-attended. As summarized by Benjamin (1993):

Care of the chronically ill [aged] had become a problem: for physicians, who could do little to treat heart disease and cancer; for voluntary hospitals, which found that their beds were occupied by the incurable chronically ill despite determined efforts to screen out patients who ostensibly undermined hospital capacity to provide beds for the potentially curable; for local and state governments, whose public hospitals bore the brunt of chronic care demands; and of course for increasing numbers of the chronically ill themselves (p. 132).

For the disabled, the need for medically-based, diagnostic certainty was ever-present as a means of both eligibility determination and fraud prevention. Until roughly the 1960s, the individual condition of disability had to be established and, once done, the

individual had to assume “the sick role,” a role to which they might be confined for a lifetime. Moreover, “because the ‘problems’ posed by disability were understood as inherent within the individual, there was no attempt at social reform” (Erkuwalter 2006: 29). Yet, having once been seen as the near-embodiment of moral hazard itself, people with disabilities in the 1970s began pressing for social inclusion, asserting that disability was more a socially constructed category than an individual condition. This recasting of the issue led to insistence for integration, accommodation, and recognition rather than care and rehabilitation.

Cross-cutting these formal problem clusters was the looming issue of private or public responsibility for fashioning and supporting some set of appropriate responses. Not put too fine a point on it, Farrow, et al. (1981) contend: “the most important policy problem [in long-term care] is a lack of consensus about the nature and extent of public responsibility for meeting long-term care needs” (p. 7). Denial, limiting, or shifting public sector responsibility has long been a central barrier to effectively addressing long-term care needs. For the old, few public sector figures wished to assume responsibility; for the disabled, many wondered if they should assume responsibility at all. Initially, towns, counties, and states tried to offload responsibility for these populations onto each other. Later, and to this day, the states and federal government have pressed each other to take the lead fashioning and paying for long-term care interventions. Employing so-called “Medicaid maximization strategies,” states frequently “reconfigured state-funded programs to be compatible with Medicaid rules and to earn federal matching funds” (Coughlin et al. 1994: 87). People with disabilities, having recast the issue as a problem with society rather than with themselves, demanded public intervention through legislative and judicial means, both centered on policy demands based on rights and transferrable into cash (Erkuwalter 2006).

Since its emergence, long-term care has constituted a set of interrelated problems and highly vulnerable populations neither of which had the standing, positioning, or resources to attract a coherent and concentrated response from policymakers. This lack of policy ownership has long meant that “the long-term care individual is *marginal* to the service providers upon which he/she depends” (Callahan 1981: 156). In more recent years, of course, initiatives involving ever-increasing amounts of public dollars have been directed toward financing and coordinating long-term care service delivery for the chronically ill elderly, though still primarily through the means-tested Medicaid program. People with disabilities were more able to find their own political voice and reconstruct both the issue and the response to it (Stone 1984). Through these two wide lenses, the conceptual contribution of the CLASS Act was to

lift age-oriented long term care out of the world of public assistance and to further extend community-based cash assistance to people with disabilities.

The Residual-Institutional Social Policy Distinction

The residual place of long-term care as a social problem and the marginal status those of need in of such services long occupied centrally shaped what occurred in the public policy arena as well. The policy application of the residual-institutional distinction is largely realized in the origins and workings of public assistance and social insurance programs. For its part, long-term care policy has long been centered exclusively in the world of public assistance, and—until the passage of the CLASS Act—efforts to extend social insurance coverage to it had long been resisted. At least in conceptual terms, the CLASS Act having extended social insurance cash-benefits to long-term care—however incompletely—represented an unprecedented development.

The critical differences between the two program types can be seen in comparing them along key program dimensions: eligibility, benefits, administration, and financing. Public assistance programs, being based on notions of adequacy, are targeted on those who are demonstrably poor or otherwise in need, and this selectivity is operationalized through the mechanism of formal means-testing. In contrast, social insurance programs are inclusive, impose no means test, have dedicated funding streams tied closely to earnings, and have benefits that are based principally on the value of equity.

The U.S. has chosen to extend *eligibility* for social insurance coverage to a selective set of risks: loss of income due to old age, unemployment, long-term disability, and to meeting acute health care needs among the old and people with disabilities (but not the costs associated with child-rearing, a benefit found in most other developed democracies). These are considered classic risks involving ordinary and expected life problems and are directed to populations whose attachment to the labor force has earned them the right to coverage. In covering only the demonstrably needy, public assistance is instead animated by notions of charity (and, in its behaviorist manifestation, control).

The principal distinction in the *benefits* offered through public programs is between cash and benefits in lieu of cash. The former, being universally accepted “currency,” offers maximum choice and control to beneficiaries. In-kind benefits, consisting of either delivered services or vouchers, constrain such choice (Gilbert and Terrell 2002). While public assistance and social insurance programs each contain a mix of benefits, cash benefits are disproportionately found among the social insurance programs and in-kind benefits among public assistance ones. Old Age, Survivors, and Disability

Insurance continue to outweigh Medicare's health services benefits, whereas Food Stamps, Section 8 housing, and Medicaid constitute a greater portion of public assistance benefits than do the Supplemental Security Income and Earned Income Tax Credit programs. With the passage and evolution of the Temporary Assistance to Needy Families program, benefits for low-income single parents have become weighted much more heavily toward service benefits than was the case under the predecessor Aid to Families with Dependent Children program.

The *administrative* dimension of policy has both vertical and horizontal components. The principal vertical tension centers on federal-state relations in the design and delivery of program benefits. For most of the half-century following the New Deal period, the pendulum swung toward Washington, whose approach to federalism rang of what Derthick refers to as a "distinct moralism." She goes on to cite the comment by long-time Department of Health, Education, and Welfare social worker Jane Hoey who, in 1969, wondered which were the "good states," only to learn that "there were no good states. There were states that had some good things about them, but there were no *good* states" (Derthick 1975: 21). With a barrage of criticism in the wake of the Great Society programs (Lowi 1969; Davies 1996), the move to Washington stalled and was partially reversed during the Nixon and Reagan years. There has long been a pronounced division of federal-state responsibility between social insurance and public assistance programs. The former have largely been centered in Washington, with essentially no role for state governments, save involvement of state-level disability officials and employment agencies in eligibility determination under the Disability and Unemployment Insurance programs. In recent years, however, a number of income-related public assistance programs—SSI, Food Stamps, and the Earned Income Tax Credit—have been nationally administered.

The horizontal administrative issue centers on program coordination and integration at respective levels of government. The loosening of federal restrictions in the post-Great Society period was engineered by governors and state budget officials who felt hamstrung by inconsistent regulations associated with numerous federal categorical grants, resulting a condition labeled by Wright (1972) as "picket fence federalism" and by Seidman (1971) as "vertical functional autocracies." More recently, easing this top-down posture has been yet more fundamentally undone with the emergence of policies which are consumer- or client-centered (DeJong et al.1992). In concept, and to a growing degree in practice, the earlier top-down model is being supplanted by a bottoms-up one, a development that represents a true paradigm shift in the public administration of in-kind benefit programs. These dynamics are becoming central to public assistance programs because their reliance on services benefits introduces an

administrative element absent from the major cash benefit programs associated with social insurance.

Financing mechanisms are the fourth core distinction between social insurance and public assistance programs. What lends a mixture of insurance aura and reality to the former programs is their separate funds supported through dedicated contributions (Thompson 1994). The FICA tax supporting OASDI programs, Part A of Medicare, and a portion of Part D of Medicare are the principal examples; employer payments are the principal source of funds for the Unemployment Insurance program.

In stark contrast, public assistance programs are supported through general tax revenues, at both the federal and state levels (and in some states, counties as well). That being the case means there is no budgetary fire wall to protect program funding, leaving public assistance interests to compete with others that may be more popular in federal, and especially, state budgetary battles. Again, because the social insurance programs are both federally and trust-fund supported, most of social policy debate and expenditures at the state-level involve public assistance programs. This situation is especially problematic in the case of Medicaid, which constitutes the second largest program in most states general fund budgets, following primary and secondary education (Kaiser Family Foundation 2010).

The Residual Standing of Long-Term Care Policy

Until passage of the CLASS Act, long-term care policy in the U.S. found itself lodged almost entirely in the world of public assistance. Historically, long-term care was the province of the family, yielding in part over time to the world or private sector charity, including community hospitals. Nascent public sector involvement centered on the almshouse or “indoor relief,” where the impoverished and frail old and people with disabilities increasingly found themselves, while those suffering from mental illness were treated separately, often in asylums (Rothman 1971). Thus, the residual nature of care was clear from the beginning, with families, charities, lodges, and fraternal orders providing what care they could and local governments providing onerous institutional care where no other alternatives existed.

By the time of the New Deal, population growth, urbanization, and dire economic need had pushed long-term care needs to a less tenuous place in the social policy world. The principal development during these years was both an ideological and budgetary desire to move long-term care populations out of institutional settings and ease them somehow into local communities. Most notable in this regard was Social Security’s Old Age Assistance program, which “forbade payments to any inmate of a public institution (Vladeck 1980: 36). In broad scope, it is important to note that cash

benefits were at the heart of most of the titles of the 1935 Social Security Act—including both public assistance and social insurance programs. Yet, not surprisingly, cash proved not enough for those impoverished individuals suffering from chronic and disabling conditions. “Pensions, it turned out, were *not* a substitute for indoor relief, at least not for the elderly who were infirm as well as poor” (Vladeck 1980: 37). This led to an expansion of “mom and pop” boarding homes, where proprietors—also suffering from the ravages of the Depression—took in boarders and their Old Age Assistance checks and also to a nascent proprietary nursing home industry that would grow enormously over the ensuing half-century.

Those in need of long-term care services continued without a clear policy or residential home up to and including passage of Medicaid and Medicare in 1965. Medically-oriented welfare amendments to the OAA in 1950 acknowledged the partial place of these individuals somewhere in the health care system, but the lack of clarity concerning their relative need for money, housing, or health care left them falling between a host of cracks. The continued unwillingness to “own” the long-term care problem was highlighted by the simultaneous passage of Medicare and Medicaid. Health care reformers—whose struggles and disappointments extended from the Roosevelt through the Truman years—were determined to see Medicare’s passage. Among other provisions omitted during that process was virtually anything that smacked of long-term care, seen as a costly and secondary element and one certainly not needed to secure passage of a major social insurance program dedicated to acute health care needs (Marmor 1970).

As something of an afterthought, the Medicaid public assistance program was enacted, expanding the earlier Kerr-Mills program directed to the impoverished aged, and providing federal matching grants to the states for the categorical public assistance populations and others deemed “medically indigent” (at state option). Provisions included medical and skilled nursing services for the poor elderly and disabled, but continued to tie them to a welfare system run largely by the states. In the watershed year of 1965, “the nursing home issue was not confronted directly. Medicaid, hastily created and enacted, was only a sideshow in the health insurance circus” (Vladeck 1980: 51).

In the ensuing years, Medicaid has dominated public financing of long-term care services. The acute care-oriented Medicare program also pays for what can be labeled long-term care services, but these are nursing home or home health stays resulting from an acute care episode, which requires some extended rehabilitative care. As for the chronically ill and disabled populations, the financing story remains largely “Medicaid and you,” with the program paying 48 percent of all monetized long-term

care costs, with an additional 18 percent paid out-of-pocket by care recipients or their families (Gonyea 2010). On a more positive note, the locus of care funded by Medicaid dollars has been gradually shifting from institutional to home and community based care (HCBC) since enactment of Medicaid waiver programs, beginning in the early 1980s. HCBC accounted for only 10 percent Medicaid long-term care spending in 1988, with that proportion having risen to 40 percent in 2007 (Burwell et al. 2007).

A last major legislative episode sheds additional light on several elements of the preceding discussion. In the wake of Richard Nixon and Daniel Patrick Moynihan's failed attempt to revolutionize AFDC through a proposed Family Assistance Program, the Supplemental Security Income program emerged, bestowing benefits on the public assistance "adult categories" of 1935; the poor old and the poor blind (the low-income totally and permanently disabled were included in 1951, constituting the third of the adult groupings). SSI remained a public assistance program, but created a nationally guaranteed minimum benefit and, unlike the predecessor programs and AFDC, was to be administered (reluctantly and, initially, poorly) by the U.S. Social Security Administration (Derthick 1990). While it involved three categories of low income individuals, Congress presumed—quite correctly in 1973—that it was mainly about the impoverished old (Burke and Burke 1974). Little mention was made of people with disabilities, but SSI proved to be a major source of cash benefits for disabled individuals in the community. Whereas most aged SSI recipients were already receiving Social Security benefits, fewer than one in five people who had been receiving benefits under the predecessor Aid to the Totally and Permanently Disabled program were also Social Security recipients (Erkulwater 2006: 78). Over time, the balance of beneficiaries and payments shifted away from the aged and toward the disabled because OASI benefits continued to succeed in "withering away" the OAA/SSI program whereas SSI's disability benefit, in conjunction with a growing advocacy movement within the disability community, served to lend both monetary support and legitimacy to the disability rights movement.

In the period immediately prior to the passage of ACA and the CLASS Act, long-term care continued to be a social problem firmly lodged in a residual policy world. For the aged, the principal connection was to Medicaid and only modestly to SSI. And even though formal care provision has increased and complemented family care, informal care provision remains dominant, with 66 percent of older adults living in the community relying on informal supports alone and an additional 26 percent rely on a combination of formal and informal supports (Gonyea 2010). Moreover, a substantial majority of those informal caregivers are women (Stone et al. 1987; Harrington-

Meyer 2000). In absolute terms, the public sector's role has grown, largely through the Medicaid program, but as a state-administered and partially state-funded public assistance program, it remains firmly in policy's residual world. For people with disabilities, the residual legacy lay primarily in state-level institutional care and a problem definition based on their individual inabilities and to a somewhat greater degree on SSI cash benefits. For both populations, the CLASS Act brings a cash benefit and eligibility based on insurance rather than poverty to long-term care.

The CLASS Contribution

The CLASS Act and selected other provisions found in ACA represented a major turning point in public long-term care policy for the chronically ill old and people with disabilities. It was not a complete transformation—indeed, some observers felt that it was not transformative enough—but it was nonetheless unprecedented in concept and might have proven to be in operation. In the context of the present discussion, the CLASS Act departed from the world of public assistance and clearly if incompletely entered the world of social insurance. In so doing, it went further than any preceding legislation in moving long-term care away from its historical residual standing.

In brief, CLASS was a voluntary, consumer-financed, publicly-administered, cash benefit insurance plan (Manard 2010). By itself and in conjunction with other provisions found in ACA and allied legislation, it brought long-term care policy into a more normative and universal policy world than it had ever before occupied. These putative gains can be seen along each of the program dimensions discussed above.

The key advance around program eligibility was, of course, the introduction of social insurance principles to long-term care. As do Old Age, Survivors, Disability Insurance and Medicare, the CLASS Act defined long-term care needs as insurable events that should be addressed through public auspice. Thus long-term care was understood as a risk that might befall anyone and, in anticipation of the possibility of that risk occurring, a risk for which resources should be pooled and safeguarded. This was a major advance over the historical understanding that long-term care needs were a condition that one must either endure alone, or perhaps in the company of family, charitable, or public assistance.

The conceptual advance noted, the CLASS Act did not meet the complete test of social insurance. Voluntary enrollment would have very much limited the universal feature associated with social insurance. As had been widely noted, and was a principal factor in the legislation's downfall, the program ran severe adverse selection risks in that those most likely to enroll were those who had or had reason to think they

might develop chronic or disabling conditions. In what might be termed actuarial understatement, Tumlinson, Ng, and Hammelman (2010: 28) observed, “The CLASS Act has generated a great deal of interest because it does not exclude individuals from enrollment based on health status, and yet it does not mandate that individuals participate.” Depending on the eventual participation rate, premiums under the program could have varied from \$62 per month (at a 30 percent participation rate) to \$124 per month (at a 5 percent participation rate) (Tumlinson, Ng, and Hammelman 2010). The CMS actuary posited the possibility of a \$240 monthly premium if the program generated only a 2 percent participation rate (Foster 2010). Firmly believing that insisting on mandatory coverage would have earlier doomed the CLASS proposal, advocates made this concession and openly conceded the difficulties it presented (Manard 2010).

Nonetheless, inclusion of the CLASS Act in health care reform was an historic breakthrough in long-term care policy. Instead of being based on demonstrated poverty and current functional impairments, program eligibility was based on an insured status that neither required that one be poor or to become impoverished. In this regard, the CLASS Act joined two other recent insurance initiatives directed toward long-term care: private long-term care insurance and state-based public/private long-term care partnerships. Private long-term care insurance policies have been available for several years, though they continue to account for less than 10 percent of formal long-term care expenditures, are relatively expensive, and are often denied to those with a range of pre-existing conditions. More intriguing have been so-called Medicaid/private long-term care insurance partnerships, which allow individuals to preserve assets equivalent to the private long-term care insurance coverage they have purchased at such time as they must resort to services through Medicaid (Pasaba and Barnes 1996). In speaking of these insurance variants, Doty (2010) observes: “what public, private, and public/private long-term care insurance approaches all have in common is that policyholders become eligible for benefits based on meeting a threshold of disability severity, not based on whether they qualify for an institutional level of care and whether or not third-party payers would prefer them to receive less expensive services in other settings” (p. 8).

Beyond introducing the social insurance paradigm to long-term care, the CLASS also introduced cash benefits. While this was not a novel notion within the disability community—where the line between income and care support has become increasingly narrow—a cash benefit for chronically ill elders was a significant development. Cash benefits have often been circumscribed in public assistance programs because of the belief and/or the reality that recipients either could not or

should not be able to spend freely. The poor could not be trusted, and those in need of health, mental health, or personal care services could not be expected to make informed decisions. The cash benefit under the CLASS Act moved the beneficiary from services client to services consumer, with the question of choice central to the distinction (Simon-Rusinowitz et al. 2010).

In particular, the cash benefit concretized the overwhelming preference people have for community-based rather than institutional care. CLASS benefits would have unquestionably accelerated the shift long underway in Medicaid programming toward home and community-based care. Moreover, within the world of community-based care, CLASS would have helped sustain so-called “cash and counseling” initiatives, which give long-term care consumers a wide degree of choice in arranging for their own care (Doty, Mahoney, and Sciegaj 2010). Control—whether onerous or beneficent—has long been a hallmark of residual programs; choice is associated with the autonomy, acceptance, and legitimacy that accompany social insurance. The CLASS Act extended such consumer choice to long-term care.

The pooled insurance cash benefit as part of the CLASS Act also partially augmented long-term care policy’s remedial approach to need by adding at least an ounce of prevention. The preventative idea in social insurance is seen most distinctly in the case of Social Security, where benefits both prevent precipitous drop in income and economic need not having to be demonstrated. Long-term care policy differs in necessitating some measure of functional impairment before benefits are forthcoming, but under CLASS these payments would have come independent of economic need and could have been used by consumers—and especially by a consumer’s family caregivers—as an income as well as a care support.

The CLASS Act’s having been about cash and, in turn, about choice would have contributed to the paradigm shift in long-term care service delivery noted earlier. Leery of being caught up in the unappealing policy world of long-term care, federal officials long kept the states on a short leash when it came to expenditure of federal matching funds. Even with the introduction of Medicaid waiver programs, they usually required that community-care residents have the same level of impairments as those individuals in skilled nursing facilities and for a period insisted that community-care provision be accompanied by a corresponding reduction in nursing home beds (Doty 2010). These strictures were loosened somewhat grudgingly over time, as a growing popular and professional consensus emerged that there was more value to community-placement than presumed budgetary savings.

As a result of liberalization of Medicaid programming and in the presence of other community-based entities, there is now in place an extended world of long-term care

service planners and providers. Yet, there is a well-documented lack of coordination and considerable degree of competition among many of these entities. What cash-carrying CLASS Act beneficiaries would have encountered upon entering this thicket of agencies remains a great unknown. They would not only have been feeling their way through the new world of “consumer preference versus professional judgment,” but they would have also potentially been dealing with multiple agencies whose interventions were colored by organizational concerns as well professional judgment. Where a client or consumer enters the so-called system, what services are available, who runs them, and how they are paid for would have likely continued to be a source of endless frustration. By itself, CLASS would have done little to remedy this state of events; indeed, in the absence of other initiatives, CLASS-generated benefits could have sown further confusion by introducing significant new unchanneled resources to this unwieldy enterprise.

Of course, policymakers and analysts have been keenly aware of these difficulties on the ground and have designed a host of interventions to overcome them. This noted, the sheer number of such initiatives itself has been cause for possible concern. The following items, as part of ACA and allied legislation and administrative actions in recent years, are in place or in various stages of development: State Balancing and Incentive Payments program; Community First Choice Option; Removal of Barriers to Providing Home and Community-Based Services; Money Follows the Person demonstration; the National Pilot Program on Payment Bundling and Related Provisions; Choices for Independence Initiative, including Aging and Disability Resource Centers, the Nursing Home Diversion program, and Evidence-Based Disease Prevention programs (O’Shaughnessy 2008; Wiener 2010). If it proves difficult for program administrators to keep these all straight, one can only imagine how consumers may struggle with this new alphabet soup. As Shugarman (2010) observes, in the absence of service delivery improvements emanating from some combination of these initiatives, CLASS would have represented something of a pyrrhic victory, with participants being “enriched with new purchasing power for needed long-term care service but would still have the same broken system to navigate.”

Yet, acknowledging problems that may arise from this administrative “noise,” the longer range view cannot lose sight of the advances CLASS would have represented and which community-based care continues to represent. Until the 1970s, long-term care was largely about institutional care, administered in a highly regulated, largely inflexible, not infrequently corrupt manner on behalf of the most vulnerable members of society. To make community alternatives available to a wider range of beneficiaries

able to participate in their own care decisions was clearly a step forward. But it also brought its own set of challenges.

The financing of CLASS, while a notable break with Medicaid's reluctant claim on general revenues, emerged nonetheless as "social insurance light." Its voluntary nature clearly limited both the volume and make-up of the risk pool. Its having been consumer-financed, even though publicly administered, rendered it closer to private long-term care insurance than the progressive funding associated with social insurance schemes. The monthly premium for low-income enrollees and students would have been only \$5, and premiums would have been age-graded, but there was no added progressivity, such as that associated with the major social insurance programs which "are designed to address such social purposes as alleviating poverty, providing added protection of families versus single workers, and providing a larger degree of earnings replacement for low-paid versus high-paid workers" (Committee on Ways and Means 1998: 5). The provision that "no federal taxpayer funds shall be used for payment of benefits" (Manard 2010: 2) also served to underscore that the CLASS Act was not an entitlement program, that is, one where the federal government is obligated to support all eligible program participants independent of fixed appropriations.

Finally, cash benefits derived from the CLASS Act being tightly tied to work in the case of younger people with disabilities and accumulated premiums in the case of older people with chronic illnesses underscored the last salient feature of the law, that of promoting personal responsibility. While enactment of CLASS meant that we would no longer target benefits only on those deemed unable to help themselves, it did not mean that the government would provide benefits—beyond those based on dedicated premium payments—to those who could and should have addressed their current needs or planned for their future needs. The government would have been in the position of encouraging and facilitating the creation of a long-term care insurance pool, but it would not have assumed added responsibility for guaranteeing or augmenting benefits generated by that pool. In what Marmor, Mashaw, and Harvery (1990) refer to as "America's Opportunity/Insurance State," CLASS represented a hybrid in which the government would have provided the opportunity to insure oneself against the costs of disability and long-term care. Unlike Medicaid, CLASS recognized chronic illness and disability as risks rather than conditions, but it limited its own exposure to costs associated with those risks more than in any other social insurance program.

Yet, despite these strictures, a combination of political resistance and operational concerns has suspended, and one must presume ended, the addition of long-term

illness and disability to the list of risks against which American government insures its citizens.

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CHAPTER 5

FREE PERSONAL CARE IN SCOTLAND, (ALMOST) 10 YEARS ON

DAVID BELL AND ALISON BOWES

Introduction

The structure of long-term care finance in the UK is characterized by a multiplicity of funding streams, conflicts over responsibility for care, and incomplete insurance. This results in genuine hardship for those that are unlucky enough to have no “safety net” to meet the costs of their care. Over the last two decades, there has been considerable pressure to find a better solution—to get from “here to there.” But, progress has been limited.

Since 1998, the process of devolution has led to the establishment of a new parliament in Scotland and assemblies in Wales and Northern Ireland. These ‘devolved bodies’ control a variety of policy areas, including the delivery of health care and long-term care (Bell 2010). They have used these powers to develop different long-term care policies.

Unlike US states, the devolved bodies have virtually no fiscal powers and therefore cannot use tax revenues to fund improvements in long-term care. They also have no powers to regulate financial markets and therefore cannot directly influence the private market for long-term care insurance. Financial regulation is entirely a matter for the UK government. So is the social security system, which, as we shall see, plays an important role in supporting those with long-term care needs.

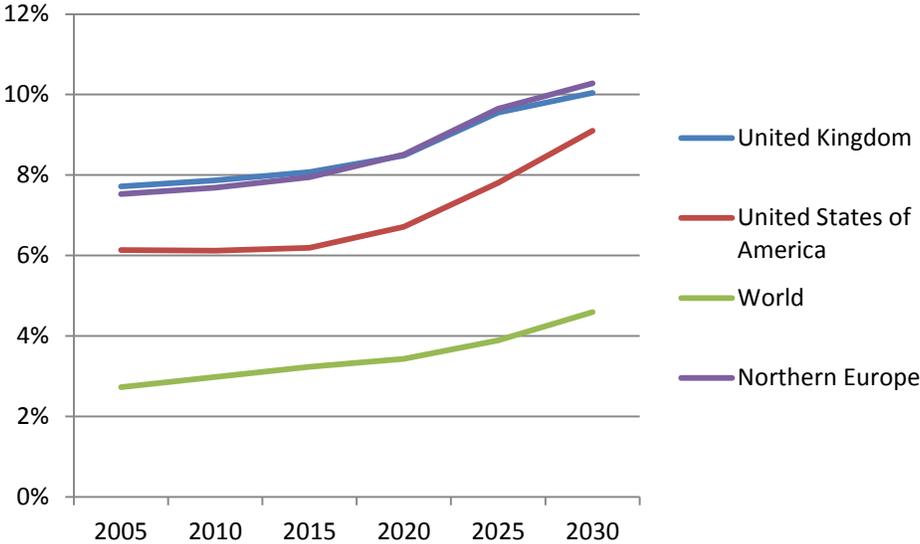
But devolution has allowed differences to emerge in the delivery mechanisms for long-term care across the constituent nations of the UK. This chapter focuses on one of the major differences that has emerged since devolution—the provision of free personal care to older people in Scotland.

We begin the chapter by describing the demand and supply of long-term care for older people in the UK. We then discuss long-term care financing in the UK, focusing on its recent history and on current efforts to “move it to a better place”. There are similarities with the US system, but also some important differences. Finally, we describe the costs and benefits of the provision of free personal care in Scotland and distil some lessons for a US audience.

Organization of Long-Term Care in the UK

Like many countries, the UK has an ageing population. Figure 1 shows that by 2030, around 10 percent of the UK population will be aged 75+. For the UK, this implies a 47 percent increase among this age group over the next 30 years, while for the US, the increase in the proportion of the population aged 75+ the increase will be 81 percent. Figure 1 shows that the demography of the UK is similar very similar to that of the rest of Northern Europe. Although the US currently has a much lower share of those aged 75+, it is expected to catch up with Northern Europe over the next 30 years. And while the proportion of the world's population aged 75+ will almost double by 2030, it will still be less than half of the share in Northern Europe.

Figure 1: Population Aged 75+ As a Share of Total Population 2010-2040



Source: United Nations Population Division (2011).

From a UK population of 61.8 million in 2009, there were 4.8 million aged 75+ (See Table 1). England is the largest part of the UK, accounting for 83.8 percent of the UK population and an almost identical share of those aged 75+. Table 1 also shows that Scotland and England have a very similar share of population aged 75+, the age group most likely to require long-term care.

Figure 2 shows recent estimates of years of poor health and of disability in different parts of the UK. Northern Ireland and Wales have generally higher levels of poor health and disability than Scotland and England. Whereas the average woman in

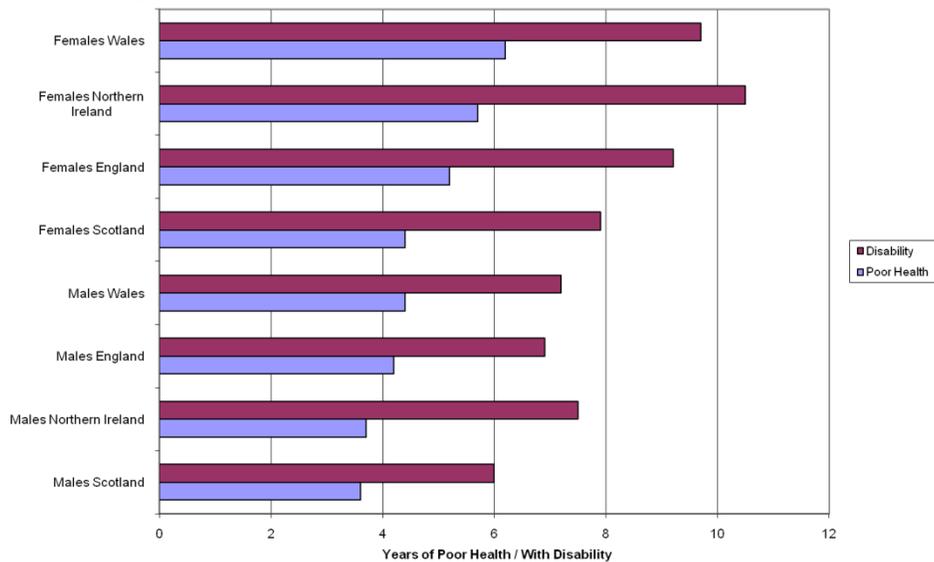
Northern Ireland can expect to experience 15 years of disability, males in Scotland are disabled on average for only six years. In Scotland and England, expected periods of ill health/ disability are roughly equal. The broadly similar levels of disability in Scotland and England reduce one major source of variability when comparing policy outcomes.

Table 1: UK Population 2009

Population	United Kingdom				Northern Ireland
	Kingdom	England	Scotland	Wales	Ireland
Total	61,792	51,810	5,194	2,999	1,789
Share of UK	100.00%	83.80%	8.40%	4.90%	2.90%
Aged 75+	4,820	4041.2	399.9	257.9	114.5
Share of UK	100.00%	83.80%	8.30%	5.40%	2.40%

Source: Office of National Statistics (2008).

Figure 2: Expectation of Years of Health and Years of Disability, UK Nations



Source: Office of National Statistics (2008).

In the UK, long-term care is provided in a variety of residential settings, including clients' own homes. Care homes typically cater for those with greater needs. Care homes are provided by the private sector, voluntary and charitable organizations and local government. In England in 2009, 8.6 percent of places were provided directly by local authorities. In Scotland, 16.9 percent of care home places for those aged 65+ were provided by local authorities in 2009. Although the local authority share in Scotland has been falling, local authorities themselves provide relatively more care home places than in England. This may reflect Scotland's greater historic reliance on public sector solutions to care provision.

The cost of providing long-term care is shared between the private and public sectors. In the public sector, long-term care is largely the responsibility of local government. In the UK, local government only raises around 20 percent of the money that it spends. The remainder comes from grants. The bodies that provide grant aid to local authorities¹ are therefore in a powerful position to influence their long-term care policies. Rather confusingly, the relevant grant-providing body to local authorities in England is the UK Parliament; in Scotland, it is the Scottish Parliament, while in Wales and Northern Ireland, it is their respective Assemblies. And Northern Ireland is an exception in that its local authorities do not manage long-term care. Instead, the Health and Social Care Board, which was established in 2009, manages health and social care services jointly across Northern Ireland. It receives around £4bn annual funding directly from the Northern Ireland Assembly.

The Organisation for Economic Co-operation and Development (OECD) estimates that in 2000, the UK and USA spent broadly similar amounts on long-term care—1.37 and 1.29 percent of GDP respectively (see Table 2). In one sense, this is surprising. The latest OECD estimates of health care expenditures show that in 2009, the USA spent 16 percent of its GDP on health care compared with only 8.7 percent in the UK. In the USA, 46.5 percent of health spending came from public sources, while in the UK, 82.6 percent of all health spending was paid for from public funds. In relation to its GDP, the USA spends much more than the UK on health care and the public sector is much less important as a purchaser of health care. The health and long-term care sectors are closely linked. So the similarity of overall long-term care expenditures in the UK and USA is remarkable, given the vast differences in the volume and composition of health expenditure in the two countries. In the USA, over 40 percent of long-term care expenditures are paid by Medicaid. Thus, the balance between private and public support for long-term care expenditures in the USA is broadly the same as the balance in health care spending.

One very noticeable difference in long-term care expenditure however, is the difference in public support for care provision at home. In 2000, the UK spent 0.32 percent of GDP on home care provision, while the US provision was much less generous, at only 0.17 percent. These statistics are consistent with Gleckman’s argument (this volume) that “[s]tate home care programs remain optional, vary widely in scope and quality, and are often underfunded. As a result recipients face either limited benefits or long waiting lists” (p. 41).

Table 2: Public and Private Expenditure as a Percentage of GDP, 2000

		UK	USA	OECD Average
Total Expenditure	Home Care	0.41	0.33	0.38
	Institutions	0.96	0.96	0.88
	Total	1.37	1.29	1.25
Public Expenditure	Home Care	0.32	0.17	0.35
	Institutions	0.58	0.58	0.64
	Total	0.89	0.74	0.99
Private Expenditure	Home Care	0.09	0.16	0.06
	Institutions	0.38	0.39	0.54
	Total	0.48	0.54	0.24

Source: OECD (2005) Table 1.2

The estimates in Table 2 are likely to significantly under-represent the current importance of home care provision in the UK, because a number of policy initiatives have taken place since 2000 aimed at extending long-term care provision at home.

Focusing on those aged 65+ with long-term care needs, gross public expenditure in England was £9.3bn in 2009/10. Local authorities recovered £1.93bn of these costs mainly in user charges, implying net public expenditure of £7.4bn. In Scotland, in 2008/09 gross expenditure on older people was £1.5 billion and net expenditure was £1.2bn. Charges comprised £201m, with a further £130m coming from other contributions. User charges understate the overall private sector contribution since

private care homes and privately purchased care at home are not covered by these data. These are not thought to be of great importance, however.

But local authorities are not the only government agencies supporting long-term care needs in the UK. Cash support for those with care needs is also provided by the UK Government through the Department of Work and Pensions (DWP). Social security and welfare benefits are determined for the UK as a whole by DWP. The devolved bodies do not determine either their level or their coverage. There are two principal cash benefits for those with care needs: Attendance Allowance (AA) and Disability Living Allowance (DLA). AA is only available to those aged 65+, while DLA must commence before age 65, but can be continued beyond 65. Both are available to individuals that are deemed by a medical practitioner to need help with things such as washing, dressing, eating, getting to and using the toilet, communicating needs, requiring supervision etc. The current upper rate for AA and DLA these benefits is £71.40 per week. In May 2010, there were 1.9 million individuals aged 65+ claiming these benefits, 19 percent of this age group. The total cost of Attendance Allowance in 2009-10 was £5.3bn. Assigning DLA pro-rata by age, a further £1.3bn was paid to DLA claimants aged 65+.

AA and DLA are cash benefits to compensate for care needs. Horton and Berthoud (2010) argue that it has never been clear whether these benefits were intended as a contribution to the costs of care or to pay for the extra expenditures faced by people with disabilities. Based on a relatively small sample of clients, they argue that AA “was seen by most claimants as a component of their general income, aimed at maintaining or improving their standard of living, rather than as a direct contribution to the costs of caring” (p. 77). Hancock et al. (2004) argue that although that one might expect AA would be allocated on the basis of care needs, in fact the odds of receiving higher-rate payment depend on income, with poorer people more likely to receive higher-rate awards; on the type of disability, with bias in favor of physical rather than mental disability and on age with bias towards the young disabled.

Importantly, neither AA nor DLA is means tested. This makes these benefits almost unique in the UK social security system, which is almost exclusively based on means testing. They therefore contrast with Medicaid, the primary source of long-term care funding in the US, which is means-tested. However local authority support for long-term care in the UK is also largely means-tested.

The existence of two quite different funding streams to support long-term care in the UK illustrates the disjointed nature of UK long-term care policy. Care clients find this

complex system very difficult to understand. The development of different policies in different parts of the UK adds further to the complexity. In this chapter, we will focus on one component of this—the policy of providing free personal care (FPC) to those aged 65+ in Scotland. For a US audience, one interesting aspect of this has been the rapid expansion of home care in Scotland, paralleling the provision of FPC. But to understand the genesis of the FPC policy, we need to trace the recent evolution of long-term care policy in the UK as a whole and to understand the mechanisms for financing long-term care.

Long-Term Care in the UK: Recent History

An important starting point for a recent history of long-term care policy in the UK is the establishment of the Royal Commission on Long-term Care in December 1998 by the Labour Government under Tony Blair. The Commission was established as a response to widespread concern about long-term care provision throughout the UK. Major deficiencies of the system were seen to be:

- The absence of effective private or public insurance to spread the risks of care costs. Consequently, those spending extended periods in care homes had to use a large proportion of their assets to support their care.
- Unmet needs due to local authorities' being unable to meet demand within their fixed budgets.
- Wide, and seemingly arbitrary, divergences in provision of long-term care between local authorities. In the UK, this is popularly described as a “postcode lottery” (The US equivalent would be a “zip code lottery”).

In addition, the Commission was asked to determine whether any proposed changes to the care system would be consistent with projected changes in the older population and in expected years of disability.

The majority report of the Royal Commission (Royal Commission on Long-Term Care 1999) recommended that the costs of nursing and personal care should be paid for by the state, but that hotel charges paid in care homes and other assistance people received at home should continue to be means-tested. It argued that personal care should be funded through general taxation and based on assessed need. But a minority report, signed by two of the Commissioners, argued that only nursing care should be provided free, and that some relaxation of the means testing system should be implemented. But, in its view, free personal care was unaffordable.

The recommendations of both the majority and minority reports were contingent on definitions of types of long-term care. For US readers, an understanding of these definitions is essential to an appreciation of recent long-term care policy in the UK. The two main types of care are nursing care, which is care involving the knowledge or skills of a qualified nurse; and personal care, which is care involving one or more of the following:

- personal toilet (washing, bathing, skin care, personal presentation, dressing and undressing);
- eating and drinking (as opposed to obtaining and preparing food and drink);
- managing urinary and bowel functions (including maintaining continence and managing incontinence);
- managing problems associated with immobility;
- management of prescribed treatment (e.g., administration and monitoring medication); and
- behavior management and ensuring personal safety (for example, for those with cognitive impairment—minimizing stress and risk).

There are other forms of support that relate to other services which disabled or frail individuals may require, including:

- for those living at home, household tasks such as shopping, cleaning and food preparation. It is recognized that these may provide an important preventative role resulting in reduced demands on the health service and on care homes;
- for those living in care homes, accommodation and meals.

Throughout the UK, the general presumption is that these other forms of support will be chargeable if provided or commissioned by a local authority. They can also be purchased privately. Local authority provision is likely to be means tested, whereas privately purchased care must be paid in full. Thus, for example, care home charges averaged £500 per week in 2009/10 (\$41,600 per annum) (Forder and Fernandez 2009). Of this, an estimated £267 per week (\$22,300 per annum) comprises charges for food and accommodation. Care home places will be purchased by local authorities on behalf of some clients, while others will meet their own charges privately.

The majority report argued that personal care should be treated as if it was part of the National Health System: it should be free at the point of delivery. The report suggested that the boundary of free health care provision should be extended to include personal care, even though personal care does not require the intervention of a

trained nurse. One of the more powerful supporting arguments was that if a cancer patient could expect to receive free treatment paid from general taxation, why should the same not apply to someone suffering from dementia? This argument was described as "diagnostic equity:" if individuals suffer from potentially terminal illnesses, it was deemed inequitable that the state should fully insure against the costs of one disease, while expecting those who contract another disease to meet all of their non-health costs.

Nevertheless, the UK government implicitly accepted the minority report and did not implement the Royal Commission's free personal care (FPC) proposal in England. The principal ground for its rejection was that the policy would be unaffordable in the light of future demographic change. But it also rejected the proposal on grounds of equity. The argument was that the removal of charges for personal care would mainly benefit relatively affluent older people. Those who could not afford to pay such charges would not gain from the introduction of FPC.

To follow this argument requires some detailed understanding of the system of charging for long-term care in the UK. So we now explain the key aspects of the UK charging system.

The system of charging for long-term care in the UK is complex and disjointed. The Law Commission (2008) described the current legal framework as:

The legislative framework for adult residential care, community care and support for carers is inadequate, often incomprehensible and outdated. It remains a confusing patchwork of conflicting statutes enacted over a period of 60 years. There is no single, modern statute to which service providers and service users can look to understand whether services can or should be provided, and what kinds of services (p. 129).

Similarly, the King's Fund (2009) argued that:

The current system for funding adult social care in England has been criticized as unfair, complex and financially unsustainable. There are significant local variations in who is eligible for what kinds of support and a host of complicated local and national rules that apply to the funding of different elements of social care services (p. 1).

Charges for long-term care are determined by local authorities, but the UK government and devolved bodies have issued guidelines that they hope will result in a

degree of consistency within their respective territories. Even though this process has led to greater consistency in charging structures and levels, the rules are still complex.

As in the US, care charges in the UK, are mainly based on means tests. The assessment of assets is critical to the means-testing process. Currently, most individuals in the UK with assets over £23,000 (\$36,800) are expected to pay their care home charges in full. Those with assets of less than £14,000 (\$22,400) in England and Scotland will have their charges fully met, but must contribute all of their income towards the costs, less £22.30 (\$35.70) per week which they are permitted to retain for their own spending. Those with assets between £14,000 and £23,000 have their charges increased by £1 each week for each £250 (\$400) of assets over £14,000.

The value of an individual's home is included in the means test from 12 weeks after entry into a care home unless a spouse or partner continues to live there. In recent years, home ownership rates in the UK among older people have increased sharply. This has had important consequences for care charging. The home ownership rate for those aged 50-64 is 79 percent and for those aged 85+ the rate is 61 per cent. Only one in five pensioners has a mortgage. In November 2010, the average UK property was worth £165,000 (\$264,000). Given that the value of the average house massively exceeds the current asset limit of £23,000 and the majority of older people have housing equity that exceeds this limit, a large proportion of homeowners are expected to meet the full costs of their care. Typically older people are "asset rich and income poor". Unable to meet their weekly care home charges from income, many are forced to sell their houses or purchase a "reverse mortgage". This causes a significant amount of distress to older people and the potential beneficiaries of their estate. It is also a significant disincentive to saving, since those with assets whose value falls below the lower capital limit do not have to pay for their care. Older people therefore have an incentive to reduce their assets before they have any contact with the care system. Local authorities have the unpopular task of preventing asset transfers – such as gifts to children – that reduce liability for care home fees. Those who do not want to sell their home to pay care home fees may be able to apply for a deferred payment agreement whereby the local authority provides an interest free loan that is recouped from the individual's estate after death. In effect the local authority acts as a surrogate bank, providing credit at beneficial rates to pay for care home charges. But estate recovery policies vary widely between local authorities. This is reminiscent of the variation in effort by states to recover Medicaid costs from clients' estates (Fox-Grage 2006). There is a strong incentive for recovery in the UK, because none of the recovered funds are returned to the bodies that fund local government. In contrast, in

the US, a proportion of recovered funds are returned to the federal government. Hence, there is less to be gained from recovery in the US.

Commercial capital markets have not been successful in solving the problem of providing long-term care insurance in the UK. The private insurance market has failed to provide products that are simple, good value and readily available to protect against care risks. Until 2004, long-term care insurance plans were not regulated by the Financial Services Authority, which has the duty of protecting consumers in financial markets. Consumer confidence might have been increased had regulation been introduced earlier or if there had been some public-sector involvement in the products. An example of the latter would be a guarantee that insurance company liability would be time-limited and replaced by public sector funding after a fixed period, say three years. But successive governments and the insurance industry jointly failed to introduce innovative products that would be attractive to both the public and to insurance companies. As a result, there is virtually no market in long-term care insurance in the UK. This contrasts with around 10 percent coverage amongst those aged 60 and over in the US (Brown and Finkelstein 2009). The only product with some market share is the immediate needs annuity, which provides a contribution to the costs of those who already know that they require care. As an example, a woman aged 80, realizing that she needed nursing care, would have to pay a premium of around £54,500 (\$87,200) to buy an annual income of £12,000 (\$19,200) to set against care costs.

Now returning to the minority report in the Royal Commission, the equity argument against the introduction of FPC was that it would only benefit more affluent older people. This is because the means testing system ensures that the relatively poor have their care entirely paid for by the state. This group would not benefit from FPC. The affluent, who could pay for their personal care, would clearly benefit. Those whose assets placed them modestly above the capital limits, but who have little income, would also gain. This group typically comprises those in the third and fourth age-specific household income deciles. It was argued that a more effective use of public funds would be to focus assistance on this group rather than to provide FPC as a universal benefit. One way to achieve this objective might be to make the means test less restrictive.

In England, there have been a number of enquiries into care funding since the Royal Commission. Most notable among these, the Wanless Review (King's Fund 2006), reported in 2006. It rejected FPC, favoring rather a "partnership model", which would entitle individuals to a minimum guaranteed amount of care. Thereafter clients would

be expected to contribute to the costs, with the state matching the contribution up to some limit.

But no legislative action was taken to put the Wanless proposals in place. And, at the May 2010 election, any hope for a political consensus on funding long-term care evaporated. With politicians keen to knock down any proposals put forward by their opponents, progress was impossible. Suggestions for a compulsory single-premium insurance taken out at age 65 were rejected. A national policy to recover care costs from a person's estate after death was labeled emotively as a "death tax." From a public finance standpoint, it may seem irrational that housing wealth is not seen as a legitimate source of funding for long-term care. But, in the UK, estate duty—a tax on individuals' estates after death—is highly unpopular. However, there is also a growing lobby that suggests that the "baby boomers" have been a particularly lucky generation. If future generations cannot expect the same good fortune, then, in the interests of intergenerational equity, perhaps the baby boomers should be expected to make the main contribution to the costs of their care rather than the (younger) taxpayer.

The new UK government that came to power in May 2010 has established yet another commission to look into all of the issues around the funding of long-term care. It will report in 2011. It is assumed that the intention of its establishment was to provide a funding solution for England. However, within its terms of reference, the commission is to consider changes to disability-related benefits for older people, such as AA and DLA. These apply to the whole of the UK, not just England. So the commission's deliberations may indirectly influence long-term care in the rest of the UK. Confusion reigns.

Thus, twelve years after the publication of the Royal Commission report, the UK government is still searching for a sustainable and equitable solution to the problem of long-term care funding in England. Getting from "here to there" in an English context has proved elusive. There has been widespread pressure from those who support those in need of long-term care, a general acceptance among politicians of all parties that "something needs to be done," but no significant progress, perhaps because long-term care does not have a high political priority.

Scotland has made some definite policy decisions. One of these is the introduction of free personal care for those aged 65 and above. In the next section, we review long-term care policy development in Scotland. We argue that the distributional consequences of FPC have been as described—it mainly helps the relatively affluent. But to focus on this outcome alone takes a narrow view of the policy, which has had a

number of intended and unintended consequences. And, if one takes a holistic view of both health and long-term care costs, the argument that the policy is unaffordable is less clear.

Free Personal Care in Scotland

In response to the Royal Commission, the Scottish First Minister, Henry McLeish, set up the Care Development Group with the task of looking into the implementation of a FPC policy in Scotland. It reported in 2001 (Care Development Group 2001); legislation was introduced in 2001 and the policy itself was implemented in July 2002. One of the key elements supporting the legislation was the definition of personal care:

...unless the context otherwise requires: 'personal care' means care which relates to the day to day physical tasks and needs of the person cared for (as for example, but without prejudice to that generality, to eating and washing) and to mental processes related to those tasks and needs (as for example, but without prejudice to that generality, to remembering to eat and wash).²

This was a less prescriptive definition than that of the Royal Commission. Inevitably, once the policy was introduced, its precise meaning was contested. The Scottish Government issued various guidance notes to local authorities with the intention of arriving at a definition agreed by all local authorities. In particular, the precise definition of "food preparation" led to disputes between the local authorities and the Scottish Government. The local authorities, seeking to contain costs, argued for a limited definition. This was hotly contested by carers and care recipients, and the Government was forced to revisit its guidance on several occasions.

Once a definition of personal care was agreed, another important aspect of the policy was the assessment of potential clients. A separate group was set up, the Care Assessment Group, to design a "single shared assessment" which was meant to streamline the way in which individuals' care needs were assessed. Previously individuals could be asked to undergo a number of different assessment procedures by different agencies such as social work, housing, NHS and occupational therapy to design a service package to meet their care needs. The single shared assessment was intended to allow one professional from a multidisciplinary team to assess individual need. It was hoped that the professional would then arrange services from all relevant agencies.

Social care funding had traditionally been "ring-fenced" within local authority budgets—resources allocated under this heading could not be reallocated to other local authority services. This had clear benefits, but also disadvantages. Some authorities spent beyond their allocations: ring fencing made it more difficult for them to defend this spending politically. Local politicians resented policy direction from the center. Ring fencing of most social care funding was abolished.

The FPC legislation simply prevented local authorities from charging for personal care. This meant that the local authority had a duty to provide personal care free once need was established through assessment. This obviated the need for ring-fencing – at least in respect of personal care. The Scottish government provided local authorities with additional resources to compensate for the loss of this charging income. The details of the FPC policy were:

- **For those in care homes**, the policy provided a flat rate weekly payment of £145. This payment was intended to compensate care homes for the costs that they incurred in providing personal care. A further £65 per week was added if the client was assessed as also requiring nursing care. Payments for nursing care were also introduced in other parts of the UK, typically at rates more generous than those provided in Scotland. Care home clients were still responsible for their "hotel" costs. Thus if the weekly charge for a care home was £500, a self-funding³ client requiring both nursing and personal care would receive a contribution of £210 per week from the local authority and would be required to meet the remaining £290 per week from their own resources. This could include contributions from state pensions and other benefits. Controversially, the DWP took the view that one of these benefits, AA, would not be payable to clients in Scottish care homes receiving FPC. This decision was based on a very strict interpretation of the AA rules and generated a substantial degree of political animosity to the DWP in Scotland.
- **For those receiving care at home**, the FPC policy meant that, so long as need was established, no charges would be levied for personal care at home. This was an open-ended commitment. It covered services from relatively modest packages of care to highly intensive arrangements that might require a carer to stay overnight or at weekends. Other forms of local authority domestic support continued to be charged. There is some evidence that charges for these services increased significantly after the introduction of Free Personal Care, though it is difficult to identify a clear causal link.

The introduction of FPC heralded a radical change in long-term care policy in Scotland. The popular view is that the policy was limited to the financial measures described above. However, in reality there were very significant organizational changes involving both health and social care provision that were linked with the policy, but which were not directly legislated. The primary example of this switch in emphasis from hospitals and care homes to care at home, which was described as “changing the balance of care.” This policy was specifically aimed at offsetting institutional bias.

Some local authorities were well prepared for the policy: others were not. Previously, local authorities had had considerable freedom to design their own social care policies. Some had already introduced elements of a FPC policy. This group found the transition relatively easy. Others had a very steep learning curve. There were inevitable arguments over whether the funds provided by the Scottish government to individual local authorities were sufficient to implement FPC.

Opponents of the policy argued that there would be large numbers of older people migrating from other parts of the UK to Scotland to take advantage of its more generous care provision. There is no evidence that such migration took place, though there are concerns around the Scottish-English border. This is largely a rural area, so the scale of movement is limited. The lack of extensive migration is not surprising, given the social and financial costs associated with moving as well as uncertainty over the future of care policy.

FPC particularly benefited those who would otherwise have had to pay for the full costs of their care. These were people with assets valued above £23,000. Thus the policy might have promoted diagnostic equity, but it was in another sense regressive. In Scotland, perhaps surprisingly, this aspect of the policy never became politically contentious, though, as mentioned previously, equity issues contributed to the rejection of FPC in England.

While “free personal care” was the phrase that grabbed the headlines, the policy should be seen as a catalyst in a wider exercise to change the structure of social care provision in Scotland. A key part of this was the impetus from long-term care clients, carers, politicians, and health and social care professionals to change the “balance of care”. This had the dual benefit of being what clients wished and of reducing average costs. It had high-level political support. The strategy of “Changing the Balance of Care” is part of the Scottish Government's set of performance indicators – the set of criteria by which it has chosen to be judged.

Some of these ramifications are shown in Table 3. The data are all drawn from Scottish Government statistics and cover the maximum time span available between 2000 and 2010. The first example of shifting the balance of care is the reduction in the number of geriatric long stay beds in hospitals. These were reduced by 39 percent between 2003 and 2008. The average weekly cost of geriatric continuing care services in hospitals was £1462 per week in 2009-10. This is more than double the average cost of a care home place. But care home places themselves declined by 4 percent for those aged 65+ and by 8.9 percent for all long stay residents between 2002-3 and 2009-10. So the decline in geriatric care beds was not offset by a compensating increase in care home places. Instead, there was a sharp increase in the number of people receiving FPC at home, the numbers increasing by 69 percent between 2002-3 and 2009-10.

Table 3: Indicators of Change in the Balance of Care in Scotland 2002-2010

Occupied Geriatric Long Stay Beds			
Year	2003	2008	% Change
Number	2,704	1,661	-39.00%
Number of Long Stay Residents Aged 65+ Supported in Care Homes			
Year	2002-3	2009-10	% Change
Number	32,248	31,082	-4.00%
Number of self-funders receiving FPC in Care Homes			
Year/Quarter	2002/Q2	2010/Q3	% Change
Number	7,068	9,922	40.40%
Number of Long Stay Residents Supported in Care Homes			
Year/Quarter	2002/Q2	2010/Q2	% Change
Number	38,529	35,082	-8.90%
Number of People Receiving FPC at Home			
Year	2002/03	2009/10	% Change
Number	27,372	46,277	69.00%
Local Authority Home Care Clients			
Year/Quarter	2004 Q2	2010 Q3	% Change
Number	69,433	64,839	-6.60%
% of people 65+ receiving personal care at home			
Year	2003	2010	% Change
Percent	44%	58%	32.90%
Home Care clients aged 65+ getting 10+ hours of care per week			
Year	2002/3	2009/10	% Change
Number	11,998	15,736	31.00%
% of people 65+ with intensive needs receiving care at home			
Year	2003	2010	% Change
Percent	26%	32%	26.30%
Total Hours of Home Care			
Year/Quarter	2004/Q2	2020/Q3	% Change
Number	545,564	673,521	23.50%

<i>(Table 3 continued)</i>			
<i>Number of self-funders receiving FPC at Home</i>			
Year/Quarter	2002/Q2	2010/Q3	% Change
Number	24,313	47,149	93.90%
<i>No. of emergency bed days in acute specialties for people aged 65+</i>			
Year	2004-5	2009-10	% Change
Number	2,811,417	2,859,999	1.70%
<i>NHS Delayed Discharges out within six week discharge planning period</i>			
Year	2001 (Jan.)	2010 (Oct.)	% Change
Number	1887	128	-93.20%
<i>Total Expenditure on Personal Care at Home</i>			
Year	2003-4	2008-9	% Change
Amount (£m)	128.8	273.7	112.60%
<i>Expenditure on FPC Payments in Care Homes</i>			
Year	2003-4	2008-9	% Change
Amount (£m)	65.3	79.3	21.50%
<i>Average Weekly Expenditure on Clients Receiving FPC at Home</i>			
Year	2002-3	2008-9	% Change
Amount (£m)	75.3	119.1	58.20%

Source: Author's compilation of Scottish Government statistics.

But this did not mean an overall increase in the total number of clients being cared for at home by local authorities. These declined by 6.6 percent between 2004 and 2010. Because local authorities now had a duty to provide FPC within the constraints of fixed budgets, they tended to reduce the provision of non-personal social care and increase charges for this type of service. The proportion of their client base receiving FPC increased up to 2010. Thus, an unintended consequence of the FPC policy was increased charges for services associated with non-personal care such as mobility, shopping etc. Increased charges may also have reduced demand, with care clients purchasing services privately.

Little is known about what has happened to these less needy clients who would previously have received local authority support. They may have become more reliant on unpaid carers or may be purchasing care from the private sector. There is a debate around whether reducing support for the less needy is cost effective in the long run. Some argue that early intervention can prevent more expensive episodes in the future, but the evidence for this is difficult to establish convincingly.

Local authorities adapted to supplying complex care packages for those living at home. Table 3 also shows that the number of clients receiving at least 10 hours of care per week and the proportion of people with intensive needs receiving care at home increased by 31 percent and 26 percent, respectively, between 2003 and 2010. The

shift to care at home resulted in a 23.5 percent increase in the number of home care hours provided by local authorities.

The number of "self-funders" in care homes increased by 40 percent between 2002 and 2010. The interaction of the means testing system and the trend towards increased home ownership may have increased the proportion of clients expected to contribute towards their care costs. There was a very dramatic increase of 93.9 percent in the numbers of self-funders receiving FPC at home between 2002 and 2010.

With a presumption towards care in the community, care homes increasingly focused on those whose needs could not be met in their own homes. So although the size of the care home population stayed roughly constant, average levels of disability of residents tended to increase.

What is the value of FPC to care home residents? A rough calculation might go as follows: the estimated average annual cost of a care home place in 2008-9 was £24,500. Given the size of the care home population, this implies that the total value of care home fees in Scotland in 2008-9 was around £860 million. Nursing care and FPC payments in care homes in 2008-9 cost £79 million. Around 30 percent of care home residents are self-funders. This suggests that FPC and nursing care payments cover around 29 percent of the care home fees of self-funders.

There is a widespread belief, which the media in England do little to contradict, that care homes are free in Scotland. This is obviously incorrect: the chance that a self-funding care home resident in Scotland will have to sell their house to fund their care is lower in Scotland than in England, but it is still significant.

But the more significant growth has been in the clients receiving FPC at home that increased from 24,300 in 2002 Q2 to 47,100 in 2010 Q3. This growth was not anticipated at the time the policy was introduced, and is well in excess of the increase one might predict from demographic trends. This implies that there was a reservoir of unmet need prior to the introduction of the policy. It also raises concerns as to whether assessment procedures were applied consistently, though this would be difficult to establish.

The average hours of care received by FPC clients increased from 6.9 hours per week on average in 2002-3 to 7.5 hours a week in 2008-9. There was a shift towards more intensive home-care packages. The average wage cost for such packages was around £13 per hour, making the average wage cost per package in 2008-9 just over £100 per week. Wages are the main component of home care costs. If one adds transport costs,

payroll taxes, training and administration costs, average weekly costs of home-care packages are still well below those in care homes. Average weekly expenditure per FPC client at home was estimated to be £119.1 in 2008-9.

Of course, patients in hospital typically have greater needs than those in care homes, whose needs in turn are greater than those receiving care at home. Nevertheless, there is some overlap between these categories and the development of intensive home-care packages has increased this overlap. And, the differences in costs are stark. On average, one week's care in a geriatric continuing care ward would buy 3.1 weeks in a care home or 12.3 weeks of average personal care packages delivered in the community. The case for community care is strengthened by clients' expressed preference to stay at home. Hospitals and care homes may provide greater quality, security and safety. But, these effects must be very strong to overcome both the cost advantage and client preference that argue in favor of focusing policy on care in the community.

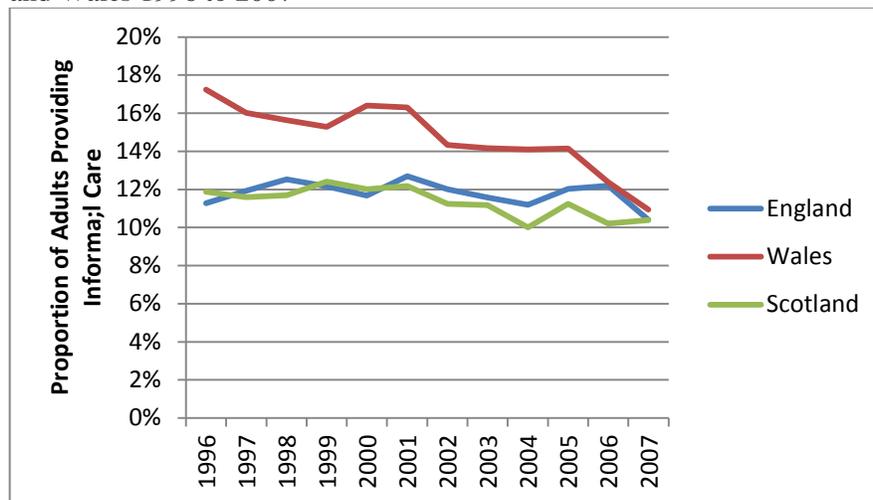
Another change in policy affecting the demand for personal care is the drive to reduce the number of delayed discharges of older people from hospitals. Frail older people are sometimes held in hospital because no suitable accommodation can be found in care homes or in the community. The beds they occupy can be put to other uses. Such "bed blocking" is an impediment to the efficient running of hospitals. Often those discharged required personal care. Table 3 shows that this policy has been quite successful. Between 2001 and 2010 the number of delayed discharges was reduced by 93 percent. But, though the net effect on costs, efficiency and patient satisfaction may be positive, the increased demand for personal care increases the costs of free personal care to local authorities. With fixed budgets and legal responsibilities to provide other services such as education and transport, their ability to respond is constrained. This raises the issue of whether hospitals should transfer funds to local authorities to facilitate the reduction in delayed discharges. This happens to a limited extent.

Our own research on the impact of FPC on unpaid carers showed that it presented opportunities for carers to make choices about the care they give. It also enabled the overall quantity and quality of care to increase. In respect of choice, our qualitative work (Bell and Bowes 2006; Bell, Bowes, and Dawson 2007) suggested that carers welcomed the possibility of not delivering personal care for their relatives. It seems that they had voluntarily provided this, but that once it was free, they preferred to withdraw. However, and this is contrary to some expectations about the effect of the policy, they did not withdraw from care altogether, but switched to performing other tasks. Examples included more social visiting and more taking the person they cared

for on outings. Estimates of the aggregate quantity of care given following the introduction of FPC showed that Scotland did not differ significantly from England: this serves to corroborate our finding that substitution rather than withdrawal was occurring, and that the second opportunity—an increase in the quantity and quality (more social activity) of care following the introduction of FPC—was also occurring.

Information on care provision by friends and relatives is available from GB-wide household surveys. The Family Resources Survey is an annual survey of representative households. Figure 3 shows the proportion of adults giving care, either

Figure 3: Proportion of Adults Providing Informal Care: England, Scotland and Wales 1996 to 2007



Source: Author's analysis of Family Resources Survey data.

in the home or outside the home, respectively. One argument raised in opposition to FPC was that it would cause a reduction in unpaid care. There is no prima facie evidence in its favor from the trends in unpaid care provision in Scotland, England and Wales shown in Figure 3. In particular, the proportion of unpaid carers in Scotland and England is approximately equal throughout the period.

Conclusions

What are the policy lessons for the US from the Scottish experiment in FPC? The first, perhaps surprising point is that there are many points of similarity between the UK and US systems for funding of long-term care. Both countries largely use means tests rather than entitlements as the basis for allocating funds to those requiring long-

term care. In both countries the private long-term care insurance is weak. Both systems are complex and disjointed with public funding coming from different levels of government. Reform has been slow due to the difficulties of establishing political consensus and urgency around long-term care. These points of similarity are surprising given the significant differences in the organization of the health care systems in the UK and the US.

Scotland has introduced the most significant change in long-term care funding in the UK over recent decades. For those in care homes it has introduced a flat rate contribution to pay for personal care. For those receiving care at home it no longer allows local authorities to charge for personal care. Free personal care has become an entitlement in Scotland, but not in the rest of the UK.

The obvious drawbacks around its introduction are its future affordability given demographic change, and the extent to which it provides a subsidy to the relatively rich who could afford to pay for their care. But it has promoted "diagnostic equity" between conditions requiring long-term health interventions and those requiring long-term care—obvious examples being cancer on the one hand and dementia on the other.

Nevertheless, the introduction of FPC also acted as a catalyst towards fundamental change in the delivery of long-term care in Scotland. There has been a very substantial relative shift over a relatively short period from geriatric hospital care and care homes as the settings for long-term care provision in favor of care at home. In US terms this would be described as removing the "institutional bias" in care provision. It also provides some important markers for how to get from "here to there." These include:

Resources

The delivery of care at home is labor-intensive. Care workers require training. They also have to be willing to provide care at the non-standard times, such as overnight and weekends. Reducing the demands on hospitals and care homes should release resources to support these workers. This will be facilitated if there is some mechanism for transferring resources from institutional care facilities to those providing care at home. It may be difficult to provide incentives for the different agencies involved to make such transfers happen. In addition, establishing a successful, well-regulated private market for home care may help to drive up quality standards.

Governance

Changing institutional bias involves a number of different agencies with different governance structures. Some may be democratic while others are corporations, charities or voluntary organizations. It is important to find mechanisms, which allow those with governance responsibility in these organizations to work together towards the common objective of shifting the balance of care.

Leadership

Significant change is unlikely to happen without strong leadership. Sen Kennedy clearly played this role in the development of the CLASS Act. In the UK, the Royal Commission (1999) had an important role in changing the debate on long-term care. But in the UK as a whole there has been no equivalent political force to Sen Kennedy. It remains to be seen whether the report of the recently appointed commission on long-term care will command sufficient political support to effect significant change. In Scotland, all of the political parties supported FPC. This may have partly been due to conviction, but it may also reflect a desire to differentiate social policy in Scotland from that in the rest of the UK.

Boundaries

In public provision, the establishment of clear boundaries between those who receive an entitlement and those who do not are essential. In Scotland, the definition of personal care was such a boundary issue. Fuzzy boundaries lead to lengthy legal disputes and hostile media attention.

Unintended or Unanticipated Consequences

In Scotland, there was an unexpectedly large uptake of FPC following its introduction. This has been ascribed to “unmet need.” Careful piloting of the policy might have alerted legislators to this possibility. In addition, it was not anticipated that the introduction of FPC would lead to a reduction in the public provision of other forms of social care. Unpaid carers may now be shifting their provision towards such forms of care. FPC may also have stimulated the private market in non-FPC care. The lesson is that very careful evaluation is required before the introduction of radical change in social care policy.

Taking the Holistic View

To meet the challenge of demographic change will require that resources be allocated to areas such as health care and long-term care as efficiently as possible. Taking a “partial equilibrium” view of resource saving can lead to the perpetuation of inefficiencies and outcomes that do not meet the needs of those requiring long-term care. Thus, for example, the resource costs of long-term care differ substantially between hospitals, care homes and care at home. Thinking of long-term care as being in a separate silo from health care runs the risk of substantial resource misallocation. The classic example in Scotland has been the success of the delayed discharge policy that has improved efficiency in health care but has increased long-term care costs. The holistic view would suggest that the net effect of this intervention has been positive. Costs have been reduced and efficiency improved and older people generally appreciate being in settings other than hospital.

Notes

¹ “Local authority” is the term used to describe a body with responsibility for local government across a specific geographical area within the UK. There are 32 local authorities in Scotland, 353 in England, 26 in Northern Ireland, and 22 in Wales.

² Regulation of Care (Scotland) Act 2001.

³ In this context “self-funding” means having assets in excess of the capital limits set in the means test.

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CHAPTER 6

POPULATION AGEING AND LONG-TERM CARE: THE SCANDINAVIAN CASE

SVEIN OLAV DAATLAND

Introduction

Similar problems should invite similar interventions, but policies have legacies and tend to follow the roads already taken. Countries are therefore attracted to different approaches even when circumstances are similar. Some tend to look for solutions in the (welfare) state, others in the family, and yet others in the market or in civil society. This chapter explores these affinities as they are played out in the long-term care area in a European context, with a special focus on Scandinavia. Scandinavian countries tends to come out as a distinct model in the major welfare state typologies, be they based in political ideology (Esping-Andersen 1990) or in cultural characteristics (Castles 1993). However, the established typologies have been criticized for being adequate for economic protection mainly, and less so for “the new social problems” (Alber 1995), which are not primarily rooted in the labour market and the class structure, but are tied to life situations, demographic change and gender. Central among these problems is long-term care—by no means new as a problem for individuals and families, but quite new as a welfare state responsibility, and representing an expanding component of modern welfare states in ageing societies.

More recently, social care services have therefore been incorporated into comparative welfare state studies, and “social care models” (Anttonen and Sipilä 1996) are added as a supplement, or possibly an alternative, to the more general “welfare state models”. This chapter adds to these efforts, but for long-term care specifically. Distinct models and their roots may be more realistically and univocally identified for limited areas of welfare policies than for the welfare state in general. Some countries do not fit easily into the grand welfare state types, and may be guided by different ideals for different domains (Pfau-Effinger 2005).

The first section of the chapter discusses whether or not there is a distinct Scandinavian model for long-term care, and if so, what the characteristics of this model are, and how well it accommodates to the more grand welfare state typologies. We shall suggest that there is indeed such a model, and a small number of contrasting models, and possibly all originating from the same ground. The second section describes the Scandinavian model more concretely in terms of volumes and profiles of services, user rates and standards, with a particular emphasis on the Norwegian case. The third section spells out recent trends and adjustments and the extent to which they

represent some convergence between models, and finally the question of sustainability is addressed: How adequate are the different long-term care models for an ageing society? What are their main dilemmas and challenges?

Welfare State Models

There is a long tradition in comparative welfare state research for trying to extract a few basic welfare state regimes from the great variety of national social policies. The separation between the Bismarck and Beveridge types of welfare states was possibly the first attempt. Whereas Bismarck aimed to protect workers (and their families) against loss of income due to sickness or old age, financed via obligatory social insurance, Beveridge sought to fight poverty via a basic income security for all citizens, financed via taxes (Blome, Keck, and Alber 2009). These differences came to prevail as distinct characteristics of German and British welfare policies, and can be identified even today.

More ambitious typologies were developed later, first by Richard Titmuss (1974), who distinguished between citizens-based, insurance-based, and needs-based welfare states, and accordingly labelled them the institutional, the insurance (or achievement) based, and the residual (means-tested) welfare models. Esping-Andersen (1990) extended this model in a manner which came to give welfare state studies new energy, when he identified the ideologies and political constellations that these policies were expressions of, thereby allowing analyses of the actors, dynamics and conflicts within the welfare state. According to Esping-Andersen, one could distinguish between a social democratic, a conservative, and a liberal(ist) welfare state regime. Among the distinguishing characteristics of the social democratic model, represented by the Scandinavian countries, is the ambitious role of the state, including active and direct regulation of the labour market, and thus protecting citizens against dependency on the market (de-commodification).

In response to feminist critique for being preoccupied with economic protection, and for being less observant of social protection and care, and thereby also blind to the gendered nature of the welfare state, Esping-Andersen (1999) later included social services in his model, and the degree to which the access to (public) social services provided protection against dependency on the family (de-familization). This expansion could, according to Esping-Andersen, be nicely accommodated within the already established model, and did not have him add or re-arrange his original typology. However, a southern welfare state regime has later been added by other scholars as a more rudimentary variant of the conservative model, or as a distinct Mediterranean (Latin) welfare regime (Leibfried 1992; Ferrera 1996).

The Esping-Andersen typology is grounded in a combination of structural and political factors, implying that a certain welfare regime has developed in response to some commonality in structure (problems) in combination with some commonality in ideology and practical solutions (outcomes). The active role of the state in Scandinavian welfare policies is, for example, attributed to the strong social democratic parties in these countries during the constituting years of the modern welfare state, motivating them to find solutions in “their” state, so to speak. Universal arrangements financed by general taxes were probably also popular because Scandinavian populations were very homogeneous at the time. Taxes, services, and clients had high legitimacy because they referred to people like oneself.

Other welfare state typologies have a cultural more than a political basis. As welfare policies seem to cluster geographically and have similar characteristics in neighbouring countries, Castles (1993) suggested that these clusters refer to a “family of nations”, with a common background in history, language, religion or family culture. The geographical location of these clusters is indicated by the labels assigned to them, such as the Scandinavian model (or cluster), the Continental model, the Mediterranean model, and the Anglo-Saxon model. An Eastern (post-communist, transitional) model has later been added.

The overlap between the Esping-Andersen and the Castles typologies is evident from Table 1. The fact that the structural (Esping-Andersen) and the cultural (Castles)

Table 1: Welfare State Typologies

Welfare State Regimes (Esping-Andersen)	Families of Nations (Castles)
Social democratic	Scandinavian
Liberal	English-speaking
Conservative	Continental
(Mediterranean)	Southern
(Post-communist)	(Eastern)

typologies overlap, suggests that they are rooted in a common ground. When we speak about welfare models or regimes, we refer to a limited number of countries with characteristic similarities between themselves, and characteristic differences vis-à-vis other countries. The background for these differences may be structural, cultural or both. The geographical location of the clusters suggests that the cultural legacy has a

strong impact even on today's policy, and probably particularly so in problem areas that are by tradition a family responsibility.

The southern family is tighter and more collectivistic than the northern according to Reher (1998). The same goes for the eastern relative to the western family, according to Hajnal (1965, 1982). They both argue that European family cultures have developed over centuries and are quite stable, yet also changing in response to more recent circumstances. Their particular forms are, however, remarkably resilient, and are basic features upon which social policies and welfare states are formed rather than vice versa.

However, the strength and character of family norms are hardly produced by geography, although climate and living conditions may have been influential in the formation of living arrangements. Differences in family norms and practices are more likely rooted in history and religion, and may follow the historical lines of Christianity and Islam, Catholicism and Protestantism (Höllinger and Haller 1990; Reher 1998). Influences from the Roman Empire may also be observed, for example in family and inheritance laws (Hantrais 2004). Later on, more or less dramatic political events may have had repercussions within the family, such as the two world wars, and the Iron Curtain thereafter. The suppressive communist era in Eastern Europe may have forced people to seek protection in the family, and then most likely in more traditional family forms (Szydlik 1996). In contrast, the north-west of Europe has a long tradition for more independent relationships between family generations according to historians such as Laslett (1983). When Britain and Scandinavia were early in the development of social services on traditional family ground, this was therefore not by chance or by opportunity only, but also by choice. Scandinavian countries eventually allowed the state an even more active role and responsibility than in Britain, a policy that reduced dependency on the family further in Scandinavia. These trends have had favourable repercussions for gender roles and opportunities in Scandinavia, although the direction of causality is not totally clear.

In real life, both the longer lines of tradition, and more recent and local influences from need pressures and political ideals are involved. The cultural legacy may represent some persistent characteristic, while structural and political factors are more responsive to current conditions. Thus, even if collective family norms are deeply rooted within a country, and this country is therefore attracted to a family care model, it may come to change policies if circumstances are compelling. This being said, the cultural, political and institutional traditions of a country represent a path dependency on the past, and a resistance to change, and may come to be played out also in the revisions that have been deemed necessary. The German long-term care insurance is a

case a point. The late inclusion of state responsibility for long-term care may be explained by the familist orientation in German welfare policies, whereas the reform itself was dressed in old and familiar clothes, as a universal and obligatory insurance arrangement.

The Scandinavian Model

Both typologies, that of the welfare state regimes and that of the family of nations, identify the Scandinavian welfare state as a distinct model, although under different labels. Whether or not there are distinct clusters of nations as far as social services are concerned is still a controversial issue (Rauch 2007). We shall conclude that there are indeed such clusters, although some of their characteristics are quite fluid, and the borders between them are blurred. Table 2 summarizes some of the distinctive characteristics, how they go together within the cluster, and how they tend to

Table 2: Policy Antecedents and Outcomes by Welfare State Cluster ca. 2005

	SC ^a	E	C	SO	P
Fertility rate	1.7	1.6	1.5	1.3	1.3
Female employment	71.4	59.1	57.7	41.3	54.4
Direct taxes	43.1	29.2	26.2	26.8	20.9
Social security contribution	14.7	25.9	32.8	29.0	30.7
Total tax revenues	50.6	36.1	43.3	37.6	31.5
Outlays of government	55.9	42.1	49.5	45.1	38.2
Social transfers	17.0	12.0	16.8	14.5	11.3
Education expenditure	7.9	4.9	5.7	4.3	5.3

^aSC = Scandanavian; E = English; C = Continental; SO = Southern;
PC = Post-Communist.

Source: Adapted from Castles and Obinger (2008), Table 2.

distinguish between clusters. The selected variables are quite general, and refer to structural and cultural conditions on the one hand, and to policies and policy outcomes on the other, and then mainly referring to the role of government (the state). Countries are in this table organized according to the Castles typology, with data adapted from Castles and Obinger (2008).

The Scandinavian countries stand out with comparatively high fertility rates and high levels of female employment, both illustrating the active role of government (politics) for equal opportunities and the reconciliation of family and work. Birth rates are particularly low in southern and post-communist (transitional) countries, where also female employment is low and indicates that welfare policies are family-based and traditional gender roles are still strong.

Table 2 also illustrates the large state sector in Scandinavian countries. Total outlays of government are higher than under any of the other clusters. Note also that tax rates are high. Other countries have lower taxes, but higher revenue from insurance. Scandinavian welfare policies are mainly financed by general taxes in combination with moderate user fees. Other welfare states are based on more or less universal insurances or on more selective arrangements, often in combination with comparatively higher user fees (Rodrigues and Schmidt 2010). And finally, the two indicators for social policy outcomes in Table 2, social transfers and education, both indicate that the level of state investments in welfare policies are higher under the Scandinavian regime than under any of the other models. The general features of each welfare state type are also played out in their long-term care systems, which we shall now turn to.

Long-Term Care Models

The distinctive characteristics of the different clusters of countries are even more evident when we limit the perspective to social services and more specifically to long-term care. Anttonen and Sipilä (1996) explored the European “social care models” empirically by comparing country levels of services for children (daycare, pre-schools) and elders (home help, institutional care). On this basis they identified two distinct, and two or three more tentative, models. One of the two distinct types was the Scandinavian model of public services, where services for both elders and children are universal and widely available, and mainly provided by local governments. The contrasting case was represented by the family care model, which is typical for Southern (Mediterranean) countries. These countries have a limited supply of social services for both elders and children, leaving these responsibilities mainly to the family. Other models were not equally distinct, but Anttonen and Sipilä also identified a British means-tested model, in which the state assumes the responsibility for services, but on a lower level than in Scandinavia, and therefore subject the services to more strict means-testing. They finally added a continental subsidiary model, represented most typically by Germany. The primary responsibility for elders is also here located in the family, but service levels are considerably higher than in southern countries, whereas the state assumes a more indirect role than in Scandinavia by

having service provision carried out primarily in the private sector on commission (and control) by the state.

Some countries do not fit squarely into these types, because they score high on child care and low on elder care or vice versa. Leitner (2003) suggests there are different varieties of familialism. Welfare policies may de-obligate families by providing services as an alternative to family care (de-familization). Policies may also, or alternatively, support and compensate families in their caring efforts (familialization). Both types of policies are present in any welfare state, but differently balanced between regimes and between sub-areas within each regime. Familialization is more often found in child care, de-familialization in elder care. Modelling therefore becomes more distinct if we consider long-term care separately. We shall then suggest that the most distinctive features of different long-term care models (or regimes) are to be found along the following dimensions: the state role, the mode of financing, the major instruments, and the eligibility criteria. On this basis we suggest four types or regimes with (1) the public service model (Scandinavia) and (2) the family care model (Mediterranean) as the two contrasting cases—the former based in state primacy, the latter based in family primacy. In-between are (3) the (state) means-tested and (4) the (family) insurance-based models, the first represented by England (and other English-speaking countries), the latter by Germany and neighbouring continental countries. The Scandinavian and English models are both tax-financed, with the state primarily responsible, but less generously (or radically) so under the English model. The Continental and Southern models are both based in family primacy, but less so (policy moderated) under the continental model. The family dominated model is so to speak the traditional order that the other models have originated from.

Table 3 illustrates the characteristic features of the different long-term care models. Norway is here representing the Scandinavian model, England the means-tested model, Germany the insurance-based model, and Spain the family care model. Post-communist countries will empirically belong to the family care model, and if so illustrating that traditional family roles have survived the state communist era. Statistics have, however, not been available for these countries.

It must be pointed out that long-term care in Scandinavia includes both younger and older clients. Older clients dominate institutional care (nursing homes), while the younger are more likely to live in assisted housing and to be served by domiciliary services. Families are, moreover, more dominant in the care for children and younger adults than in elder care. The long-term care regime is for these reasons quite differently balanced for young and old clients in Scandinavian countries. This chapter concentrates on elder care. Other countries may have other practices, and valid

comparative statistics are therefore hard to find. Readers should take these uncertainties into consideration.

This being said, table 3 summarizes the distinctive features of each model. The state assumes a primary responsibility for long-term care under the (Scandinavian) public service model, a more limited role under the other models. This is seen both in terms

Table 3: Policies and Outcomes of LTC Under Different Models, ca. 2005

LTC models	Public service	Means tested	Insurance based	Family care
Illustrative country	Norway	England	Germany	Spain
State role	Primary	Residual	Subsidiary	Subsidiary
Major instrument	Services	Mixed	Transfers	Mixed
Eligibility		Selective (means-tested)	Universal	Selective (family-tested)
LTC expenditure (% of GDP) ¹	2.3%	1.4%	1.4%	0.6%
Public LTC exp. ¹	86.0%	65.0%	70.0%	26.0%
User rates: % 65+ ²				
... in institutions	5.3%	3.5%	3.8%	4.1%
... in home care	19.3%	12.6%	6.7%	4.2%
Total	24.6%	16.1%	10.5%	8.3%

¹ OECD (2005); ² Huber et al. (2009); ³ May include younger clients/residents.

of legislation and in practices. Family legislation varies across Europe (Millar and Warman 1996; Hantrais 2004). Formal obligations are in southern countries assigned to the extended family, with the state in a subsidiary or residual role. Continental countries tend to confine responsibilities to parents and children, not to the wider family network. Northern countries have no legal obligations between adult family generations, hence the primary responsibility for long-term care rests with the state, at least in theory. In real life, families take on a large, if not a dominant, role also in

Scandinavia. England and other liberal(ist) regimes tend not to impose legal obligations for care on the family, and family relationships are in general not strictly regulated. But as the state is not very generous, the means-testing leaves more responsibility to the family and other private sector than in Scandinavia.

The family is dominant in elder care in (nearly) all countries, possibly with the exception of Scandinavia. The comparative OASIS survey found a fairly equal family-state balance for Norway, whereas the family was clearly dominant in Spain, with Germany and England in intermediate positions (Daatland and Lowenstein 2005). The SHARE study found family help to be less intense, but more frequent, in Scandinavia in comparison with continental and southern Europe (Albertini, Kohli, and Vogel 2007). Other estimates have suggested a 50-50 split in the Scandinavian case, while a 25-75 split is indicated for other developed welfare states, with even more family dominance under the family care model (Huber et al. 2009). The estimated 50-50 division between the family and the welfare state in Scandinavia refers to hands-on-care. If also other activities were included in the equation, such as emotional support, companionship, transports, and care management, the family (and other informal helpers) would probably dwarf the role of any formal care system.

While the state is criticized for being on the retreat in Scandinavia (Szebehely 2005), state responsibilities are expanding in countries like Germany and Spain (OECD 2005) - in Germany via the obligatory long-term care insurance from 1995 onwards, and more recently in Spain via a new legislation on protection under dependency. Service levels may for these reasons come to increase on the continent, and possibly decrease in Scandinavia, and if so to produce some convergence between models.

Services are the main instrument in Scandinavian long-term care policies, and provided mainly by local governments (municipalities), but monitored and financed by the state. Countries operating under the insurance and family care models are inclined to give higher priority to cash transfers (cash-for-care) in support of family care. The German long-term care insurance illustrates this, as rights may be drawn in cash or in kind. The insurance has, however, also allowed a financing of more nursing homes, but is primarily used as (cash) support for family care, which was also the original motivation. Other long-term care insurances may be provided in cash only (Austria) or in kind (as services) only (Japan). Cash transfers are also available in Scandinavia, but are provided to few, and then mainly to families of dependent children or younger disabled.

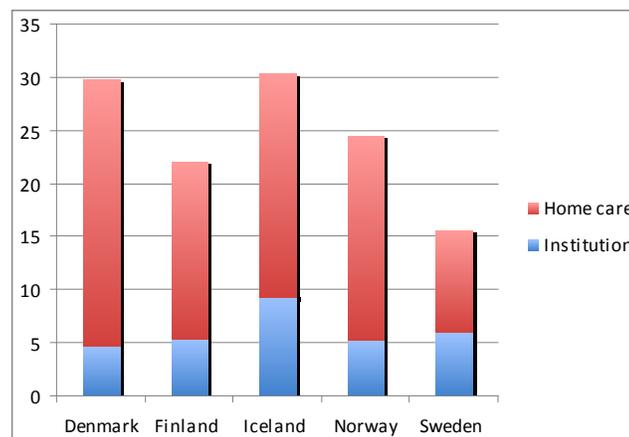
Outlays on long-term care are for these reasons high in Scandinavia, as illustrated in Table 3 by the higher expenditures in Norway (2.3 percent of GDP) than in England and Germany (1.4 percent), and lower still in Spain (0.6 percent). Outlays are even

higher in Sweden and Denmark than in Norway, but somewhat lower in Finland and Iceland. Most of these expenditures are in Scandinavia channelled through the public sector, 86 percent in the Norwegian case, compared to 65-70 percent in England and Germany, and only 26 percent in Spain.

Service levels are therefore quite high in Scandinavia; in particular as far as community (home) care is concerned, possibly because a professionalization of domiciliary care is in more obvious contrast to traditional family values than the more professionalized institutional care. The high(er) institutional care rate in Scandinavia is to some extent also a response to the household structure, with high rates of single households among elders, and few in shared households with adult children.

There is considerable variation in service levels and standards also within Scandinavia, as illustrated in Figure 1. Services are more accessible in Denmark and Iceland than in Sweden. Iceland has the largest institutional care volume, while

Figure 1. Access to Home Care and Institutional Care in Scandinavian Countries



Source: Huber et al. (2009)

Denmark gives comparatively stronger priority to community care. A few other countries are equally ambitious in terms of levels and outlays on long-term care, most notably the Netherlands, which uses an even higher share of its GDP to long-term care than the Scandinavian countries according to Huber et al. (2009). Netherlands also has a record high rate of institutional care, perhaps for historic (and idiosyncratic) reasons.

Recent Trends

Scandinavian trends over the last couple of decades identify Denmark and Sweden as contrasting cases (Daatland 1999). Denmark has maintained a stable and high access to services. Sweden has become more selective in distribution, with declining user rates, but with more resources (intensity) provided to the selected few. The lower access to services implies a push towards more family responsibility, representing a re-familization of care according to Johansson et al. (2003). Common to all Scandinavian countries—perhaps with the exception of Iceland—is a de-institutionalization trend, with sheltered housing and community care in expansion, whereas traditional institutions (nursing homes) are in decline relative to the 80+ population. More home-like nursing homes, and development of assisted housing as alternatives to institutional care, have blurred the earlier distinction between intra- and extra-mural care. If assisted housing had been added to the nursing home rates in Figure 1, some 8 to 12 percent of the 65+ population, and 20 to 25 percent of the 80+ population, could have been listed as residents of “special housing” (Szebehely 2005).

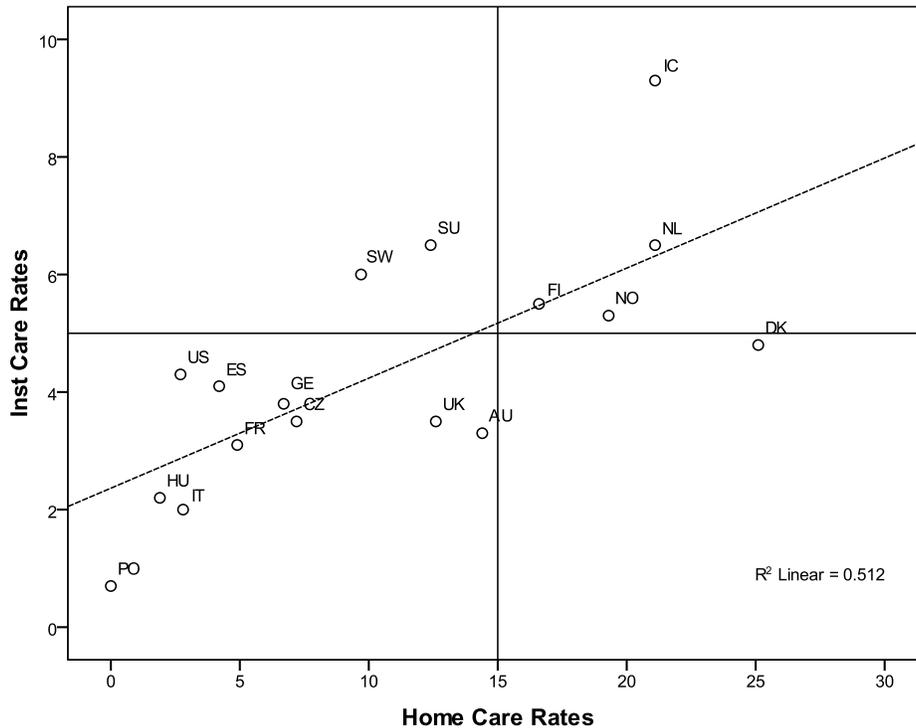
Institutions used to be the dominant form of long-term care in Scandinavia as well as in most other countries. Resources (expenditures) are today more equally split between institutions and community services, but to a varying degree within Scandinavia. Denmark has a tradition for operating a more open care regime, Norway and Iceland give higher priority to institutional care, which is now consuming around 70 percent of long-term care resources for elders in the Norwegian case. User fees (co-payment) are still moderate, and represent 2 percent of the community care costs, and around 15 percent of the costs for institutional care in Norway (in 2009), possibly even lower in other Scandinavian countries. Home help is, for example, free-on-delivery in Denmark.

Services have increasingly been contracted out to private providers, and more so under conservative than under social democratic governance. And yet, services are still mainly (80-90 percent) public. Private provision is, however, on the increase, which is another indication of a possible convergence between Scandinavian and the Continental long-term care.

Scandinavian countries are, however, yet standing out from most other European welfare states in that both institutional care and home services are quite generously provided, as well of a high standard. Nursing homes provide single rooms to (nearly) all residents, and staffing is quite high (around 1:1, one full-time staff per bed). Public opinion is yet quite critical, and then partly due to high expectations.

Levels of services are illustrated in Figure 2, where institutional care and home care rates are plotted against each other for selected countries, including the USA. Scandinavian countries, with the exception of Sweden, are located in the upper right cell of the diagram (together with the Netherlands), with high scores (levels) on both types of services. Note also the positive correlation between the volumes (user rates) of extra-mural and intra-mural care. Some countries are low on both, some are high on both, only few have a compensatory pattern, where low rates on one are compensated by high rates on the other. Note also that as the diagram lists only services, the total volume of long-term care is underestimated for countries with comparatively higher investments in cash transfers, such as Germany.

Figure 2. Access to Long-term Care by Country (percent 65+ with home care and institutional care)



Source: Huber et al. (2009)

Present Dilemmas, Future Sustainability

Having established that welfare states differ not only in their efforts, but also in the direction these efforts take, it may be pointed out that all of them have some form of

mixed responsibility between the family and the state for long-term care, with supplementary efforts also from other actors such as neighbours, friends, civil society, and the market.

Long-term care was traditionally a family responsibility throughout, and still is in many countries, but some form of public, and collective, responsibility has expanded in response to modernization. Governments first developed pensions for economic protection against income loss under illness or old age. Such autonomy between family generations was later on also guiding the development of institutions, assisted housing, and domiciliary services to support independent living. Some countries did so only reluctantly, others—and first and foremost the Scandinavian—went a long way in defining long-term care as a government responsibility in order to protect citizens' autonomy also vis-à-vis the family. The (central and local) state therefore came to share hands-on-care with the family, even to replace family care for the most needy, but normally left families to cater for social and emotional needs.

Family care yet survived, but partly in other forms. The state has not replaced families even in Scandinavia. The two have become partners in care. Long-term care has to an increasing extent become a mixed responsibility for the family *and* the welfare state, but these mixes are quite different. Family care is still dominant in elder care in most welfare states.

How adequate the different models are for an ageing population is a controversial issue, not only because welfare policies are rooted in political and ethical norms about the normal (traditional) and right (moral) thing to do, but also because countries are differently located as far as population ageing is concerned. The observed convergence in elder care (less state in Scandinavia, more state in continental Europe)—however small—may be a response to more similar problem pressures in terms of population ageing on the one hand, and family change on the other.

The between-countries variation in population ageing is quite solidly documented, even when we allow a considerable range of uncertainty the further ahead the projections are taken. There is yet sufficient knowledge about mortality, fertility, and migration to conclude that some countries are facing a far more radical population ageing than others. Germany and Spain may serve as examples. These two countries are expected to increase their 65+ populations from around 16 percent today to around 30 percent in 2040. Even more radical is the expected change for Italy and Japan, as their 65+ populations are projected to reach around 34 percent by 2040, nearly a doubling since the year 2000. The 80+ population, with the highest risk of needing care, will increase even more, and most radically so in Japan, from close to 4 percent

of the population in 2000 to 14 percent in 2040. Italy and Switzerland can also expect to reach the 10+ percent level for the 80+ population before 2040 (Table 4).

Scandinavian countries were early in the demographic transition, but future ageing will be more moderate. The 65+ population is expected to increase from around 15 to around 24 percent between 2000 and 2040 in Scandinavia, while the 80+ population will nearly double and reach around 8 percent in 2040. Ageing will therefore be substantial in Scandinavia too, but considerably lower than in continental and southern Europe, such as in France, Italy, and Switzerland, where the 80+ population

Table 4: Indicators of Population Aging for Selected Countries

Percent of population...	Age 65+		Age 80+	
	2000	2040	2000	2040
Denmark	14.8	24.1	4.0	6.9
Finland	14.9	26.2	3.4	9.0
Iceland	11.7	22.6	2.8	7.1
Norway	15.2	26.3	4.3	8.6
Sweden	17.3	25.2	5.0	7.9
England	15.9	25.4	4.0	7.3
The Netherlands	13.6	25.5	3.2	7.6
France	16.1	26.6	3.7	9.1
Germany	16.4	29.7	3.7	8.7
Switzerland	15.3	33.1	4.0	11.1
Italy	18.1	33.7	4.0	10.0
Spain	16.9	30.7	3.8	8.5
Poland	12.2	24.1	2.0	7.5
Czech Republic	13.8	28.8	2.4	8.5
Hungary	15.1	25.7	2.6	7.1
USA	12.4	20.4	3.3	6.0
Japan	17.4	35.3	3.8	14.1

Source: Huber et al. (2009)

will nearly triple between 2000 and 2040. Looking beyond Europe, Japan stands out with the most rapidly ageing population, where more than 14 percent are expected to be 80+ in 2040, the double as that of the USA—a country with as yet a quite young population thanks to high fertility and in-migration.

The radical population ageing in countries like Germany, Italy, Spain, and Japan is mainly explained by their low birth rates (Gaymu et al. 2008). An additional factor is the high life expectancy in Japan and Mediterranean countries, now exceeding that of Scandinavia, which used to be world leading in terms of longevity. Scandinavia is, however, blessed with higher birth rates than these other countries, thanks to an active family and equal opportunities (gender) policy, which have made it easier to combine work and child rearing for women. Scandinavia is thus facing a slower pace of population ageing than central and southern Europe. The ironic thing is that countries in southern and eastern Europe, with the strongest and most collectivistic family culture, are the very countries where people are now most hesitant to establish new families (Esping-Andersen 1997). The more individualistic north and west of Europe, with a tradition for weaker family ties, is currently a more favourable territory for family formation.

These countries face different dilemmas. For Scandinavia the challenge is one of solidarity between age groups: Will younger workers continue to support the expensive Scandinavian welfare state and the high taxes needed to sustain it? For Continental Europe the challenge is related to family solidarity and equal opportunities: Is family care dominance feasible and reasonable when populations are ageing and women are entitled to equal opportunities?

The Scandinavian welfare states need strong(er) solidarity between age groups when populations are growing even older. The good news is that European populations, including the Scandinavian, are still very supportive to the welfare state, and to provisions for older people in particular (Taylor-Gooby 2004). Older people score high on deservingness; they so to speak embody the most honourable of clients, and attract more support in popular opinion than any other needy group, although more so for long-term care than for old age pensions (van Oorschot 2006).

Long-term care is therefore still protected in public opinion and as such in democracy, but further population ageing may add to these demands and put intergenerational solidarity at risk on both the societal and family levels. Will younger cohorts and younger family generations be able and willing to respond?

The problems are located both in demography and in the welfare state. Population ageing is general, but challenges are in fact quite different because the rate of change

varies, and so also do the already established policies. Some countries are privileged by a well-developed care system and moderate population ageing ahead. Others are in a double jam, and are squeezed between poorly developed services *and* a rapidly ageing population. Scandinavian countries are among the more fortunate, but with distinct challenges and dilemmas in the searching for sustainable solutions.

The familialist welfare states need larger and stronger families when they in fact grow smaller and weaker. Family dominance in care is therefore hardly feasible when the older generations are increasing in numbers, whereas the younger are decreasing. Italy is currently trying to fill the gap with close to one million migrant carers from post-communist countries, but the Italian solution can hardly be made into a general norm.

Interestingly, each model seems to have resonance in their populations. While family care seems to be the preferred choice in familialist welfare states, services are the preferred choice in countries where services are available and of a decent standard (Huber et al. 2009). Elders in the more northern regions of Europe try to live by the ideal of intimacy at a distance. They prefer independence for themselves, and fear becoming a burden on their families. Other ideals prevail in more familialist countries, where family care is expected, if not wanted, from both sides of the relationship (Daatland 2009). Common demographic, financial, and political realities may speak for a convergence of trends. It seems to me that the Scandinavian model is not the worse position from which to confront this eventuality.

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CHAPTER 7

LESSONS ON LONG-TERM CARE FROM GERMANY AND JAPAN

MARY JO GIBSON*

Introduction

The international data and literature on long-term care (LTC) now available through international governmental and non-governmental organizations as well as individual countries forms a rich but largely untapped resource for scholars, policy analysts, and others in the United States. With some notable exceptions, such as the US, policy changes that move toward universal LTC benefits have occurred in most other developed nations within the last two decades. Close examination of their experiences will give U.S. stakeholders a clearer picture of what drives policy change and the lessons learned after changes are implemented, both positive and negative.

The focus in this paper is on Germany and Japan, which have implemented mandatory social insurance programs in which eligibility is not based on income, assets, or availability of family caregivers. Germany began implementing its program in 1995 and Japan in 2000. Both countries also have recently made important changes in their programs, Germany in 2008 and 2012 and Japan in 2006 and 2012.

The 2010 health care reform legislation in the US included the recently suspended Community Living Assistance Services and Support Act (CLASS), a significant and unexpected step in LTC financing reform. Although not comprehensive in benefits or universal in coverage, it would have provided cash benefits to eligible persons with disabilities who enrolled without means-testing or medical underwriting. Without international counterpart, it was a national voluntary system with some characteristics of public insurance, some of private insurance, and a continuing key role for Medicaid in LTC financing (Gleckman 2010). Especially in light of the fate of CLASS, it is important to examine the experiences of countries that have successfully implemented mandatory social insurance programs, such as Germany and Japan.

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Why Examine Germany and Japan?

With higher rates of fertility and immigration, the US population is considerably younger than that of Germany, which is one of Europe’s oldest countries as well as the most populous, and of Japan, which is the world’s oldest nation. The proportion of people age 65 or older in the US will not reach that in Germany and Japan today until 2050 (Table 1). Moreover, by 2050, the share of persons age 80 or older in the US will still be only about half that in Germany and Japan.

Table 1: Percent of Population ages 65+ and 80+ in Germany, Japan, and the U.S., 2010-2050

	Age 65+			Age 80+		
	2010	2030	2050	2010	2030	2050
Germany	20.5	28.2	32.5	5.1	8.0	14.1
Japan	22.6	30.8	37.8	6.3	12.9	15.6
U.S.	13.0	19.8	21.6	3.8	5.2	7.8

Source: United Nations Population Division (2009)

Germany’s universal LTC legislation passed in 1994, when 15.8 percent of its population was age 65 older. Japan’s legislation passed in 1997, when 15.7 percent were age 65 or older. In the US, the share of the older population age 65 or older will cross that same line toward the end of this decade (Campbell, Ikegami, and Gibson 2010).

Prior to reform, Germany and Japan faced problems similar to those in the US today, including:

- Burdens on family caregivers; aging of family caregivers
- Benefits targeted to persons with low income and limited family support
- Stigma of using means-tested services
- Fears of the increasing burdens of LTC spending on other social programs
- Widely disparate benefits depending upon where one lives
- Fragmentation across programs and levels of government
- Concerns about quality of care

In enacting contributory social insurance programs, the German and Japanese experiences seem more consonant with the US history with Social Security and

Medicare than a Scandinavian-style program funded through general taxation. In addition, Germany and Japan's broad social policies are more similar to those in the US than those of many other Western European countries. Also, they have strong private market LTC delivery systems, in which services are provided primarily by private sector providers rather than by government agencies.

Gender and LTC

Women in Germany, Japan, and the US, as well as in many other countries, are more likely than men to provide long-term care, either as unpaid family caregivers or as part of the paid LTC workforce, and to need long-term care. With longer lives, higher rates of disability and lower incomes than men on average, women in all three countries typically face greater challenges in obtaining and paying for long-term care. Economic insecurity among older women, especially those 75 or older who live alone, remains a problem today even in rich countries such as Germany, Japan, and the United States.¹ Public long-term care insurance (LTCI) can help to reduce the risk of falling into poverty in order to receive means-tested LTC and buffer the financial and health risks faced by unpaid family caregivers.

Purpose and Method

The purpose of this chapter is to identify key implications of the evolution of the German and Japanese mandatory LTC systems for the United States.² It discusses Germany and Japan's decisions about LTC goals and policies, as well as the debates before their programs were implemented. It also examines the results thus far, including discussion of recent reforms. The scope of the paper includes: (1) coverage, eligibility, and benefits; (2) financing; and (3) family caregiving policy. Workforce and quality policies are critically important but beyond the chapter's scope. Each section concludes with "lessons for the US", which identify the broad policy principles that Germany and Japan's experiences imply for the US, and briefly compares provisions in the German and Japanese systems with those of the recently suspended CLASS Act in the US.³ The findings in the paper are based on an extensive review of the English language literature on the German and Japanese LTC systems. National experts on LTC in Germany, Japan, and the US have reviewed the chapter for factual accuracy.

We now turn to some of the sharp contrasts between LTC policy heritage, design and debate in Germany and Japan.

Germany: Building on Tradition

LTCI (*Pflegeversicherung*) was the fifth building block of Germany's social insurance system, which began with Bismarck's health insurance act of 1883, followed by mandatory accident, pension, and unemployment insurance (Geraedts, Heller, and Harrington 2000).

As pressure grew on state (Laender) social assistance budgets,⁴ multiple LTC reform proposals emerged, leading to a protracted debate of almost twenty years prior to enactment of reform legislation in 1994. The key political stakeholders' proposals generally fell into three broad categories: the employer-oriented Liberal party favored private insurance; employee-oriented Christian Democrats favored social insurance, and the trade union-oriented Social Democrats favored a tax-funded approach but later threw their support behind social insurance (Heinieke and Thomsen 2010). In the end, a social insurance approach, consistent with Germany's long tradition, won out. Substantial opposition by employers to increased payroll taxes was resolved when the Laender agreed to give up one paid holiday, the day of repentance, in all states (except Saxony).

From the beginning, reducing reliance on social assistance benefits due to the need for LTC was considered a key policy objective. Encouraging family caregiving and home and community-based services (HCBS) were other important goals. Both official and scholarly sources in Germany emphasize that its program always was intended to provide partial coverage of risk, not the comprehensive coverage available under its health insurance program.

The guiding principle of Germany's LTC program, then and now, is captured in its slogan: *Prevention and rehabilitation before long-term care. Home care before institutional care.*

Japan: A Break with Tradition

In contrast to Germany, Japan's mandatory LTCI, *Kaigo Hoken* (care insurance), represents a sharp break with tradition. According to John C. Campbell and Naoki Ikegami, "Japan's implementation of its mandatory LTCI insurance program in 2000, came as a surprise in light of its strong tradition of family care for the elderly, its reputation as being 'laggardly' as a welfare state, " and its economic troubles at that time (Campbell and Ikegami 2000). Indeed, few Western observers would have expected Japan to initiate what is one of the world's most generous LTC programs under the slogan *kaigo no shakaika* (the socialization of care)—underscoring that the responsibility of providing care, traditionally borne by daughter-in-laws, should be spread among the entire society.

Although the policy design of Japan's program broke with tradition, the "problem of an aging society" had been high on Japan's policy agenda for several decades. Since 1973, health care for the elderly, including hospital care, had been first a free and then very low cost entitlement. LTC services under its social welfare program⁵ were means-tested based on the income of both care recipients and their children, with the burden especially high for middle income users (Japanese Ministry of Health, Labor and Welfare 2008). Coupled with the limited supply of nursing homes and home care, the much lower cost of hospital care to consumers led to the overuse of hospitals providing long-term institutional care. Such hospitals became like nursing homes, with about one-third of hospital inpatients age 65 or older being hospitalized for more than one year (Ikegami 1997).

Not surprisingly, Japan was interested in reining in rapidly growing health care costs, especially hospital costs for older persons (Matsuda and Yamamoto 2001). Other problems included limited service availability and choice of providers available through the social welfare program, in which services were provided directly or contracted out by municipal governments. Broader societal forces, such as increasing numbers of nuclear rather than extended families, as well as cutbacks in social spending, also set the stage for reform.

The most hotly debated issue was whether to include a cash option. Arguments by Japanese feminists, who feared that the cash would disappear in family budgets and family caregivers would continue to be exploited, were influential in its rejection. Other arguments against cash were that (1) formal services would not expand sufficiently if cash were offered; and (2) it would not cost-effective because everyone eligible would enroll immediately, with no time to phase-in funding. Japanese feminists with the help of favorable media coverage, successfully argued that family caregivers wanted liberation, not recognition (Eto 2001).

The Japanese LTC program was a major shift in Japanese social policy toward what has been described as a new "social contract" based on mandatory contributions, uniform and explicit entitlements and consumer choice (Izuhara 2003). In doing so, Japan opted for a social insurance system similar to Germany's rather than a Scandinavian model of broad entitlement to social services funded at the local level, financed by national and local taxes (Campbell and Ikegami 2000).

Coverage, Eligibility and Benefits

Germany's LTC program provides universal coverage for persons of all ages. Its benefits are basic, with individuals expected to bear a large share of the costs. In contrast, Japan's program provides comprehensive benefits but coverage is universal

only for persons age 65 or older. This distinction helps to highlight some of the crucial policy decisions made in both countries.

Consonant with coverage under Germany's other social insurance programs, the decision to cover persons with disabilities of all ages was not controversial. In contrast, in Japan some thought all workers should pay, while others worried about the reaction of younger people to paying a new premium. In the end, the compromise was to start contributions at age 40, and to give 40-64 year olds coverage for age-related disorders only (Campbell and Ikegami 2003). Older people receive 96 per cent of total expenditure from the long-term care insurance program while people aged 40-64 with age-related disabilities receive only four per cent (Glendinning and Moran 2009).

Eligibility Criteria

Both nations determine disability levels as measured by functional impairment and the length of time help is needed each day. Eligibility criteria are nationally uniform in both countries, with Germany basing benefit amounts on three levels of disability and Japan on seven. Germany's eligibility criteria are stricter than Japan's, largely because Germany's disability thresholds are higher. At least half of those receiving benefits in Japan would not be eligible for benefits in Germany (Campbell, Ikegami, and Gibson 2010). For several years, Germany has been studying the effects of making major revisions in its definition of who needs care, which has been repeatedly criticized as being heavily oriented toward persons with physical disabilities, e.g., by excluding persons with dementia who need supervision and persons with serious mental illnesses. An Advisory Board has recommended new criteria organized in five degrees of need for long-term care (Implementation Report May 2009). A draft tool, based on the degree to which a person's independence is impaired, has undergone national testing and eventually may be adopted as the new eligibility assessment tool for LTCI (Buescher, Wingenfeld, and Schaefer 2011). However, calculations of the cost of adopting the new definition of need for care indicated that expenditures would be expected to increase (Rothgang et al. 2008). The political debate on the implementation of this new assessment procedure is still underway (Theobald, 2011).

In late June 2012, Germany enacted reform of some aspects of its LTCI program, primarily by increasing access to home and community -based services for persons with dementia (German Federal Ministry of Health 2012). Beginning in January 2013, there will be higher benefits for persons with dementia and additional support for family caregivers, such as a greater financial incentive to use respite services, which are typically underused by caregivers. The bill also includes subsidies to develop small group homes and shared apartments for persons with disabilities.

In Germany, in-home assessments are conducted by units of the health insurance funds, by geriatric trained nurses. The 2012 reform requires that these assessments be timely, and that eligibility decisions also be made more quickly. In Japan, assessments are conducted by municipal officials, using a computer-based classification based on 74 items. The final classification is made by a local committee with a doctor, usually a social worker, and other personnel.

Table 2: Monthly Benefit Ranges and Cost-Sharing in Germany and Japan, 2008⁶

	Germany	Japan
Benefit Range		
Cash allowance	\$250-\$794	NA
Formal home care	\$490-\$1,790	\$1,440-\$3,400
Nursing home care	\$1,200-\$1,730	\$1,680-\$3,670
Cost-sharing		
Nursing home care	Room and board not covered	One-third of room and board costs covered (100% for low-income people); residents in AL pay all room and board costs.
Personal care/home help	No coinsurance	10% coinsurance

Benefits in Germany

The differences in the benefit ceilings between the two countries are substantial, as shown in Table 2. In Germany, LTC benefits cover about 50 percent of the average cost of institutional care and roughly the same for home care (Rothgang 2007). In Japan, benefits cover 90 percent of formal caregiving costs in both institutions and in the community (Campbell, Ikegami, and Gibson 2010).

HCBS benefits under Germany's LTCI program provide a choice of cash benefits that can be used to pay relatives or, for example, migrant workers, agency- provided home care, or both cash and services, up to a ceiling at each level of care. The ceiling on the unrestricted cash allowance is roughly 50 percent lower than that for direct services. Other covered benefits include assistive aids, such as a special bed; and home modifications. Benefit levels were increased in the 2008 reforms, the first benefit increase since the program was implemented. The increases, which are being phased in between 2008 and 2012, are proportionately larger for HCBS than for institutional

care. As of 2009, all individuals receiving LTC became entitled to comprehensive care management to arrange for necessary LTC services, provided by a care counselor (European Commission 2008). Some benefit increases, especially for persons with dementia, are also part of a 2012 reform discussed briefly above.

LTCI is administered by non-profit “care insurance funds,” regulated by the government, under the umbrella of Germany’s health insurance funds. These funds are independent self-governing corporations under public law; their health insurance and LTC functions are carried out separately. They collect contributions and contract with providers to deliver LTC services. Persons who elect agency services can choose among the various agencies with which their LTCI fund has contracted. The 2008 reforms also made it possible for individuals to select “approved” independent providers who are contracted with funds, which had only been possible in exceptional cases prior to the reforms (German Federal Ministry of Health 2009).

Fees are negotiated regionally by the LTC funds and providers for HCBS and nursing home care, based on approximately 20 specific bundles of service packages. The LTC funds are able to review providers’ quality results during negotiation (Cuellar 2003).

Trends in Use of Home and Community-based Services

The cash allowance continues to be by far the most popular choice, despite its lower value. However, the share of those choosing formal home care services, either alone or in combination with cash, has been growing modestly, i.e., from 24 percent in 1998 to 30 percent in 2008. Compared to some countries, use of formal home care services by Germany’s older population is relatively low. In 2000, the rate of home help use in Germany among persons 75 or older was 6 percent compared with 33 percent in Norway and Israel (Daatland and Herlofson 2008).

Trends in Institutional Care

The share of all German beneficiaries in nursing homes increased from 25.7 percent in 1998 to 27.6 percent in 2008, and from 3.2 percent to 3.4 percent among younger persons with disabilities in full-time residential care (German Federal Ministry of Health 2010). The supply of nursing homes in Germany is generally perceived as adequate, with little waiting time, although there are regional variations. Relatively few nursing homes offer specialized care for dementia, although the qualifications of staff have been improving. The 2008 reforms addressed quality in particular, including requiring that nursing homes be inspected at least once a year and the results publicized using an easily understood school grading system (Rothgang 2010; Schulz 2012).

Benefits in Japan

Preventive Benefits

Because benefit use by persons with lighter care needs was expanding rapidly in the early years of the program, Japan encouraged benefits for these persons aimed at prevention of further functional decline in its 2006 reforms. This policy is intended to encourage the use of day care services and to contain the use of home help services that provide IADL support. The preventive benefits, provided in adult day care centers, focus on strength, exercise and nutrition training. However, home help service users were found to have a lower risk of functional decline than day care service users in one recent study (Ishibashi and Ikegami 2010).

LTC Benefits

Japan offers a wide range of services in the home and in institutions. Some services from both health care and social services were transferred to LTCI. Visiting nurses, in-home and day-care rehabilitation, and some LTC hospitals were transferred from health care, while home help services, some day care, nursing homes, bathing services, assistive equipment, and home modifications were transferred from social services.⁷

Care management services have been available to all beneficiaries without cost since the program began and are widely used. Care management is seen as a key to providing more integrated medical and LTC services and helping to assure care quality. Care managers provide advice and coordinate with other providers (Tamiya et al. 2011). Clients make the decision about which services to use, how much (up to ceilings) and who will provide them. At the inception of the program, care managers had high case loads, which were subsequently lowered from 50 to 35 clients.

Trends in Use of Services and Residential Care

More people were eligible initially than had been predicted—about 16 percent of persons age 65 or older in 2005 versus the 12 percent expected (Glendinning and Moran 2009). LTCI permitted for-profit HCBS providers to enter the market for the first time, and the volume of home help service providers increased substantially even in the first year of implementation. Clients use only about half of the maximum amount of HCBS for which they are eligible, a proportion that has not changed much since the program began (Campbell, Ikegami, and Gibson 2010).

Demand for institutional care increased immediately, in part because so many individuals had become newly eligible and because all “room and board” charges in nursing homes were covered. In addition, nursing homes seem to have something of a

halo in the eyes of reporters and the public, with reports of poor quality being less common than for acute hospital care (Wiener et al. 2007). The continuing high demand for institutional LTC has resulted in long waiting lists and greater demand for housing alternatives, such as assisted living. LTCI also has led to rapid growth of Alzheimer's group homes, small residences serving nine residents each with five to six staff, for which residents pay about \$1,000 a month (Campbell 2010).

Lessons for the U.S.: Coverage, Eligibility and Benefits

Provide universal coverage through social insurance rather than means-tested coverage

The inequities and cost of Germany and Japan's former means-tested systems were driving forces in providing universal coverage. Their mandatory systems, which provide universal benefits, regardless of income or family support, have garnered political and public support and reduced pressures on social assistance and health care budgets. Coverage under CLASS would not have been means-tested. Participation would have been voluntary and therefore not universal. Indeed, everyone would not have been eligible. Only persons who were actively employed would have been eligible to enroll, not their dependents.

Middle class Americans are increasingly caught between two tiers of care depending upon income: Medicaid for the poor, often in nursing homes, and privately financed residential or home care for the wealthy, with wide disparities in access and quality. While not universal in coverage, CLASS would have provided cash benefits to broaden the options available to middle income persons and diminish the need for them to impoverish themselves in order to receive help.

Provide universal coverage rather than selective coverage by age

Germany's decision to provide coverage for persons of all ages was never controversial because of the legacy of its other social insurance programs. Japan's decision to provide unconditional coverage solely for persons age 65 or older reflects its demography, culture, and institutional structures, which include a separate disability program for persons under age 65. Nonetheless, periodic debate occurs in Japan about extending coverage to younger persons.

In the US, persons under age 65 with disabilities represent about half of the broadly defined LTC population in the community (Kaye, Harrington, and LaPlante 2010). Another reason to cover persons of all ages is that preferences for long-term services and supports and for having more control over services were not found to vary

substantially by age, at least when comparing persons ages 50-64 to those ages 65 and over (Gibson et al. 2003).

Participation in the CLASS program would have been open to full-time students and employed adults age 18 or older but not to those fully retired. A “vesting “ period would have been required in which enrollees paid premiums for at least five years and worked for at least three of those years before becoming eligible for benefits.⁸ The earnings requirement was only \$1,120 per year.

Start with basic benefits and expand to more comprehensive benefits over time

Japan’s program covers 90 percent of formal caregiving costs, far more than Germany’s. Germany’s decision to provide basic benefits while encouraging private responsibility seems more consistent with US history and parsimonious social policies than Japan’s decision to implement an expansive program. Japan has modestly cut back benefits over time, although only for people with such light care needs they would not be covered at all in most countries, while Germany has modestly expanded benefits.

Today, only a small proportion of persons age 65 or older with disabilities (11 percent) in the community in the US are receiving any type of publicly funded home care, alone or in combination with family care, as are only 23 percent of those with severe disabilities (Houser, Gibson, and Redfoot 2010). What is clearly important is to first ensure that persons with severe levels of disability receive appropriate services, which requires careful attention not only the needs of persons with physical disabilities but also those with dementia, other cognitive impairments, and severe mental disabilities.

As a cash allowance, the CLASS benefit would have averaged at least \$1,500 a month in 2012, when benefits were to be designated, about double that of the German cash allowance at the highest level of disability. However, it would have been considerably lower than formal home care and nursing home benefits in Japan. In terms of its buying power, average prices for home care and nursing home care may be lower in Germany and Japan than the US because prices are negotiated annually with providers by the German LTCI program and set by the Japanese LTCI program.

CLASS was intended to provide basic protection against the risks of disability to eligible enrollees. Costs not covered under CLASS were to be the responsibility of the private sector, either through private insurance or out-of-pocket. Persons with low incomes who had exhausted their assets would have continued to be protected through Medicaid. As in Germany and Japan, enrollees would have been able to receive lifetime benefits if they met eligibility requirements, with no lifetime caps on benefits

like those typically found in private LTC insurance policies in the US (See Gleckman, this volume).

Promote consumer choice and flexibility through options for both cash and formal services

Both Germany and Japan provide greater consumer choice and flexibility in benefits than the U.S. today because they cover an impressive array of formal home care and institutional care benefits in their public programs, with Japan's being less costly for consumers because of higher benefit ceilings. They both also include benefits for assistive technology, and home modifications. A range of home care services and institutional care were included in the original benefit packages adopted in each country, as was respite care and day and night care. Care management, not originally provided in Germany, is now an entitlement in both countries, suggesting it may be essential to meeting needs of some (not all) beneficiaries.

Germany provides greater flexibility in offering the option of cash or a combination of cash and services. In contrast, Japan does not provide cash partly because women's groups in Japan feared that any cash benefit would trap daughters-in-law in "caregiving hell", in part because co-residence between families and older persons was common (Eto 2001). Other arguments against cash were that family caregivers benefit most from direct services (Tamiya et al. 2011), and that cash could deter caregivers from entering the formal labor force. The cash allowance in Germany, however, is relatively low compared to average wages and seems unlikely to serve as a financial incentive for family caregiving.

Real choice depends not only on affordability but also on the supply of direct care workers and good quality services. Major improvements are needed in the US in both areas. (See Stone, this volume.) Some European experts have argued that the impact of LTCI in stimulating new HCBS in Germany has been limited, and that the presence of the cash allowance restricts consumer pressure for a wider range of formal services (Glendinning and Moran 2009). However, the majority of German beneficiaries continue to choose the cash allowance despite other options. In addition, a cash option is consistent with the evolution of consumer-directed service options in state Medicaid programs.

Use uniform national eligibility standards determined by an objective process

Both Germany and Japan have uniform national eligibility standards that are published, reviewed, and changed periodically if problems are discovered. In the US, Medicaid eligibility standards for HCBS vary widely by state and often are not easily transparent to consumers.

Germany's new draft assessment tool for persons of all ages, which has been tested and may eventually be adopted nationally, is worth examining. The criteria go beyond those typically used in the US today. For example, the draft includes difficulties in communication, behavior, and caring for oneself when ill, all of which often require help from family caregivers. Conducting in-home functional assessments, as is done in both Germany and Japan, may also be a practice worth adopting.

Financing

Germany is a mixed public-private system of financing, with about 90 percent of the population covered under public LTCI, and 10 percent of the population covered under private LTCI that is required for the categories of people permitted to "opt out" of the public system. (The cost of services exceeding benefit amounts are paid either out-of-pocket or through social assistance.) Until the 2008 reforms, benefits were not increased to adjust for inflation, resulting in serious erosion of their purchasing power. Now, benefits are to be reviewed every three years for adjustments to keep pace with increases in the cost of living.

Germany has been described as a "capped" entitlement; maximum benefit levels are set by federal law in order to contain spending within premium levels. In contrast, Japan's financing system was designed to increase expenditures in the early years as services became more available

As shown in Table 3, Germany's system is entirely financed by premiums, while Japan's is funded half by premiums and half by taxes.⁹ Germany does not adjust premiums by regions, resulting in regional variations. In contrast, Japan makes regional adjustments. For Japanese age 65 or older, premiums are linked to local government spending levels, and hence vary some. For those 40-64, premiums are pooled at the national level and redistributed to municipalities so that those with more low- income residents and persons age 75 or older receive more funding.

Private LTCI

In Japan, the private LTCI market is quite small (OECD 2011). Germany's private *mandatory* LTCI covers about 9 percent of the population (OECD 2011). As with health insurance, German civil servants, high- income employees, and the self-employed may opt out of the public program but must obtain private insurance. This market is much more heavily regulated than private LTCI in the US. Private insurance plans are required to offer equivalent coverage, terms and benefits to the public program. In addition, premiums may not exceed contribution levels for the public program.

Table 3: Financing Provisions for LTCI in Germany and Japan

Germany, 2010	Japan, 2010
Mandatory social LTCI premiums: Workers pay 1.95% of income up to ceiling (\$51,882 in 2009) split equally between employers and employees at 0.975 percent each. (Childless adults pay 2.2% of income.)	Half by mandatory premiums; half by taxes
Dependent spouses and children are covered at no cost if their income does not exceed a ceiling	1/3 of premium revenue from 65+; six levels based on income. Deducted from pensions
Childless individuals pay an additional 0.25 of gross income	2/3 from those ages 40-64 at 1% of income, up to a ceiling (\$46,800 in 2009) split equally between employers and employees; paid as supplement to health insurance
Retirees pay full contribution rate of 1.95% of income, up to ceiling	
Private mandatory LTCI: premiums are based on purchase age, but cannot exceed the maximum contribution for public LTCI	

While social LTCI is designed on a pay-as-you-go basis, private LTCI in Germany has been described as a “prospective entitlement”, in which provisions are kept separately for each individual. Employers contribute a subsidy equaling half of the total premium. Premiums are primarily based on age at purchase; there is no underwriting. The vast majority of the policies provide a daily cash benefit, not services. Germany also has a small private voluntary supplementary insurance market to cover out-of-pocket costs, such as room and board charges in nursing homes. The Federal Cabinet recently decided to introduce public support for voluntary private long-term care insurance policies as part of the 2012 reform (Federal Ministry of Health, 2012). The subsidy will be 60 € per year regardless of income.

Reforms to Enhance Sustainability

Germany has introduced a series of modest steps to improve financial sustainability. In 2004, pensioners began paying the full contribution of 1.70 percent, which formerly had been shared between retirees and the pension funds.¹⁰ As of 2005, those who are childless began paying a supplement of 0.25 percent. One rationale was that the childless, on average, will receive higher benefits. The 2008 reforms raised premium contributions across the board from a rate of 1.70 to 1.95 percent of income, an increase intended to be sufficient until 2014, although this may not be the case, especially in light of the economic recession (Rothgang 2010).

Japan reduced fees to providers in 2003 and 2006, leading to an overall four percent reduction in institutional care fees and one percent for community care. It also increased consumer payments for room and board costs in institutional care. In 2006, Japan made further reforms, including moving “lighter “ need clients to preventive care with lower ceilings and more limited services. Fees were slightly raised in 2012 in order to raise careworker wages.

Trends in Expenditures

The German goal of reducing social assistance for LTC appears to have been largely met. According to a recent assessment by the Federal Ministry of Health, LTCI clearly reduced the level of dependence on social assistance by individuals. Today, about 5 percent of those who receive LTC at home, and about 25 percent of those in institutions, require additional social assistance benefits. Prior to the introduction of LTCI, roughly 80 percent of those in need of care in nursing homes received social assistance. In addition, social assistance budgets have been spared expenditures of roughly \$6 billion euros annually due to LTCI (German Federal Ministry of Health 2009). Since the introduction of the program, expenditures by the social assistance program for nursing home care have been reduced by roughly two-thirds (Rothgang and Igl 2007). Nonetheless, out-of-pocket spending for LTC services remains significant, representing about one fourth of all LTC spending for nursing homes and seven percent for home care.

By requiring contributions for five years before benefit eligibility began¹¹, Germany built up financial reserves for several years. Later, expenditures per beneficiary remained basically stable, although spending exceeded revenues by about two percent in almost all years (Gibson and Redfoot 2007). This imbalance was due in part to decreased revenue because of high unemployment, especially in the former East Germany, along with low wage and pension growth.¹²

Given the growth in Japan's "old old" population, it is not surprising that total expenditures for LTC have been growing every year, rising from 3.6 trillion yen in 2000 to 7.4 trillion yen in 2008. Premiums for persons age 65 or older have increased by about 44 percent over the same period (Japanese MHLW 2008). These premiums, which are income-related, averaged about \$420 per year in 2010.

The Japanese cost containment measures discussed above have substantially slowed the rate of spending growth. In the first implementation phase (2000-2002), spending increased by 44 percent; in the second phase (2003-2005), by 12 percent, and in the third phase (2006-2008), by 7 percent (Japanese MHLW 2008). Spending growth after the 2006 reforms has been the "sole result of increased spending in the size of this (75 or over) age group" (Tamiya et al., 2011). Japan reviews its spending and benefits every three years. Municipal governments set premiums for older persons based on projected service costs so that financial conditions can be balanced throughout each three year period.¹³ Because the premium increases get lots of attention, they create pressure to hold down spending.

Future Financing Reforms

Germany will need to make further financing reforms in the near future, which it recognizes in its planning efforts. Its goal has been to provide stable real benefits with stable contribution rates. However, demographic shifts make meeting this goal problematic because contribution amounts will decrease while expenses will increase with population aging. The increase in contributions by 0.25 percentage points (to 1.95) in its 2008 reforms is expected to be sufficient until about 2015. However, according to the Council of Economic Experts, demographic and revenue trends mean that the contribution rate will have to be increased to 2.5 percent by 2050, i.e., by 0.55 percentage points over a 35-year period (European Commission 2008).

Almost all German financing reform proposals seek to increase contributions.¹⁴ Merging the private insurance and social LTCI systems also has been suggested because the better risk profile of persons in the private system would ease pressure on the social LTCI funds. However, the most actively discussed options are to add some tax funding (for example, to cover costs for children) and to increase contribution rates and the income base upon which they are levied (Rothgang, 2010). The recent 2012 reform will raise premium contributions across the board by 0.1 percentage points, or to 2.05 percent of income beginning in 2013, as part of the expansion of benefits for persons with dementia and other cognitive impairments.

Japan continues to have one of the higher institutional rates in the world (if people in hospitals for long periods, under health insurance, are included), reflecting its legacy

of extended hospital benefits for long-term care. Further increases in room and board costs for institutional care paid by consumers are still under discussion. In addition, the government may eliminate many chronic hospital beds and tighten standards, trying to eliminate “social” admissions (Campbell 2010).

As part of its 2012 reform to strengthen the LTC service infrastructure, Japan is developing more community-based supports for people living at home, especially those with dementia, such as small-scale centers for day care, home visits available 24 hours a day, 365 days a year, and greater access to respite care (MHLG 2011). More radical proposals to either expand or cut back LTCI often appear in the press, but neither seems likely. Many municipal governments are calling for increasing the proportion paid by taxes, claiming that the premiums charged to their elderly residents have reached their limit (Campbell 2010). The 2012 reform is intended to help slow increases in the premiums (MHLG 2011).

Comparative Financing Data

Public spending on LTC appears to be similar in the Germany, Japan, and the US as a percent of GDP at about 1 percent in 2005 (Gleckman 2010). However, because Germany and Japan’s populations are much older than that in the US, aggregate measures are less useful than more discrete measures that compare spending by age. Public LTC spending in 2005 in the US per person age 65 or older was recently found to be higher than in Germany (\$1,605 versus \$1,185), and almost as high as in Japan (\$1,605 versus \$1,751) (Campbell, Ikegami, and Gibson 2010). At the same time, fewer Americans age 65 or older receive publicly-funded care—about 4.5 percent in the US compared with 10.5 percent in Germany and 13.5 percent in Japan. The reasons for the differences in spending have yet to be examined. Because the US spends more on nursing home care than either other country, its high cost in the US is likely a factor. Private LTC spending on a per capita basis is also likely far higher in the US than in either other country, although precise estimates are not available.

One factor that is often overlooked in LTC financing discussions is the degree to which revenues depend upon other broad macroeconomic trends, including unemployment and limited wage growth. In Germany, deficits in some years arose primarily due to declining revenues rather than to growth in spending.

Lessons for the US: Financing

Make financing sustainable over time

Germany and Japan have fiscally responsible LTC financing systems that permit them to plan for and implement cost containment measures as the need arises. They also

share demographic characteristics that are likely to make financial sustainability even more difficult in the coming decades. Notably, projections in both countries point toward stable or declining fertility rates, increasing life expectancy, increased female labor force participation, and increasing numbers of single person households. Placed in comparative perspective, the dependency/support ratios in the US, both today and in the future, look much more manageable than often thought.

Germany and Japan both require premiums for workers, which are split equally between employees and employers, a provision likely to be opposed by the US business community, as also occurred in Germany and Japan. Both countries also require premium contributions from older persons/retirees. While Germany's program is funded exclusively by premiums, Japan's combines premiums with general revenue funding, an approach more similar to Medicare financing in the US.

Germany only recently began adjusting benefits for inflation. Without inflation protection, the erosion in benefit values in the US might be greater than in Germany and Japan, which negotiate or set fees with providers respectively. CLASS benefits would have been indexed to the consumer price index.

Public expenditures in the US, with its fragmented, means-tested system, are more per person age 65 or older than those in Germany, and almost as much as in Japan. Unlike Germany and Japan, CLASS would have been a voluntary program entirely funded by individual premiums, which also would have been the only source for generous low-income subsidies for full-time students and workers with incomes below the federal poverty level. By law, tax funding was prohibited and CLASS was required to be self-sustaining for 75 years.

Premium projections for CLASS varied rather widely prior to its enactment. After extensive analysis, the Department of Health and Human Services estimated in 2011 that premiums would have been from \$235 to \$391 per month, a key factor in the suspension of the program. Premiums are much lower in Germany and Japan (Table 4), and are not age-based, although retirees in both countries make contributions based on income. In the US, premiums would have been based on the age at which one first enrolled in CLASS.

The most pressing challenge for CLASS would have been to attract sufficient participation by persons unlikely to need benefits relatively soon, in order to prevent serious adverse selection, and to keep premiums affordable. Another challenge in implementing the program was to encourage voluntary participation by employers, whose employees would have been automatically enrolled unless they chose to opt out.

CLASS was to have been to be fully evaluated ten years after implementation. By comparison, Japan evaluates its system every three years. Germany made modest reforms about eight years and more significant reforms about twelve years after its program was implemented.

Table 4. LTC Financing in Germany, Japan, and the US

Germany	Japan	US - CLASS
Maximum annual premium in 2009, \$506 each by employer and employee (\$1,012 combined) ^a	Income-related premiums (age 65+ average \$420 per year)	Voluntary premiums, age-based; no underwriting
	Maximum premium per year ages 40-64, \$234 each by employer and employee (\$468 combined)	Premium estimates were between \$235 and \$391 per month (DHSS, 2011)
Those permitted to “opt out” of public program must obtain private LTCI ; private LTCI heavily regulated	No private LTCI market	No mandate to obtain private LTC but room for private market to compete and fill gaps left by CLASS
State funded social assistance nursing home spending decreased	Pressures on health insurance reduced somewhat	Impact on Medicaid spending might have reduced “spend- down”

^a Converted to \$US using the OECD purchasing power parity (PPP) rate of 0.85 euro to the dollar and 115 yen to the dollar in 2009.

Reduce social assistance spending through a social insurance program but maintain the “safety net”

Germany’s social insurance program has substantially reduced its social assistance spending, by about two-thirds for nursing home care. CLASS benefits would have been in addition to Medicaid benefits; they could not supplant or replace Medicaid or any other federally funded health benefits. However, the availability of benefits to CLASS enrollees might have helped to delay or prevent nursing home entry as well as

spend down onto Medicaid, thus reducing Medicaid spending over the longer term. Importantly, both Germany and Japan have maintained their social assistance safety-nets for persons with low incomes to meet any LTC costs not covered by their universal programs, such as room and board costs in assisted living residences or nursing homes.

Permit private LTCI but regulate it more extensively

It is unlikely that the US, with its long history of private sector health financing, would adopt a system that does not provide a role for private LTC insurance. (See Cohen, this volume.) Today, about eight million private LTC policies are in force, representing a small share of the adult population. The enactment of CLASS sparked considerable debate about how it would interface with the private LTC market. Germany regulates its private LTCI market quite extensively, e.g., by requiring uniform benefits and premium ceilings, mandatory reserves, and consumer protections in marketing. Such regulations could increase consumer confidence in the US that private LTCI benefits would be paid and that rates would remain relatively stable over time, hence increasing demand. In addition, the German model of permitting certain groups (such as higher income individuals) to opt-out of a public system but be required to obtain private insurance may prove viable in the US in the future.

Differentiate financing responsibility for health care, housing, and LTC

The reforms in Germany and Japan led to a clearer delineation of which programs cover which costs than is the case in the US, and hence to less confusion among consumers and certainly fewer opportunities for cost-shifting between health and LTC. Germany and (to some extent) Japan have taken the position that room and board costs in both institutional and residential care should not be the responsibility of public LTCI. As a cash benefit, CLASS benefits could have been used to help pay for LTC and other “non-medical” services in any setting, as well as for some housing related costs. The legislation is ambiguous about what restrictions might have applied to the use of the cash benefits (Wiener 2010).

Family Caregiving

Both Germany and Japan have strong traditions of filial responsibility for the care of older persons, although attitudes are changing. In Germany, if beneficiaries cannot afford the room and board costs in nursing homes, social assistance is available. Their children may be charged for these costs, if they can afford them, or beneficiaries may have to sell their homes, a controversial practice. While a number of court decisions have decreased the financial responsibilities of families, social assistance boards still

have the authority to reclaim funds from children of recipients (Glendinning and Igl 2009).

In Japan, cultural beliefs about filial piety continue to influence family caregiving patterns, but co-residence between children and older parents has declined markedly, from about 80 percent in the 1970s to below 50 percent today (Japanese MHLW 2008). Today, only 20 percent of primary caregivers of the frail elderly are daughters-in-law (Long, Campbell, and Nishimura 2009). In addition, the family system has shifted from the extended family headed by older parents to older parents functioning as an independent family unit (Sugiura et al. 2009).

How System Design Affects Family Caregiving

Given the importance of family caregiver contributions to all aspects of LTC, from financing to workforce to quality, it is surprising that the effect of policies on family caregivers is rarely explicitly discussed as a design goal/dimension in policy development in the US (See also Levine, this volume). Federal and state programs offer only modest assistance to family caregivers through the National Family Caregiver Support Program, along with Medicaid HCBS waivers and some state-funded programs, which provide the majority of public financing to support family caregiving (Feinberg, Newman, and Fox-Grage 2005). In the US, fears among some stakeholders that publicly supported services will supplant family care combine with assumptions that families should bear the sole responsibility for care of adults with disabilities. Such attitudes are consonant with filial responsibility laws in 30 states that legally require adult children to financially support parents unable to provide for themselves, although such laws are rarely enforced (Ross 2008).

In Germany, encouraging family support was a key objective of its public LTC program. In addition, the very nature of social insurance for LTC makes care for older persons a societal as well as private responsibility. However, Japan may be unique among other developed countries in the prominence of the women's movement in the debate about how to structure the program to help relieve family caregivers' burden, with the explicit goal of shifting a portion of responsibility from the family to the state.

Why do the majority of Germans in need of care continue to choose care provided by family members, despite the option to choose publicly-funded services by agencies? Two main reasons for the persistence of family care are: (1) older persons and their families hold traditional care values favoring family care; and (2) older persons and care agencies have quite different definitions of good quality care (Eichler and Pfau-Effinger 2009). Only a small proportion of family caregivers surveyed said that the

need for additional income was decisive in their choice of family care (11 percent), while about 10 percent said it would help secure inheritance of the family's assets. The vast majority cited cultural values and moral responsibility, influenced by lack of trust in formal caregivers, turnover, and the speed with which formal caregivers carried out their tasks.

In 2009, about twice as many Germans were being cared for informally and receiving only the cash allowance (1.03 million) as those receiving any formal home care service (504,000), including respite and short-stay services (Buescher and Kesselheim 2010). However, attitudes seem to be changing. In a 2007 Eurobarometer survey, 68 percent of adults in Germany agreed with the statement "Dependent people have to rely too much on their relatives," higher than the EU average. In a 2008 Eurobarometer survey, 55 percent of German adults said having family care would be the best option if their elderly parent needs LTC and lives alone, while about 45 percent preferred formal care at home or in a nursing home (Huber et al. 2009).

In Japan, caregiving patterns changed after the introduction of LTCI (Campbell, Ikegami, and Gibson 2010). Use of formal caregiving services by older persons increased and financial burdens decreased (Tamiya et al. 2011). In addition, male spousal caregiving, which began before LTCI was introduced, is continuing to increase steadily, i.e., from 11.2 percent in 1984 to 17.9 percent in 1986 to 22.6 percent in 2004. (Sugaira et al. 2009, citing the Japanese Ministry of Health, Labour, and Welfare.) As has also been found in some US research, male spouse caregivers are more likely to use LTC services than are female spouses to help alleviate the burden of caregiving (Sugaira et al. 2009). Women carers spent significantly less time on elderly care in 2006 than 2001, while men slightly increased their involvement in caring (Tamiya and Shikata 2009). The hours spent by family carers declined significantly only for middle and upper income groups (Tamiya et al. 2011), a finding consistent with some other research on the lower use of formal services by lower income families. Nonetheless, the proportion of family members spending very long hours (more than eight per day) caring for the elderly declined significantly after LTCI was introduced (Shimizutani and Noguchi 2004).

LTCI has helped to remove the stigma in Japan of use of formal services for LTC. Such services are now widely accepted, even in rural areas. Indeed, adult day care as a form of respite is far more widely used in Japan than in Germany, by a factor of at least 100 to 1 (Campbell 2010). Many older Japanese do still live with family members (typically the son and daughter-in-law), but adult day care, home care, and respite in nursing homes provide an opportunity for less friction and more independence. Further, as in Germany, generational attitudes seem to be gradually

changing. Permitting “strangers “ to come into the house and provide intimate personal care remains a challenge, but the younger generation in Japan is said to welcome the shift to state responsibility (Izuhara 2003).

Policies to Support Caregivers

In Germany, LTCI pays social security (public pension) and accident insurance contributions for those who do not work more than 30 hours per week and provide at least 14 hours of care per week in the person’s own home. Over 90 percent of caregivers who meet this standard are women (European Commission 2008). In 2011, Germany passed a new paid family leave policy to permit workers to care for relatives who need long-term care.¹⁵ Respite care of up to four weeks a year is available to those whose usual caregivers take a vacation or are otherwise unable to provide care. LTCI will cover up to roughly \$1,730 per year if the temporary caregiver is a professional or distant relative. If that person is a close relative, the benefit only equals the usual cash allowance, although it can be increased to reflect additional costs the substitute caregiver may incur for travel or loss of earnings. The 2008 reforms reduced the contribution period prior to receiving respite care benefits from one year to six months, and increased funding for respite care centers run by charitable volunteer organizations.

There is a separate benefit for short stays in a German day or night care facility when necessary to supplement home care. The 2008 reform made it easier to combine the day/night care benefit with basic benefits, either cash or in-kind, up to 150 percent of the value of the basic benefit. The use of respite care remains low but has been gradually increasing, i.e., from 0.2 percent in 1998 to 1.4 percent in 2008, as a share of all beneficiaries (German Federal Ministry of Health 2010). Day care and night care services are also rarely used, i.e. by only 0.4 percent of beneficiaries in 1998 and 0.9 percent in 2008. The limited use of these benefits may reflect inadequate supply, bureaucratic obstacles (Lamura et al. 2008), and the lack of information available to family caregivers that such services are available. German caregivers indicated that “information about help available” was the most important of 15 support options they might need (Doehner 2007).

In Japan, respite care is provided through day care and night care (in a nursing home), although the number of short stay beds is inadequate (Tamiya 2011). Adult day care is quite widely used in Japan compared to most other countries. For example, about 1,600,000 older persons, many with dementia, attend day care in Japan, 6 percent of persons 65 or older compared with 0.6 percent in Sweden (Campbell 2010).

Lessons for the US: Family Caregiving

Incorporate the perspectives of family caregivers in all aspects of LTC system design

The Japanese debate over cash versus services provides a critical lesson: family caregivers in the US should be a central part of broader LTC reform --not just with respect to what specific caregiver supports are needed. The potential impacts on family caregivers of varying policy choices are rarely examined closely in US policy discussions of access, quality, training, or financing (Table 5).

Germany	Japan	US
Caregiving concerns not prominent when program was started. Program was designed to encourage family caregiving.	Key focus in reform was to remove burdens on family caregivers and to shift some responsibility to the government	No national debate yet about balance between family and government responsibility for LTC
Cash+ formal services, respite and some other caregiver supports	Services only, widespread adult day care; no cash	CLASS: Cash only
Most LTCI beneficiaries in the community continue to rely entirely on family caregivers	Most care recipients in the community now rely on both family care and formal services	In the U.S., more care recipients age 65+ in community rely entirely on family caregivers than a decade ago

The differing goals of encouraging family caregiving versus removing family caregivers' burdens are more frequently discussed in the LTC literature in Europe and Japan than in the US. (Glendinning and Moran 2009; Triantafillou et al. 2010) The US has not yet had a debate about the appropriate balance of responsibilities between the family and the government with respect to LTC, or the limits of family care. In Europe, changing public attitudes on this issue are studied by the EU and through other research (Huber et al. 2009; European Commission 2007).

Many scholars contend that the future will be one of “mixed care arrangements” combining both formal and informal care (Hoffman and Rodrigues 2010). Indeed, there is little evidence that family caregivers will stop providing care if formal services are made available—witness Germany and Japan. However, the type of support families provide may change, as in some Scandinavian nations, where families no longer provide as much physically demanding personal care but can focus instead on giving routine domestic help and psychosocial support. Or, as in Japan, gender patterns in family caregiving may gradually change.

In the US, recognition of the need for stronger partnerships between families and formal care providers, including nurses and social workers, is growing (Kelly, Reinhard, and Brooks-Danso 2008). However, a lower proportion of older community residents in need of LTC were receiving formal services to supplement family care in 2004 than they were in 1994 (Houser, Gibson, and Redfoot 2010).

Adopt policies and programs to support family caregivers, and phase in family caregiver services and supports before other benefits

As with LTC in general, programs to support family caregivers in the US differ widely by state, meet only a small portion of need, and are vulnerable to budget cutbacks. The two most important federal programs, the National Family Caregiver Support Program and Lifespan Respite, receive only miniscule funding (Feinberg et al 2011).

CLASS benefits could have been used to pay family caregivers directly or to purchase home care services, assistive equipment, or other supports. The ability to combine a cash allowance with a formal service benefit, as in Germany, would afford both consumers and family caregivers considerable flexibility. In addition, Japan’s widely used network of publicly funded adult day centers is worth examining closely for implications for US practice and policy.

As a general principle, Germany’s decision to permit enrollees to obtain respite care services before other benefits makes sense. In addition, the following covered benefits in Germany and/or Japan are all relatively inexpensive, and could be expanded fairly quickly as part of incremental reforms in the US: (1) adult day care; (2) respite care benefits, both short-term and longer term; (3) training programs for family caregivers; (4) information and counseling; and (5) social security tax credits for family caregiving.

Conclusion: Is Universal LTC Reform Feasible in the US?

Germany and Japan adopted many LTC reform goals and policies consonant with their existing structures, funding arrangements, and cultures, and the US is likely to do the same. However, especially in its decision to shift some of the responsibility for care of older person from the family to the state, Japan does show that major changes are possible. It also adopted its reform in the midst of economic recession.

The evolution of both German and Japanese policies demonstrates that, while LTC reform ideally should address coverage, financing, delivery, and quality issues at the same time, mid-course corrections to address major gaps and problems can work. When the program was initially developed in Japan, almost all of the attention was on caregiving, on who would provide care and how it would be delivered, with little attention to spending projections. In contrast, the focus in Germany primarily was on financing issues and sustainability. Hence the Japanese reforms in 2006 were mainly aimed at controlling spending, while Germany's 2008 reforms primarily aimed to increase access to care through adjusting benefits for inflation, introducing care management and local support centers, and expanding access to care by persons with dementia. Germany's recent 2012 reforms also primarily focus on expanding benefits. Today, the German and Japanese LTC social insurance systems are demonstrably superior to the US system in terms of access to services and cost to the public purse.

Current US policies are constrained by tax aversion, anti-government sentiment, and political polarization. Proposals to expand public financing for health care and LTC are countered by arguments that Americans are already over-taxed. However, the reality is that the United States (and Japan) do not have high rates of taxation compared with other OECD countries (OECD 2011).¹⁶

As in Germany, states may be the prime movers in further structural LTC reform, as burdens on health and LTC Medicaid budgets and the fragmentation and complexity of state LTC programs increase. As in Japan, the women's movement may come to play a prominent role in framing LTC as a women's issue for care recipients as well as caregivers, both unpaid and paid. In the US, open debate about the appropriate balance of responsibilities between the family and the government, as well as the limits of family care, has yet to occur. Older women in the US, an often marginalized group, are those most at risk of spending down into poverty and of incurring substantial LTC expenses.¹⁷ Further, the gender gap in family caregiving persists while the gender gap in disabilities among older persons in the US is growing (Redfoot and Houser 2010). As the prevalence of family caregiving increases with the aging of the population, these issues are likely to become increasingly urgent,

especially as more women look to their own potential futures as caregivers and care recipients.

CLASS was a controversial yet important building block that helped to make LTC more prominent on the national agenda. Its suspension suggests that it may not be possible to design a voluntary system that is affordable to most Americans while providing adequate protection against the risks of disability. Germany and Japan, with mandatory social insurance systems, have made and will continue to make significant reforms as their systems mature. These reforms have expanded the contribution base and the services available. They also have made changes in policies to support family caregivers and to improve quality and infrastructure.

Despite the fate of CLASS, LTC reform in the US should be less controversial than the debate over health care reform. (1) Both Germany and Japan, along with many other developed nations, adopted universal LTC systems after they had adopted universal health care systems. The recent health care reform legislation moves the US substantially toward universal coverage; (2) As in Germany and Japan, universal LTC reform would be an improvement for almost everyone compared to the status quo. That was not the case with health care reform in the US, which was threatening to the well-insured; (3) LTC as a percentage of total health care spending is much smaller in the US than in Germany and Japan because the US spends so much on health care—16 percent of its GDP in 2007 compared with 10.4 percent in Germany and 8.1 percent in Japan. Compared to health care reform, further LTC reform in the US should not be as threatening to powerful interests—compare the wealth and influence of hospitals to nursing home chains and home-care agencies, of the health insurance industry to the private long-term care insurance industry, of physicians to nurses and social workers, of the pharmaceutical industry to any providers in the long-term care field. Indeed, many LTC providers have advocated major LTC reform.

Both Germany and Japan enacted their mandatory LTC social insurance programs when about 16 percent of their population was age 65 or older, a line the US will cross sometime around the year 2020. While demography is not destiny, pressures to cover everyone, provide help to family caregivers, and contain both private and public costs for LTC are likely to increase. CLASS may have been a way station on the road to social insurance.

Notes

¹ Comparable cross-national data indicate that the poverty rate among women age 75 or older living alone was 17.7 percent in Germany compared with 48.3 percent in the US. However, older women in this age group are far more likely to live along (61 percent) in Germany than in the US (42 percent) (Choi 2006).

- ² This chapter extends the discussion of policy implications for the US of the LTCI experiences of Germany and Japan in Campbell, Ikegami, and Gibson, 2010.
- ³ References to the CLASS legislation are based on a number of sources: (1) primarily, the statute itself [[H.R. 3590](#)]; (2) National Health Policy Forum, [The Community Living Assistance Services and Supports \(CLASS\) Act](#), June 9, 2010; (3) AARP Public Policy Institute, 2010; [Understanding the New Community Living Assistance Services and Support \(CLASS\) Act](#), by Rhonda Richards and Lina Walker; (4) “Bringing CLASS to Long-Term Care “ *Public Policy and Aging Report*, 2010; and (5) Kaiser Family Foundation 2010; [“More Than Meets the Eye: Long-Term Care Provisions in the New Reform Law “](#), transcript from Alliance for Health Care Reform program Oct. 1, 2010. References to CLASS after the program was suspended are cited separately.
- ⁴ Social assistance in Germany refers to tax-financed, means-tested support for persons in need of care who do not receive support from other people, somewhat similar to the US Medicaid program. It is financed by Laender (states) under uniform, national standards for income and assets. The term also includes cash benefits and other income supplementation for low-income persons. In Japan, social assistance (public assistance) refers to cash payments to low-income individuals, similar to the US SSI program, while social welfare refers to means-tested services provided by municipal governments, either directly or contracted out, as in Scandinavia.
- ⁵ See note above.
- ⁶ Converted to \$\$ using the purchasing power parity rate (PPP) of 0.85 euro to the dollar and 116.32 yen to the dollar in 2008 (Campbell, Ikegami, and Gibson 2010).
- ⁷ Some post-acute services remain under health insurance, e.g., about 20 percent of the total for visiting nurse agencies and over 90 percent of rehabilitation services are provided under health insurance, while maintenance rehabilitation is under LTCI. (Naoki Ikegami 2008).
- ⁸ Germany also required a five year vesting period prior to the beginning of benefits; it recently reduced this period from five to two years.
- ⁹ The specific breakdown is as follows: 19 percent - premiums by persons 65+; 31 percent - premiums by persons 40-64; 25 percent - federal government; 12.5 percent - prefectures; 12.5 percent - municipality.
- ¹⁰ Pensioners’ contributions are based on their public pensions and other income.
- ¹¹ Germany reduced the contribution period before benefits begin from five to two years in its 2008 reforms.
- ¹² Contributions to the LTCI fund for unemployed persons are paid by unemployment insurance fund and social assistance but are lower than would be paid by employed persons.
- ¹³ The formula is set by the national government and allows relatively little autonomous decision making. The main variation comes from how many people are in institutions.
- ¹⁴ For the range of reform proposals, see Heinicke and Thomsen (2010), Rothgang and Igl (2007), and Rothgang (2010).

- ¹⁵ Workers can work half time and continue to be paid 75% of their salary. So they do not game the system, they are obliged to return to full-time work again with the 75% salary until the caring time is balanced (WHO 2012).
- ¹⁶ According to the most recent OECE revenue data available, total tax revenue as a percent of GDP in Japan was 28.1 percent (in 2008), in the U.S. 24% (2009), and in Germany 37 percent (2009). The OECD average in 2008 was 34.8 percent.
- ¹⁷ Older women in the US “face an exceptionally high risk of income poverty” relative to women in Germany, Sweden, and the UK (Gornick et al. 2009).

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CHAPTER 8

THE LONG-TERM CARE WORKFORCE: FROM ACCIDENTAL TO VALUED PROFESSION

ROBYN I. STONE

As millions of baby boomers march inexorably toward older ages, there are increasing concerns about the capacity of the caregiving workforce to meet the demand for long-term care. Much long-term care, in contrast to more medically oriented services, is unpaid assistance provided by family and friends (Spillman and Black 2005; Gonyea 2009). There are uncertainties, however, about the extent to which family members will be willing and available to continue to play their pivotal role in caring for disabled older adults in the future. In addition, many long-term care policy officials, providers, worker and consumer organizations and researchers agree that the formal long-term care workforce is already in crisis (Harahan and Stone 2009). The crisis is reflected in labor shortages, rapid staff turnover among administrators, clinicians and direct care workers, the inability of many consumers to find willing providers outside their families, and grave concerns about the quality of the workforce and how that translates into quality of care (IOM 2008). Many people enter the field “accidentally,” often moving into long-term care positions from other parts of the health care sector or other fields. They lack the understanding, education and training that is needed to work in this complex and rapidly changing environment.

This chapter provides an overview of the formal, paid long-term care workforce including the direct care workers that deliver the bulk of formal services and the professional staff who oversees, manages and delivers agency- and facility-based long-term care to older adults. This is followed by a discussion of the current workforce challenges, the factors contributing to this crisis and the reasons why this issue must be addressed. The chapter concludes with recommendations on short and longer-term solutions to the workforce crisis and some brief comments on implications for the future.

It is important to note that approximately 49 percent of the population needing long-term care is under age 65 (Kaye, Harrington and LaPlante 2010). Since younger people with disabilities differ with respect to needs, preferences and goals—particularly in the areas of school participation and employment—the workforce providing services to the under age 65 population warrants separate consideration beyond the scope of this chapter. Many of the concerns about and solutions to the elder care workforce crisis pertain to those caring for younger disabled populations as well.

The Formal Providers of Long-Term Care

The paid (“formal”) long-term care workforce serving America’s elderly population is made up of licensed professionals and unlicensed direct care workers who manage and deliver services in nursing homes, assisted living facilities, other residential and community-based care settings and private residences.

Direct Care Workers

Direct care workers are the core of the long-term care system, responsible for helping frail and disabled older adults carry out the most intimate and basic activities of daily life such as eating, bathing, dressing and toileting. They represent the largest component of the long-term care workforce, have the most frequent contact with care recipients and are most likely to directly influence the quality of care and quality of life provided to elderly consumers. In 2006 an estimated 2.3 million direct care workers—certified nursing assistants, home health care aides, and home care/personal care workers—were providing care to older adults in the United States (USDoL 2010). This figure greatly underestimates the actual size of the direct care worker population because it does not capture many workers hired privately by elderly consumers and their families.

To become certified as a nurse aide, federal law requires less than two weeks of training or passing a certification exam although most states add on to these requirements. Home health aides must pass a federally mandated competency exam for their employers to receive reimbursement from Medicare. Federal continuing education requirements for home health aides and nurse aides are minimal and content is left to states and providers. The regulation of other direct care workers, including those who work in assisted living, and personal care and home care agencies is determined by the states. Typically staff in these settings receives little or no training (Seavey 2007).

Registered Nurses

Registered nurses are responsible for ensuring the quality of clinical care, developing clients’ treatment plans, delivering certain types of care, supervising licensed practical nurses in various settings and direct care workers in the home health sector, and instructing patients and their families in self-care. Federal law requires that the director of nursing in a skilled nursing facility be a registered nurse; there are no federal requirements for other settings. In 2006 approximately 312,000 registered nurses were employed in long-term care settings serving elderly populations (USDoL 2010). By 2020, an estimated 287,300 registered nurses will be needed to work in

nursing homes, an increase of 66 percent from 2000. The comparable estimate for home health nurses is 275,600, an increase of 109 percent from 2000 (HRSA 2004).

Licensed Practical/Vocational Nurses

Licensed practical/vocational nurses (LPNs) provide direct patient care, including the taking of vital signs and administering medications. Approximately 26 percent of all LPNs work in nursing homes; there are no comparable estimates for the percentage employed in other long-term care settings (BLS 2007). Although their scope of practice is more limited than that of registered nurses, a survey conducted by the National Council of State Boards of Nursing (Smith and Crawford 2003) indicates that more than 60 percent act as charge nurses or team leaders with responsibility for supervising and directing the care provided by nursing assistants and other direct care workers. In 2006, an estimated 297,000 licensed practical nurses were employed in a range of long-term care settings (USDOL 2010). Anecdotal evidence suggests that because of the difficulty in recruiting RNs in many states, it is not unusual for LPNs to be the only category of nursing professional—other than the director of nursing who is required, by regulation, to be an RN—employed by the nursing home (Harahan and Stone 2009).

Mental Health Clinicians

Mental health professionals in long-term care settings include social workers and clinicians trained in psychiatry, psychology and nursing. Several studies (President's New Freedom Commission on Mental Health 2003; Bartels, Moak, and Dums 2002) show there is a severe shortage of practitioners in the mental health workforce who can provide mental health services to older adults regardless of setting. A majority of older adults in residential care are reported to have a significant mental health disorder and are in need of mental health services. A review of medical records by the Office of the Inspector General (USDHHS 2003) in a sample of skilled nursing facilities showed that 95 percent of the residents who received a psychosocial assessment had at least one psychosocial service need. However, 39 percent did not have a care plan indicating how these services were to be delivered.

The only published data on mental health clinicians in long-term care focus on social workers. In 2006, approximately 36,100-44,200 licensed social workers were employed in long-term care (USDHHS 2006). Licensed social workers are hired to address the psychosocial needs of elderly residents/clients and family caregivers across the full range of long-term care settings. Many are involved in the admissions process to a nursing home or assisted living facility. A subset of individuals trained as social workers provide care management services to community-dwelling elderly

individuals. A 2004 national survey of licensed social workers found that social workers in long-term care report facing greater challenges than their peers in other care sectors. These challenges include lower pay, higher caseloads, a greater proportion of tasks below their skill levels, and a lack of peer networks and agency support. All of these factors tend to compromise job satisfaction and continued participation in the field.

Licensed Therapists

Physical therapists provide services that help restore functioning and improve mobility for people who need rehabilitation following a hospital discharge. These services also help maintain functioning or prevent further deterioration for those with chronic physical and cognitive disabilities. Occupational therapists also help residents/clients to improve or restore functions related to activities of daily living such as dressing, bathing and eating. Approximately 40 percent of the 173,000 physical therapists in 2006 were employed in some type of long-term care setting (USDOL 2010). No comparable data exist for occupational therapists.

Physician Medical Directors

A physician medical director, responsible for overseeing residents' medical care and participating in care planning, is required at each nursing home reimbursed by Medicare or Medicaid. In 2004, over two thirds of all nursing homes had a medical director who spent four or fewer days per month in the facility; only 14 percent had a medical director who spent 11 or more days in the facility (Resnick et al. 2009). Assisted living and home health agencies are not required to have a medical director, but home health agency care plans must be approved by a physician. Coordination and communication between physicians and home health agencies has long been regarded as inadequate (Markeley and Winberry 2008).

Consultant Pharmacists

The role of the pharmacist in the interdisciplinary care of older adults was reinforced in 1974 when Medicare first mandated drug regimen reviews in nursing homes by consultant pharmacists (Levenson and Saffel 2007). The consultant pharmacist's role includes the provision of information and recommendations to physicians regarding medications, identification of improper use of medications or the prescription of incompatible medications, and collaboration with the medical director and other staff to develop proper protocols for response to adverse events. This role has become more important as the number of medications administered to chronically ill and disabled elderly patients/residents has increased.

Administrators

Nursing home, assisted living and home health administrators are responsible for staff supervision and management and for compliance with federal and state regulations. The federal government requires states to license nursing home administrators, although there are no national standards. The credentialing of administrators of other settings is at the state's discretion.

States' nursing home administrator licensing requirements vary greatly; some require only a high school diploma and passing an exam. The number of people who take such exams has declined by 40 percent since 1998, and pass rates have fallen. Barriers to recruitment and retention include a lack of reciprocity in states with more rigorous requirements to honor licenses issued in other states, inadequate job preparation, the requirement in most states that candidates for nursing home administrator jobs serve an unpaid "preceptorship," dissatisfaction with pay and co-workers and work overload, and the burden of being responsible for federal regulatory requirements (Lindner 2007).

The Workforce Challenges

Numerous federal agencies (the U.S Department of Health and Human Services, U.S. Department of Labor, the Institute of Medicine), more than 35 state commissions and task forces, and many privately sponsored employer, union and consumer groups (including the National Eldercare Workforce Alliance) have identified the development and sustainability of a quality long-term care workforce as a serious challenge in the 21st century (Kovner, Mezey, and Harrington 2007; IOM 2008; Stone and Harahan 2010). There is a widespread consensus that there are insufficient numbers of competent licensed and direct care staff to manage, supervise and deliver services to the elderly population and younger people with disabilities (Harahan and Stone 2009; IOM 2008).

Long-term care providers and consumers face a double-edged sword. It is difficult to recruit staff—from physicians and nurses to direct care workers. Once hired, staff turnover is rapid, leaving large numbers of positions vacant, putting heavy burdens on the remaining workforce and creating further barriers to attracting and retaining a quality workforce. The most recent national data on turnover and vacancies from AHCA's 2007 nursing home staffing survey showed an annual turnover rate among certified nurse aides of 66 percent and a vacancy rate of 9.5 percent, a shortfall of about 60,300 workers (AHCA 2008). In 29 states, the average turnover was above the 66 percent figure. Freestanding rural facilities had the highest turnover rates for direct care workers. In 2007, furthermore, the perceived difficulty in recruiting nursing

assistants was greater than the perceptions about problems with recruitment of RNs and LPNs.

Comparable national estimates of turnover are not available for home care and other community-based settings. A recent state study of the homecare and hospice markets in North Carolina, however, found a 60 percent turnover rate among homecare agencies and a 30 percent turnover rate among hospice providers (Dill and Cagle 2010).

A confluence of factors—including a negative industry image, noncompetitive wages and benefits, a challenging work environment and inadequate education and training--makes it very difficult to recruit professional clinical and administrative staff and direct care workers (Stone and Dawson 2008; Stone and Harahan 2010).

Negative Image

Negative stereotyping of long-term care environments and workers discourages new job entrants. Ageism in the broader culture, the sensationalizing of nursing home and assisted living problems in the media and negative attitudes of educators and leaders in professional schools and associations conspire to reinforce the image of long-term care as a poor career choice (Kaiser Family Foundation 2007). Among high school students considering a nursing career, for example, almost half have no interest in specializing in geriatrics, whereas 87 percent report having an interest in pediatric nursing (Evercare 2007).

Noncompetitive Compensation and Benefits

Compensation and benefits for all staff categories are not competitive. For instance, compared with nurses in hospital settings, RNs who work in nursing homes or other extended-care facilities receive lower annual earnings on average, even though they work more hours per week, incur more hours of overtime, and have a larger percentage of overtime hours that are mandatory (BHP 2006). Stakeholders in some states have observed that acute care hospitals are able to draw staff away from long-term care employers by offering higher salaries and /or better benefits (Center for Health Workforce Studies 2005).

In 2007, Forbes magazine profiled personal and home care aide jobs as one of the top 25 worst-paying occupations in America (Maidment 2007). In 2005, the average annual earnings of female direct care workers were significantly lower than the average annual earnings of female workers in general (\$17,228 versus \$30,441), and 19 percent of female direct care workers had incomes below the poverty level; versus eight percent of female workers in general (Smith and Baughman 2007). Employers,

furthermore, have a diminished capacity to increase wages because more than 70 percent of their financing comes from Medicaid and Medicare, which seek to limit costs regardless of labor market conditions.

Direct care workers also have limited access to employee benefits, including health insurance coverage, sick leave and retirement benefits (Smith and Baughman 2007; Stone and Dawson 2008). Often these workers are unable to afford their share of health insurance premiums or they are ineligible for coverage because they work part time or they work independently of an agency.

Challenging Work Environment

Workforce environments typically do not support front-line supervisors and direct care workers, starting with a hierarchical chain of command structure that discourages involvement of lower-level staff in care planning and ongoing decision making. Not surprisingly, LPNs, nursing assistants and home health/home care aides do not feel that their jobs are respected, a perception that contributes to job dissatisfaction and high turnover rates (Bishop et al. 2008; Bowers, Esmond and Jacobson 2003; Wiener et al. 2009). Other workforce challenges include inflexible work flow and job design, ethnic and racial tensions due to cultural diversity of staff and consumers in long-term care settings, and a paucity of career advancement opportunities (Wiener et al. 2009; Castle and Engberg 2006).

Caring for older adults can be physically taxing. Direct care staff in nursing homes has one of the highest rates of workplace injury among all occupations. In 2006, the rate of non-fatal occupational injury and illness involving days away from work was 526 incidents per 10,000 workers among nursing aides, orderlies and attendants (BLS 2007). This was four times the average rate among all occupations and was a higher rate than found among either construction workers or truck drivers. Nursing aides, orderlies and attendants also had the highest rate of musculoskeletal disorders among all occupations examined.

Inadequate Education and Training

The preparation of potential candidates for long-term care positions is out of sync with the realities of the long-term care demand and practice. Medical, nursing and social work students have little exposure to long-term care in their curricula or clinical placements (Harahan and Stone 2009). Only a fraction of these students receive training in geriatrics, and even then, the focus is primarily on acute and primary care (IOM 2008; Stone and Harahan 2010). Administrators, nurses and medical directors are poorly prepared for the management and supervisory roles with which they are charged in long-term care settings, and there are few in-service training programs to

help those who are already employed in these positions (Bowers, Edmonds and Jacobson 2003; IOM 2008; Resnick et al. 2009).

The strategies employed by regulators and educators to prepare and license or certify the workforce and to assure that personnel are able to keep pace with changes in the clinical knowledge base and new technologies are not effective. There are relatively few standards or competencies that are specific to long-term care. There is, furthermore, a huge shortfall of personnel who are competent and committed to educating and preparing both professional and direct care workers for long-term care careers. This translates into a dearth of people—both current and in the pipeline—who are adequately trained and educated to assume increasingly complex jobs across the long-term care settings.

This inadequacy of investment in education and training is compounded by the need for better knowledge and skills to respond to new philosophies and models of care. Emerging philosophies such as person-centered care and culture change in nursing homes, have catalyzed the design of service delivery models that emphasize the role of the consumer and family members in decision making and that empower lower-level staff to be more involved in the management of the workplace and resident/client decisions (Hamilton and Tesh 2002; Kane et al. 2007). The growth in publicly-funded consumer-directed programs that give the consumer the resources and the authority to hire and fire their workers—including their own family members—raises serious workforce issues. These include the magnitude and scope of training that should be required, and the roles and responsibilities that consumers can or must assume when they become employers (Foster et al. 2003).

With the expansion of home and community-based services, many states have changed their nurse practice laws to allow nurses to delegate tasks to direct care workers under their supervision (Reinhard et al. 2003). The implications of delegation for training and oversight in such areas as medication management and wound care are significant, leading the National Council of State Boards of Nursing and the American Nurses Association to call for the development of competencies and training programs for supervisory nurses to facilitate safe empowerment of direct care workers (Harvath et al. 2008).

The increasingly complex health and functional needs of the elderly long-term care population also present training and education challenges. The presence of multiple chronic conditions and dementia in long-term care recipients exacerbates the already difficult problem of effectively coordinating and managing transitions back and forth across settings: hospitals, nursing homes, assisted living and home care (Coleman and Berenson 2003). It is difficult to see how the new chronic care management and

transitional care demonstrations funded by the Patient Protection and Affordable Care Act of 2010 (PPACA) can be successfully implemented in light of the lack of trained, competent professional and direct care staff to carry out the required roles and responsibilities. The growth in hospice programs in long-term care settings and the proliferation of palliative care approaches to end-of-life services delivery (Huskamp et al. 2010) underscore the need for better formal and in-service training for all licensed and direct care staff.

The trend toward the use of more sophisticated information technology in care planning and coordination within and between care settings highlights another gap in the education and training of long-term care staff. The success of health information technology in improving efficiency and quality is dependent on a competent, knowledgeable staff that understands how to operate the system and use the data. Most professional and direct care staff is currently not trained in how to use these data tools and systems.

Why Workforce Matters

Workforce shortages, instability and inadequate preparation contribute to 1) significant access problems for many consumers; 2) extreme workload burdens and stress on the existing workforce; 3) unnecessary costs for employers resulting from the need to continuously recruit and train new staff; and 4) a seriously compromised quality of care for many long-term care recipients.

A 2001 Institute of Medicine (IOM) report on quality in long-term care identified workforce development as one of its nine guiding principles and acknowledged that quality of care depends largely on the performance of the caregiving workforce (Wunderlich and Kohler 2001). Until recently, most of the discussion of workforce issues has focused on achieving minimum staffing levels for nurses and direct care workers in nursing homes. However, the landmark 2008 IOM report—*Retooling for an Aging America*--made it clear that enhanced training and education—both formal and ongoing in-service--for clinical staff, managers and direct care workers—are essential to improve the quality, not just the quantity, of the workforce.

A growing body of empirical evidence supports the relationship between the quality of the workforce—particularly direct care workers-- and quality of care/quality of life outcomes for elderly residents/clients. In one of the early studies examining this relationship, Eaton (2001) documented reductions in mortality and pharmaceutical use and increases in resident functioning after the introduction of innovative organizational programs that improved the work environment of nursing home aides. These programs included the development of self-managed work teams, improved

information-sharing between nurses and direct-care staff, and enhanced responsibilities for the direct care workers themselves. In their evaluation of the Wellspring nursing home quality improvement program, Stone and colleagues (2002) found that the empowerment of the direct care workers, including their significant participation in care planning and care plan implementation, was associated with reduced turnover, a reduction in health deficiency citations from state surveyors and a decrease in incontinence rates. Bostick and colleagues (2006) found that lower nursing assistant turnover rates (a measure of job satisfaction and a quality work environment) were associated with improved quality outcomes including reduced use of physical restraints, catheters and psychotropic drugs, fewer contractures and pressure ulcers and fewer quality-of-care state survey deficiencies.

The literature underscores the critical role licensed nurses play—particularly in nursing home settings—in improving the quality of care (Harrington et al. 2000; Rantz 2003; Reinhard and Reinhard 2006; Bostick et al. 2006). One recent longitudinal analysis of California state survey data on nursing home quality from 1999 to 2003 found that registered nurse staffing levels were negatively associated with the number of quality of care deficiencies (Kim et al. 2009). Several studies have shown that nurse practitioners can have a positive effect on nursing home residents' care outcomes (Garrard et al. 1990; Rosenfeld et al. 2004).

There is a paucity of studies on the role that other professionals play in determining the quality of care for long-term care consumers. One recent study did find a positive relationship between having a certified medical director on staff (an individual with additional education tied specifically to the medical director role) and nursing home quality outcomes (Rowland et al. 2009). Analyzing nursing home deficiency data from the Centers for Medicare and Medicaid Online Survey Certification and Reporting database, the research team found that the standardized quality score of facilities with certified medical directors were higher than the scores of facilities lacking a medical director with a special certification.

The shortage of direct care workers in the home care industry has a direct impact on consumer access to services. Evaluation results from the Cash and Counseling demonstration program found that participants who relied on the traditional agency-based service system were often not able to obtain the services because of worker shortages (Dale and Brown 2007). In their analysis of five years of data from the National Long-Term Care Survey, Spillman and Black (2005) found that the proportion of community-dwelling elderly care recipients who relied on formal care dropped from 43 percent in 1994 to 34 percent in 1999, while the proportion who relied entirely on informal care increased from 57 percent to almost 66 percent. While

some of this reduction may have resulted from federal budget cuts in the Medicare program, the authors also attributed this reduction, in part, to a shortfall of paid home care/personal care workers.

While there are no published studies examining the effects of nurse or home health aide turnover on patient quality of care, studies have highlighted the important role that a positive relationship between the patient and the aide plays in both quality of life outcomes (Eustis and Fischer 1991; Rodat 2010). Frequent turnover of aides, where clients are constantly faced with establishing new relationships, is likely to negatively affect quality of care and quality of life.

High staff turnover and vacancies are expensive. Seavey (2004) conducted a meta-analysis of the literature and concluded that a minimum direct cost of frontline turnover per worker is at least \$2,500. Most of the studies she reviewed estimated the costs of separation and vacancy, hiring, training, and increased worker injuries. Seavey noted, however, that the indirect costs of turnover (lost productivity until the replacement is trained, reduced service quality, lost clients to other organizations, deterioration in the organizational culture and employee morale) may be substantial and tend to be overlooked because they are less visible and hard to measure. This estimate, furthermore, does not include the costs of managerial and licensed clinical staff turnover—including administrators and directors of nursing.

Solutions to the Workforce Crisis

To meet the current and future long-term care demands of an aging society, policymakers, providers, educators and other stakeholders must take action in a number of key areas.

Expand the Supply

Explicit policies must be developed to expand the supply of personnel entering the field. Today's developers of advanced training programs in geriatrics for professionals other than physicians must look to private foundations for support, or else it falls on the individual students to pay for the programs. For example, in 2007 the John A. Hartford Foundation awarded a \$5 million grant to the Gerontological Society of America for the purpose of preparing doctoral students in geriatric social work. This program and others funded by the private sector, however, do not focus specifically on building the long-term care workforce. A number of public policy strategies have been identified to help attract individuals into administrative and clinical professions in the long-term care sector (IOM 2008; Harahan and Stone 2009). These include the creation of financial incentives such as grant programs to foster greater interest among people considering the long-term care field; scholarships, federal traineeships and

residency programs for people preparing for advanced degrees in long-term care; matching grants to fund administrator-in-training programs for people interested in management positions; and loan forgiveness programs for people who commit to long-term care careers.

The PPACA established a 15-member national commission to review projected workforce needs and recommend ways to align federal healthcare workforce resources to meet them. Grants would be available for states to do comprehensive workforce planning and development. The health care reform law also increases the loan amounts in the nursing student loan program and specifically identifies long-term care as one of the priority areas.

The U.S. Department of Labor's Long-Term Care Regional Apprenticeship program illustrates how targeted programs can be used as public policy tools to expand the supply of direct care workers. Currently available in 20 states and in the process of being evaluated, this program combines classroom and on-the-job training with career advancement opportunities to expand the pool of nursing assistants and home care aides (Anderson et al. 2010; Kuehn et al. 2011). The public authority model--established in certain states (California, Washington) and localities (many counties in California) to support independently hired personal care workers—could be used more extensively to recruit individuals into these direct care jobs.

Older workers also provide a potentially rich pool of direct care workers (Hwalek, Straub and Kosniewski 2008). Research findings indicate that both older adults and long-term care providers are interested in exploring the potential of older workers and retirees to fill some of the current and future workforce gaps. Accordingly, several grantees of the Senior Community Service Employment Program, administered by the U.S. Department of Labor, have developed initiatives to train and employ lower-income older adults as direct care workers.

Another potential pool of long-term care workers is the TANF recipient population. Recognizing this opportunity, in 2010 the U.S. Department of Health and Human Services' Administration for Children and Families announced a \$51 million Health Profession Opportunity Grants program that will fund up to 17 five-year projects that provide training for and support educational paths to careers in health professions for TANF recipients and other low-income individuals (ACF 2010). Long-term care professions—including nursing assistants, home care aides and registered nurses—are specifically identified in the call for proposals. Projects must integrate the education and training with supportive services (e.g., transportation, dependent care, temporary housing) and must result in an employer- or industry-recognized certificate or degree.

A number of long-term care providers have also partnered with local high schools to develop on-site training and internship programs for students, to attract them to careers in this field. These programs combine didactic, classroom education with on-the-job training, support from mentors, opportunities for communication with and shadowing of various long-term care staff, and the offer of jobs upon successful completion of the program.

Another important source of professional and frontline staff to strengthen the pipeline is the immigrant population. A recent study of the role of migrant workers in caring for the elderly reported that approximately one out of seven professional staff working in long-term care is foreign born; the comparable estimate for direct care workers is one in five (Martin et al. 2009). Although immigrants are viewed by many employers as a valuable resource, there are a number of impediments to this strategy as a solution to the pipeline problem. Immigrants may only come into the United States with a temporary or permanent visa. Visas for all temporary and permanent less-skilled workers are capped at 5,000 per year, making it almost impossible for long-term care employers to draw on them to recruit new personnel. Limits for higher-skilled personnel such as nurses and physicians are less restrictive (Leutz 2007). The future of immigration remains unknown but it is clear that the decisions made will have significant implications for the development of the long-term care workforce.

Invest in Workforce Education and Training

A high quality workforce depends, in large part, on the investments that society makes in education and ongoing training of new and experienced personnel. The formal system of education, both initial and continuing, of long-term care managers, licensed professionals and direct care staff must undergo significant reform. Policymakers at the state and federal levels, educators, employers, workforce developers and organizations representing the various occupational categories should jointly assess the adequacy of current educational efforts, including the extent to which these efforts specifically address the developmental needs of the long-term care workforce.

The research literature provides little insight into the similarity between the geriatric competencies needed by health and social work professionals and those needed to effectively perform in long-term care settings (Harahan and Stone 2009). Utley-Smith (2004) compared the perceptions of hospital administrators, nursing home administrators and home health administrators in three states regarding the importance of selected competencies of recent baccalaureate-level nursing students. Competencies were categorized as health promotion, supervision, interpersonal communication, direct care, computer use and case management. The administrators from the three settings gave similar mean importance ratings to interpersonal communication and

direct care competence. Home health agency respondents gave the highest rating to health promotion competence. Nursing home administrators differed strongly from their peers in the other settings in the importance they attached to supervision competence—a finding that reinforces the need to address the deficiencies in the preparation of nurses to supervise other staff and/or delegate or monitor the work of others in the nursing home and other residential care settings.

Policymakers and other stakeholders should also evaluate the effectiveness of professional schools, community colleges and other vendors in providing the education. Based on these assessments, they should determine the curricula and the competencies that are necessary to strengthen and expand the long-term care workforce—with a particular focus on how care should be delivered in emerging home and community-based care settings and through new service delivery approaches (e.g., transitional care, integrated care, consumer direction). Financial incentives should be made available to recruit and develop qualified faculty who have the skills and knowledge and are committed to educating and preparing long-term care managers and clinicians for work in the long-term care sector.

Educational policies need to ensure that students in professional schools are required to take courses and have clinical site placements that provide knowledge and skills tailored for long-term care service delivery. The nursing field appears to have taken the lead in this arena. The University of Minnesota's School of Nursing is an example of a professional school that requires all students to take a course that introduces them to the roles, necessary skills and contributions of nurses in a range of long-term care settings. The course integrates curriculum models with on-site assignment to a nursing home. As part of the course, students must complete a clinical practicum in a long-term care facility and are assigned to specific residents.

Other schools of nursing are beginning to tackle gaps in the preparation and ongoing training of nursing home nurses as a result of funding from the John A. Hartford Foundation and the Atlantic Philanthropies. These foundations have established a partnership between the Hartford Centers of Geriatric Nursing Excellence at the Universities of Arkansas, California at San Francisco, Iowa, and Pennsylvania and the Oregon Health and Sciences University, nursing home providers, regulators and advocacy and payer groups. The goal is to increase the expertise, authority and accountability of RNs through the development of a long-term care nurse practice model that promotes the acquisition of geriatric nursing competencies and the special management skills needed in long-term care (Bourbonniere and Strumpf 2008; Beck 2008).

In 2006, the Visiting Nurse Service of New York (VNSNY) and the Hartford Institute for Geriatric Nursing at the NYU College of Nursing (with funding from the NY City Department for the Aging and the Fan Fox and Leslie R. Samuels Foundation) began to collaborate on a pilot project to assure that home health care nurses were prepared for geriatrics, with an emphasis on assessment and management of geriatric conditions and syndromes (CNYGEC 2010). The program provides both traditional face-to-face synchronous training and asynchronous internet training to VNSNY nurses using nationally recognized evidence-based best practices training materials. As of spring 2010, the goals of this program have been to prepare 40 nurses in best practices in care for older adults. RNs completing the educational module will sit for the American Nursing Credentialing Center's Gerontological Certification Exam, and participants completing the 40 hours of the educational program receive Certificates of Completion from the Consortium of New York Geriatric Education Centers. This program is currently being evaluated.

Other incentives, such as matching workforce development grants to long-term care providers, are needed to motivate existing professionals and direct care staff to obtain training in geriatrics, management, and cultural competency. Research on the content of continuing education for long-term care professionals is weak (Harahan and Stone 2009). Most studies address the relative effectiveness of various formats for delivering training to practicing professionals but not the content that is provided (Bourbonniere and Strumpf 2008). This knowledge gap is particularly problematic for the vast majority of nursing home and assisted living facility RNs who only have an associate degree or nursing diploma. They are, therefore, dependent largely on in-service opportunities to improve their clinical competence in areas such as geriatrics, supervision and leadership.

Both the initial training and the continuing education of direct care workers appear to be inadequate (Menne et al. 2007; IOM 2008). There are concerns about inadequate number of hours and the content of the educational offerings. The IOM (2008) recommended that the state and the federal governments increase minimum training standards for all direct care workers. Federal requirements for minimum training of certified nursing assistants and home health aides should be raised to at least 120 hours and should include demonstration of competence in the care of older adults as a criterion for certification. States should also establish minimum training requirements for personal care/home care aides.

One area seriously lacking in the current educational content for direct care workers is geriatric competency (IOM 2008). This includes a better understanding and ability to address the needs of elderly residents/clients with multiple chronic problems,

dementia and those at the end of life. There is also a dearth of initial and in-service training programs that help direct care workers to improve their teamwork and problem solving knowledge and skills. A number of programs have begun to address this gap, including the initiatives developed by PHI, the largest training and advocacy organization focused on the direct care worker in long-term care. The SCAN Foundation recently supported five California-based projects that are designing and testing in-service training programs that incorporate various elements of geriatrics. The ultimate goal of this initiative is to infuse the curricula into California's basic in-service requirements for nursing assistants and home health aides. The SEIU in the state of Washington has developed a new training program with expanded geriatric content for home care aides and independent personal care workers that will be rolled out over a three-year period

The PPACA included some provisions in health care reform that specifically address the inadequacy of training and education of the long-term care workforce. It authorizes three years of funding for new training opportunities for direct care workers. The act also authorizes funds for geriatric education centers for training in geriatrics, chronic care management and long-term care for faculty in health professions schools and for family caregivers. Another provision expands geriatric care awards to advanced practice nurses, clinical social workers, pharmacists and psychologists and establishes traineeships for individuals preparing for advanced degrees in geriatric nursing, including those who are interested in the long-term care sector.

Make Jobs More Competitive

Federal, state and local workforce policymakers should use multiple policy levers to make the long-term care professional and direct care jobs competitive in the broader health care market as well as with other sectors. Potential approaches include raising the wages for long-term care workers so that they are at least in line with their peers in hospitals. Communities can also raise wages for the direct care workers by passing living wage ordinances.

A number of states have used Medicaid "wage pass through" strategies, in which states allocate extra funds to nursing home or home health agency reimbursement rates with the proviso that these dollars will be used specifically by the providers to increase the wages of the direct care work force (IOM 2008). This approach has had limited success, has been difficult to enforce, and is not likely to be considered when states are experiencing significant budgetary problems. Given the major role that Medicaid plays in paying for long-term care, such a strategy needs to be improved and reconsidered in the future.

Long-term care staff—particularly direct care workers—must have access to affordable health insurance coverage. Currently, more than one in four—26 percent—of all direct care workers are uninsured. Twenty-two percent of those working in nursing homes and one-third of those employed in home and community-based settings lack coverage (PHI 2010). The PPACA has the potential to ameliorate the lack of coverage for many direct care workers, but the implementation will take time and the outcomes are uncertain. Policymakers also need to explore mechanisms through Medicare and Medicaid to increase compensation for medical directors and directors of nursing, who assume federally mandated responsibilities in nursing homes and home health agencies.

Another approach is to institute payment reform that ties Medicaid rate increases to the success of long-term care employers who demonstrate a significant reduction in turnover, increased staff retention, and better quality outcomes through workplace redesign and continuous quality improvement (Stone and Harahan 2010). Several state Medicaid agencies (Colorado, Georgia, Iowa, Kansas, Oklahoma, Utah and Vermont) have begun including select workforce measures in their pay-for-performance schemes for nursing homes (Bryant, Stone and Barbarotta 2009; Konetzka and Werner 2010), but there has been no evaluation of the effectiveness or consequences of these programs.

Implications for the Future

After 20 years of debate about how to reform long-term care, the development of its workforce is finally beginning to receive attention from policymakers, providers, professional and worker associations, consumers and researchers. The 2008 Institute of Medicine report on retooling the health care workforce for an aging society explicitly acknowledged the need to strengthen and expand this workforce at all occupational levels. Several provisions in the PPACA are designed to enhance the recruitment of individuals into the long-term care sector. The Department of Labor has also developed a number of initiatives specifically targeted to the expansion of direct care workers—particularly in home care and personal care. A number of national and state-level foundations have also identified the long-term care workforce as a priority funding area.

Several trends underscore the immediacy of this issue and the need to address the workforce challenge sooner than later. The oft-cited aging of the baby boomers ensures that there will be an increased demand for a trained, competent workforce to deliver and manage the services. At the same time that demand is increasing, the labor pool that has historically provided caregiving services to the long-term care population is shrinking. Baby boomers had a smaller than average number of children

than their parents, raising uncertainties about the future availability of family caregivers to provide unpaid services. The native-born population aged 25-44, from which both paid and informal long-term care providers largely come, is not projected to increase over the next decade, and the availability of immigrants to fill this gap is uncertain in light of a lack of a defined national immigration policy. In addition, aging nurses are retiring and there is a serious shortage of young nurses to replace those leaving the field. Those entering the field, furthermore, are much more likely to be employed in the acute care sector than to seek a job in the long-term care sector. As a consequence, long-term care employers cannot rely on traditional sources of labor.

Assistive technologies such as canes and walkers, and housing adaptations such as ramps, wheelchair-accessible showers and toilets and grab bars help disabled older adults reduce or even eliminate the need for human assistance in carrying out routine activities. Other technologies such as sensors that help prevent falls or medication reminders that help older adults comply with their medication regimens may also reduce the need for hands-on or even supervisory assistance (Center for Technology and Aging 2009). Telehealth strategies, particularly in rural areas, have the potential to create the efficiencies that can help to reduce the demand for human labor. Questions remain, however, about the extent to which technological advances will replace the long-term care workforce. It is more likely that these mechanisms will complement the professional and direct care workforce. Either way, the expansion of technology will require additional educational efforts to ensure that the staff is adequately trained to use the technologies appropriately and efficiently.

The development of this workforce needs to be viewed as an opportunity as well as a challenge. The long-term care sector—and home care in particular—is one of the fastest growing occupational areas in the country today (CNYGEC 2010). So it is important that we recognize the pivotal role that investment in this workforce can play in driving economic development as well as achieving better quality of care and quality of life for those receiving the services. To achieve this goal, we must shift the perception of work in long-term care as an accidental occupation to one which is attractive, rewarding and valued by society.

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CHAPTER 9

THE PERVERSE PUBLIC AND PRIVATE FINANCES OF LONG-TERM CARE

LEONARD E. BURMAN*

One of the first lessons of economics is that people respond to incentives—and the incentives in our long-term care system are all wrong. Medicaid pays for almost half of long-term care (Komisar and Thompson 2007), but only after a disabled person has spent down almost all of her wealth. That amounts to a nearly 100-percent tax on assets for many people. Medicaid provides nearly comprehensive long-term care insurance, but only after private insurance has paid. Since, for many people, private policies largely pay for services that would be covered under Medicaid, there is little reason to pay for insurance.¹

The response to the existing incentives is predictable: Americans save very little and few purchase long-term care insurance. Although the implicit Medicaid tax is only one among many factors at work, its perverse incentives are clearly counterproductive.

These incentives increase reliance on Medicaid, whose costs are a significant component of the ballooning federal deficits and create tremendous pressure on state budgets. While this is a problem even now, the future costs for federal and state governments will only grow as the enormous baby boom generation ages and requires more increasingly expensive long-term care services. In short, government policy discourages individuals from saving for long-term care without itself setting aside resources to meet the responsibilities it has taken on. This is a recipe for economic catastrophe (Burman et al. 2010) and places in doubt the government's ability to actually deliver the services it promises in the future.

Although these issues might discourage those who would like to make access to long-term care universal, a fundamental reform of the system of financing long-term care presents an opportunity to realign incentives and bolster both federal and state finances. A well designed universal long-term care system would eliminate the asset test and the strongest savings disincentives under the current system. Of course, any

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program that guarantees payment for all or a significant fraction of long-term care expenses will reduce incentives for private saving (compared with a system where individuals are fully responsible). The solution is to require full prefunding of the nation's long-term promises, either through a system of mandatory private long-term care insurance or through a fully prefunded federal program. There are, alas, both practical and political problems with both approaches. For that reason, incremental options to realign private incentives might be more feasible.

The plan of the paper is as follows. The first section outlines the effects of the dysfunctional long-term care financing system on federal and state budgets and private households' decisions. Next, the implications for public policy and several reform options are examined. A concluding section discusses limitations and challenges and suggests some broad benchmarks for evaluating public policy options.

Public and Private Finances

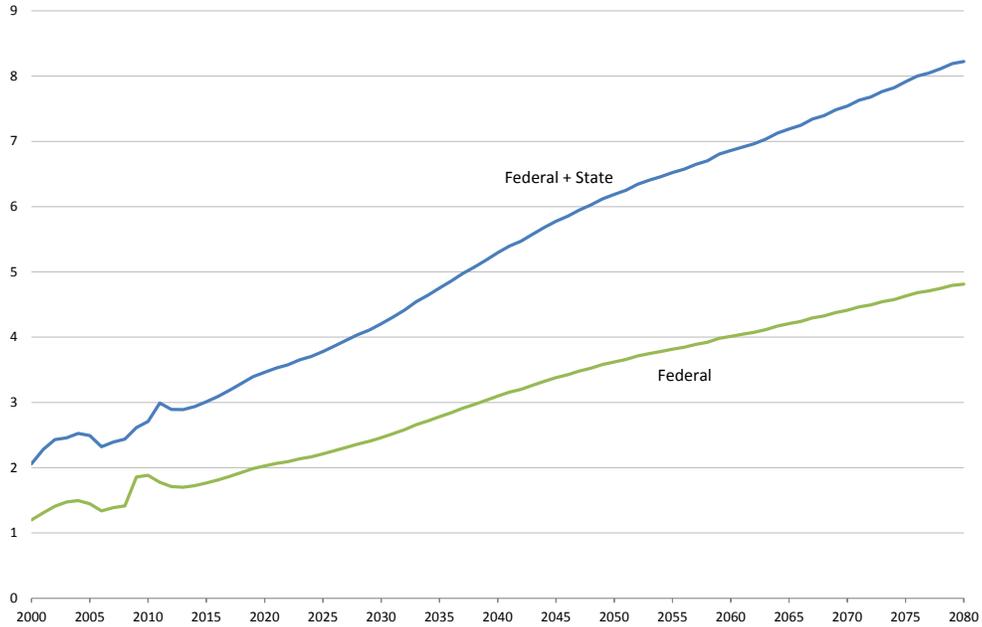
This section focuses on the effect of current long-term care financing on national and state budgets, savings, and households' ability to finance long-term care needs when they arise.

Effects on Public Finances

The current system of financing long-term care is a significant factor in the deteriorating long-term budget situation of both federal and state governments. In 2009, federal and state spending on Medicaid was about 2.7 percent of GDP² (see Figure 1.) That is more than half of spending on defense, which is less than 5 percent of GDP. In 2008, 30 percent of Medicaid spending paid for long-term care (Center on Budget and Policy Priorities 2008), but that percentage will increase dramatically over time as baby boomers age and their long-term care needs rise. Assuming a continuation of current policy, demographic and health cost trends, federal and state spending on Medicaid will exceed spending on defense by 2040.³ This presents serious challenges, especially as we consider expanding access to long-term care.

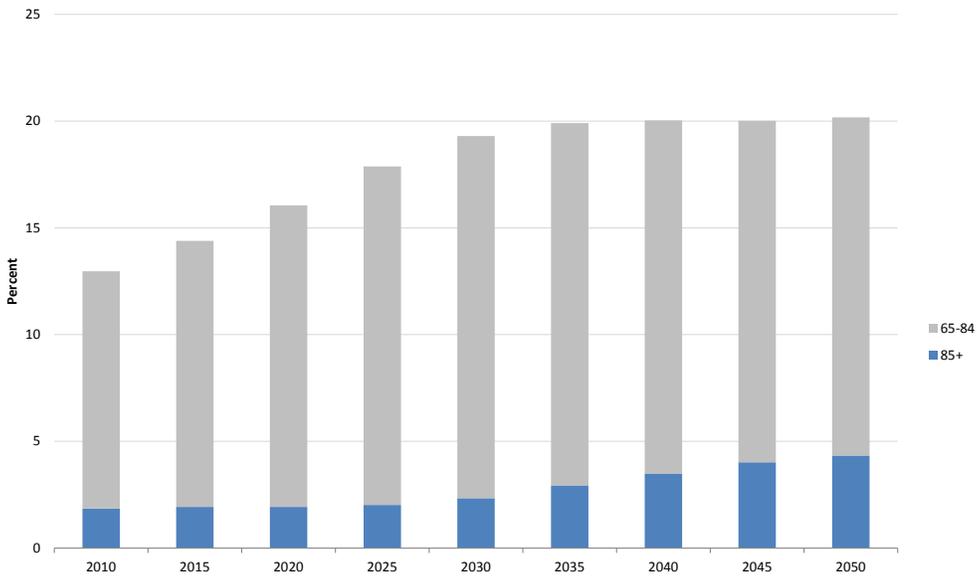
There are two primary cost drivers. First, the proportion of the population aged 85 and over will almost double between now and 2040 (see Figure 2). More than one-fifth of this group was in nursing homes in 1995.⁴ Second, health care costs continue to grow faster than the economy—by more than two percent per year on average. (Congressional Budget Office 2009) Assuming nursing home costs track health care spending, this translates into steadily increasing Medicaid spending relative to GDP.⁵

Figure 1. Public Medicaid Spending as a Percentage of GDP, 1965-2085



Source: Government Accountability Office (2010), supplemental data (personal correspondence).

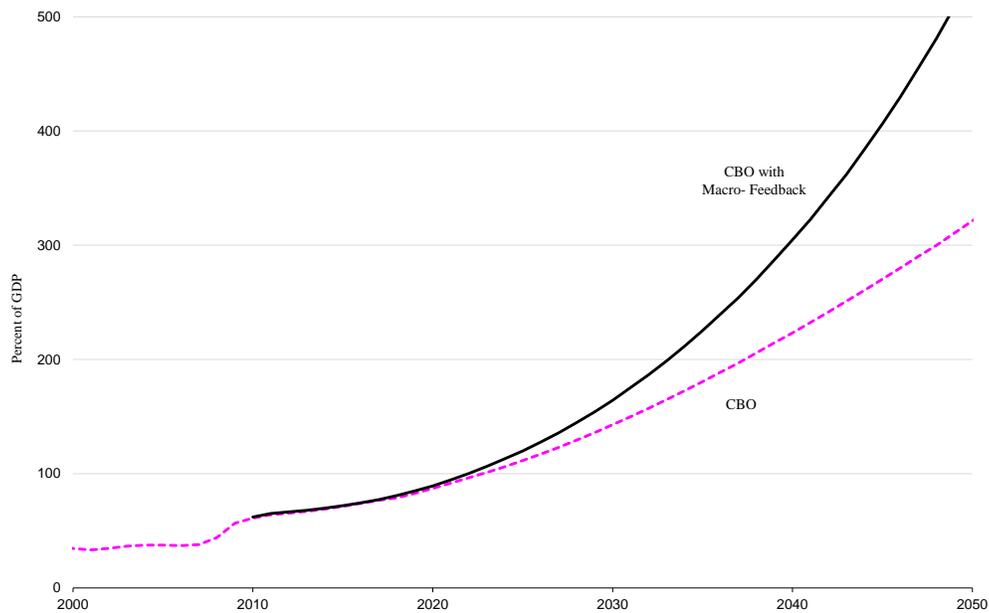
Figure 2. Percentage of Population 65-84, and 85 and over, 2000-2050



Source: U.S. Census Bureau, <http://www.census.gov/population/www/projections/files/nation/summary/np2008-t2.xls>

Medicaid is an important element in the unsustainable growth in public spending over coming decades. Burman, et al. (2010) estimate that if current policies continue, the debt will reach at least 100 percent of GDP by 2022 and 200 percent by 2034 (See Figure 3) with potentially disastrous consequences for the economy. Higher taxes would slow the rate of growth of debt, but cuts in entitlement spending will also be necessary over the long run.

Figure 3. Projections of Debt Held by the Public, 2000-2050



Source: Burman, Rohaly, Rosenberg, and Lim (2010)

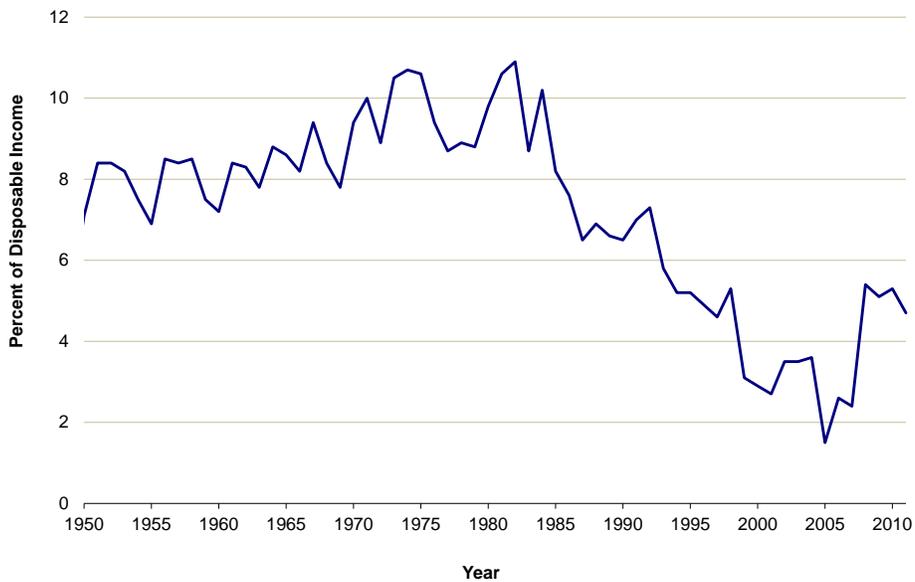
Almost all states have balanced budget requirements, so rising Medicaid liabilities will not translate directly into increased debt,⁶ but long-term care financing pressures threaten to exacerbate states' already precarious finances. State spending on Medicaid was less than 1 percent of GDP in 2010, in large part because of temporary federal aid under the American Recovery and Reinvestment Act. (Kaiser Family Foundation 2010) The Government Accountability Office (2010) estimated that the state share of Medicaid spending increased to 1.2 percent of GDP in 2011 and will grow to 1.7 percent of GDP in 2020, and 2.2 percent in 2030 if current trends continue. Combined with rapidly growing underfunded liabilities for public employees' pension and health benefits, this will create pressures on state budgets every bit as daunting as those facing the federal government.

Medicaid is an important part of the nation's long-run fiscal problem and reforming Medicaid could contribute significantly to a solution.

Effects on Saving

The federal borrowing binge would be less problematic if individuals were saving more, but personal saving has been declining dramatically over time. (See Figure 4.) One factor in that trend is the strong disincentives for saving built into the Medicaid program. For many older individuals with long-term care needs, Medicaid amounts to a 100-percent tax on assets above the threshold for eligibility for assistance (typically, \$2,000 for a single person). Medicaid also strongly discourages purchasing long-term care insurance because much of what is covered under private insurance simply replaces services provided for free under Medicaid.

Figure 4. Personal Saving Rate, 1950 - 2011



Source: Department of Commerce, Bureau of Economic Analysis, NIPA Table 2.1. Personal Income and Its Disposition, line 35.

Absent federal aid, the potential need for long-term care would encourage precautionary saving both during working years and retirement. The risk of high medical expenses and disability would provide a powerful incentive for workers to save (Hubbard et al. 1995; Palumbo 1999; Scholz et al. 2006; Vidangos 2009). And the high cost of nursing home care (and other medical expenses unreimbursed by

Medicare) would contribute a strong reason to maintain substantial asset reserves during retirement (De Nardi et al. 2010).

However, the availability of essentially free nursing home care for people with depleted assets and low incomes completely reverses the incentives. Like all social insurance programs that have asset tests, Medicaid depresses saving for two reasons:

First, the provision of support in the bad states of the world reduces the uncertainty facing households and therefore decreases precautionary saving (this effect would be present even in the absence of the asset test). Second, the restriction on asset holdings implies an implicit tax of 100 percent on wealth in the event of an earnings downturn or large medical expense. The possibility of facing this implicit tax further reduces optimal saving (Hubbard et al. 1995: 363).

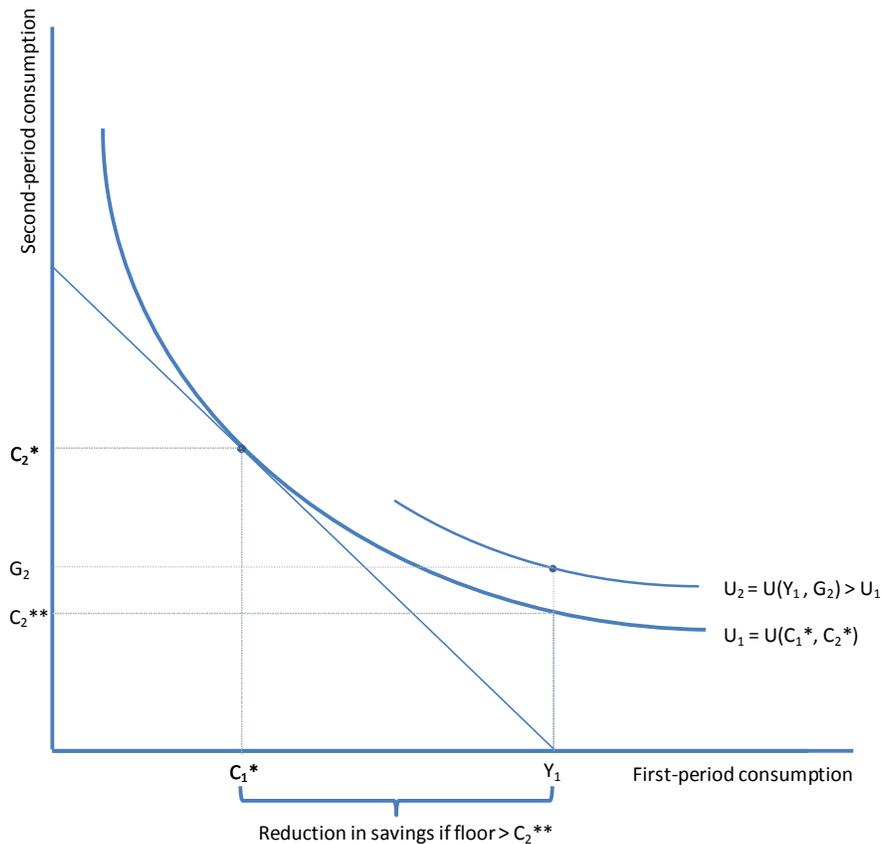
The main factor appears to be that Medicaid offers a guaranteed benefit—covering room and board and necessary medical expenses for seniors who become disabled. This is an intentional policy choice—a safety net for seniors who suffer what would otherwise be devastating long-term care expenses—but it means that older people at almost all income levels have less incentive to maintain a reserve to pay for such expenses, and workers have less incentive to accumulate a substantial retirement nest egg.

It is common in the economic literature to model Medicaid as providing a guaranteed minimum consumption level—basically subsistence for people with disabilities. In this context, De Nardi et al. (2010) simulate the effect on saving among the elderly of different Medicaid program rules and conclude that the highest three income quintiles would all save much more if the consumption floor (minimum benefit) were cut in half. In one version of their model, the top income quintile would maintain a roughly constant average asset balance until age 90 with the lower guaranteed benefit, compared with steadily declining asset levels under current rules. De Nardi et al. (2010) conclude that Medicaid encourages asset depletion at all income levels, although by a negligible amount for the bottom two quintiles since they enter retirement with few assets.

Presumably, if their sample had allowed for finer divisions, they would have concluded that those with very high incomes would be unaffected by the Medicaid consumption floor because it is so much lower than the desired level of consumption in retirement. Figure 5 illustrates the effect of a consumption floor in a very simple standard two-period life cycle model.⁷ Absent the social insurance program, an individual who has income Y_1 in period 1 and no income in period 2 (retirement)

chooses first period consumption, C_1^* and saving ($Y_1 - C_1^*$) to maximize lifetime utility.⁸ Second-period consumption is C_2^* , equal to savings plus interest. Now suppose the government guarantees second-period consumption of G_2 . If $G_2 > C_2^{**}$, the individual can achieve greater utility ($U_2 > U_1$) by spending his or her entire lifetime income (Y_1) in period 1 and consuming the minimum guarantee (G_2) in period 2. Saving decreases from $Y_1 - C_1^*$ to zero.

Figure 5. Effect of Retirement Consumption Floor on Saving



The intuition is straightforward. The government guarantees a certain benefit level that can be attained with no saving. This makes the individual better off than without the guaranteed benefit, so the optimal strategy is to not save at all and enjoy a much higher level of consumption during working years in exchange for only a modest reduction in living standard in retirement.

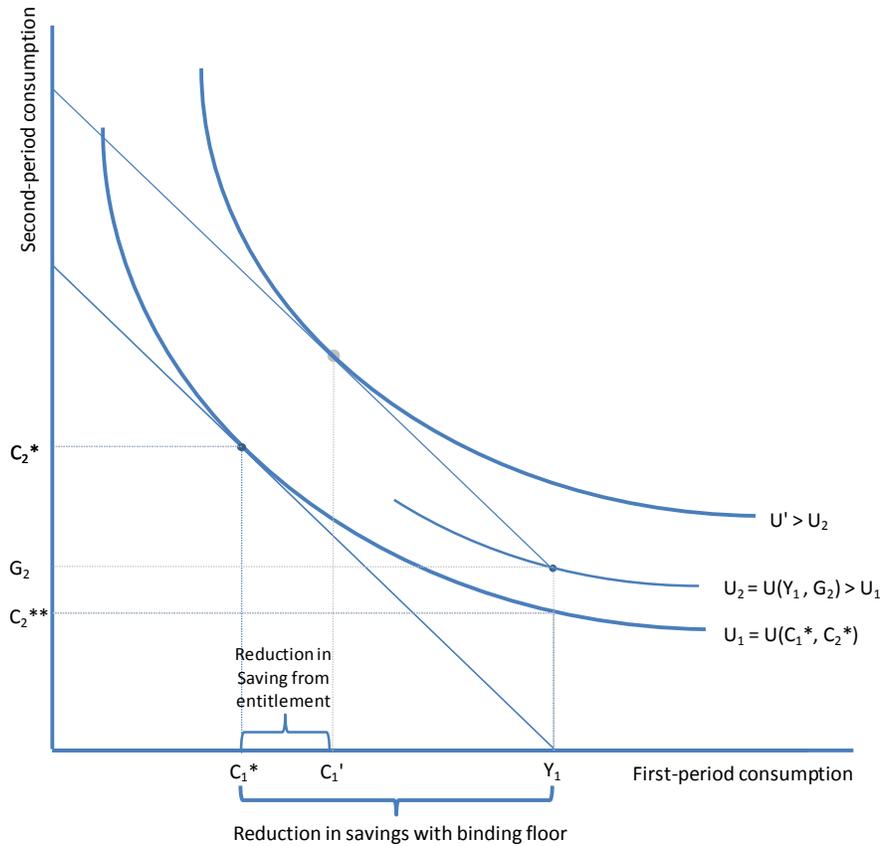
Obviously, this example is vastly over-simplified. Medicaid provides a floor on only one component of retirement consumption, covered long-term care services, which only have value for the minority of seniors who end up needing them. Most people cannot predict whether they will become disabled so there is uncertainty. And Social Security augments retirement income for seniors. Because of that program, many people would save little or nothing even before considering Medicaid and the possibility of needing long-term care. But the simple example sheds some light on how Medicaid nursing home care affects saving decisions.

People with very low and very high income are unlikely to be affected by the Medicaid guarantee—the former because Social Security provides more retirement consumption than they would choose if they could borrow against future benefits, and the latter because their desired retirement consumption is high relative to the guarantee amount (so $C_2^{**} > G_2$). For the rest of the population, the likelihood of being affected by the Medicaid floor depends on the probability of needing long-term care and the cost of that care. Increased longevity and a propensity toward certain illnesses such as diabetes or Alzheimer's disease increase the risk of needing long-term care services at some point. The higher the probability, the more powerful is the saving disincentive. Finally, as costs for long-term care services increase, the Medicaid guarantee becomes more valuable relative to planned retirement consumption, which further discourages saving.

The two-period model also illustrates how replacing the floor with a universal entitlement would affect behavior. Suppose Medicaid long-term care services were made available to everyone, regardless of asset levels or income. In this framework, that is equivalent to a grant of G_2 in period 2 (for those who need long-term care), which raises lifetime income, shifting the budget constraint out. This makes higher consumption in both periods feasible, and the individual responds by raising first period consumption from C_1^* to C_1' . Moreover, in this case, the person continues to save ($C_1' < Y_1$) so second period consumption also increases—to $G_2 + (Y_1 - C_1')(1+r)$, where r is the interest rate. Second-period consumption is higher than in the case where Medicaid simply provides a floor or than it would be if Medicaid did not exist.⁹

Savings falls (by $C_1' - C_1^*$) because of the income effect (consumption is a normal good and thus increases when lifetime income increases).

Figure 6. Effect of Universal Entitlement on Consumption



The income effect could be offset by raising taxes to pay for the new entitlement. A lump-sum tax with present value of $G_2/(1+r)$ would completely eliminate the income effect, but collecting it from lower-income households would be counter-productive (since the whole point of the policy is that many families cannot afford adequate long-term care while maintaining a minimum consumption level) and, in any event, infeasible. Another possibility would be to finance the new entitlement with a flat rate consumption tax, like a Value Added Tax (VAT). In this model, that would be equivalent to a lump-sum tax, but that is because income (Y_1) is assumed to be fixed. In reality, consumption taxes are tantamount to taxes on labor since they reduce the after-tax value of consumption that can be obtained from an hour of labor. So the VAT would create a labor distortion.

The bottom line is that the current system penalizes saving and alternatives exist that, if properly financed, might reduce the size of saving distortions.

Effects on Demand for Private Long-Term Care Insurance

Medicaid's most obvious distortion is that it crowds out private long-term care insurance (Brown and Finkelstein 2008). For low-income people with no assets, Medicaid is a perfect substitute for long-term care insurance. Since Medicaid rules generally require that private insurance be the primary payer, any long-term care insurance payments would reduce Medicaid payments dollar for dollar. Effectively, Medicaid constitutes a 100-percent tax on private long-term care insurance for people with low incomes in the sense that \$100 spent on private insurance reduces the value of Medicaid reimbursement by the same \$100 (see Figure 7).

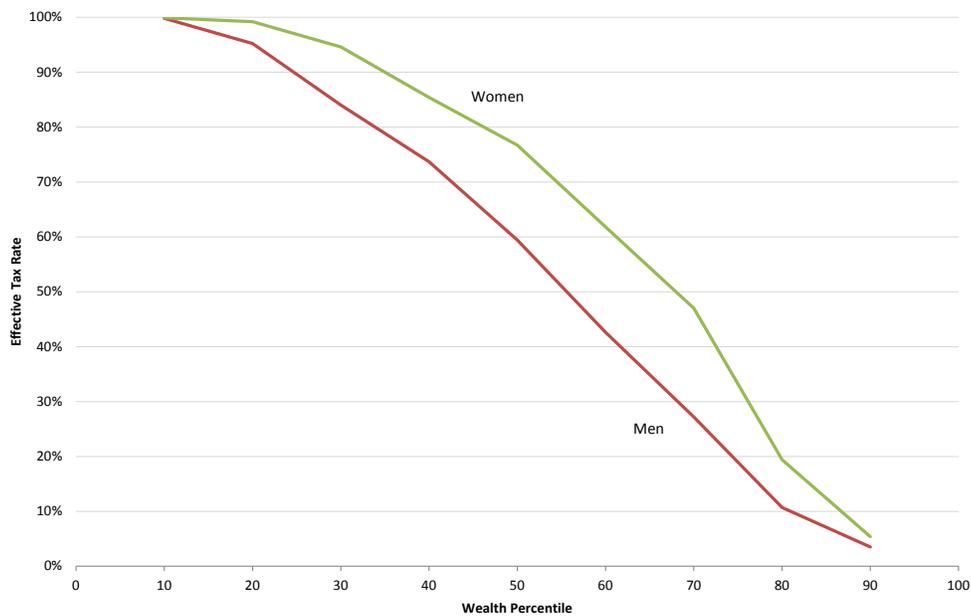
Private insurance is more valuable for families with more assets to protect. Long-term care insurance allows those with higher incomes to preserve their assets for longer. However, even families at the median wealth level face a substantial risk of a long spell of disability that would exhaust their assets despite partial reimbursement of expenses by the insurance. In that situation, long-term care insurance is simply substituting for Medicaid until the insurance policyholder's assets are exhausted. Brown and Finkelstein (2008) estimate that the implicit tax for such families exceeds fifty percent.¹⁰ Put differently, less than half of the long-term care insurance premium goes to coverage (asset protection) that isn't provided by Medicaid. Brown and Finkelstein (2008) calculate that the tax makes private long-term care insurance a bad deal for all but high-income households.

The crowd-out of private long-term care insurance has several undesirable effects. First, it reduces private sector saving since insurers have to maintain substantial reserves to pay future benefits. Second, it reduces public saving (increases deficits) because a larger share of long-term care expenses are paid by the public through Medicaid. Third, it entails a substantial welfare loss to individuals because Medicaid is very incomplete insurance. Individuals with assets can become nearly destitute before reaching Medicaid's asset threshold, and those whose stint in a nursing home is temporary return to the community with substantially diminished resources. Brown and Finkelstein (2008) estimate that most people would be willing to pay a substantial amount to purchase the asset protection insurance that Medicaid lacks, but such "top up" coverage is precluded by Medicaid's rules.

Some reforms have been aimed at encouraging the purchase of private long-term care insurance. A 1996 law made employer-provided long-term care insurance a tax-free fringe benefit, like health insurance. This lowers the after-tax cost of insurance

acquired at work, but it is a poorly targeted subsidy. The subsidy value of an income tax exclusion increases with income (and marginal tax rates), but lower-income workers face the highest implicit taxes on long-term care insurance. As a result, Brown and Finkelstein (2008) estimate that the tax exclusion would not suffice to make private insurance a good deal for most workers. Most states also offer tax deductions or credits. While the credits appear to be more effective at encouraging coverage, the net effect of tax subsidies is very small (Stevenson et al. 2009).

Figure 7. Implicit Tax on Long-Term Care Insurance due to Medicaid, by Wealth Percentile and Gender



Source: Brown and Finkelstein (2010).

Some states also raise the asset eligibility threshold for people with private insurance. However, since Medicaid is the secondary payer, the problem remains that a significant share of private insurance pays for benefits that would otherwise have been provided free under Medicaid. Thus, Brown et al. (2007) find only a modest effect on demand for private insurance from higher asset thresholds.

The actual effect of Medicaid on the demand for long-term care insurance is difficult to ascertain both because of inherent flaws in the private insurance market and the fact that individuals' actual behavior deviates significantly from the kind of life cycle optimization commonly used in the literature (including in this paper). Long-term care insurance carries very high loads—marketing, commissions, and other overhead costs built into insurance premiums. Brown and Finkelstein (2008) estimate the average

load to be 50 percent of premiums for males, although long-term care insurance is roughly actuarially fair for women. (The discrepancy arises because premiums cannot vary by gender and women are much more likely to require long-term care services than men.) Private insurance typically pays for only a fraction of nursing home costs (\$150 per day in 2005) after a waiting period of 90 days.¹¹ About a quarter of policies still have no inflation protection, which makes the insurance especially risky given that benefits might not be claimed for 30 years or more. It is difficult, also, to anticipate how long-term care will be delivered decades in advance so there is a risk that a current plan will not cover tomorrow's delivery mechanism.¹²

Moreover, although premiums do not increase with age after initial purchase, an insurer can raise premiums for an entire class of policyholders based on their claims experience, sometimes at double-digit rates. (Consumer Reports 2008) As a result, policies may lapse because policyholders cannot afford the escalating premiums. And, given the uncertainty about usage of long-term care, the future solvency of any insurer with a substantial portfolio of long-term care insurance is uncertain. For example, if there are great advances in preventing cancer and heart disease, many more Americans might live long enough to develop dementia and require long-term care services, which could bankrupt an insurer that specialized in long-term care. (Conversely, a cure for Alzheimer's disease could provide a windfall to insurers.)

Finally, even if the Medicaid tax did not exist and safe, comprehensive long-term care insurance could be purchased on an actuarially fair basis, many Americans who could afford the insurance might not buy it. Liebman and Zeckhauser (2008) catalogue a number of reasons why people might have too little health insurance and consume too little health care, despite large incentives to over-insure and over-consume. Those factors would apply to long-term care insurance as well. Humans, as opposed to hyper-rational "Econs" (Thaler and Sunstein 2009), are myopic and subject to inertia. Instead of discounting future income and expense at a constant rate, they tend to apply a very high discount rate over the near term (say a year), even though they plan to discount subsequent years at the modest rates that are consistent with economic theories of behavior. This "hyperbolic discounting" (Laibson 1997) leads to procrastination and a need for precommitment mechanisms that will make it possible for humans to follow up on their good (but inconsistent) intentions. Humans have difficulty evaluating small or distant risks and are prone to irrational optimism. (Thaler and Sunstein 2009)

Humans have trouble evaluating risks that are not salient. For example, they overestimate (and tend to over-insure against) the risk of plane crashes, because they make big news when they happen, but humans underestimate more common risks

such as car crashes and resulting disability, or diabetes. (Liebman and Zeckhauser 2008) Long-term care insurance creates a special challenge because people in their 40s or 50s might have little experience with the health problems of people in their 80s. That is, the risk covered by insurance has low salience.¹³

The bottom line is this: Medicaid creates prohibitive implicit taxes on private long-term care insurance for all but those with fairly high assets. However, even if the Medicaid distortions could be eliminated, it is not clear how many more people would purchase the insurance.

Implications for Public Policy

This volume's title asks, "Can we get [to universal coverage of long-term care] from here?" The answer is that it will not be easy. Any voluntary program will fall far short of universal coverage, especially if the inherent flaws in the current system are not adequately addressed. Moreover, since the current system is fiscally unsustainable, adding subsidies or a new entitlement for universal long-term care without a new source of revenues or offsetting spending cuts to pay for it would hasten the arrival of a fiscal disaster. If that happens, coverage for long-term care—and the rest of the social safety net—will all be at risk.

In my view, the ideal system for providing universal long-term care would be entirely self-sustaining. That is, on balance, the present value of expenditures net of revenues would be approximately zero. If the program is run as a public insurance plan, then reserves accumulated in excess of payments must be removed far, far off budget so that they do not simply facilitate large budget deficits in the short term (without providing any real resources to finance benefits as baby boomers age and health care costs increase). And the program should reduce the disincentives to save in the current system.

Medicare Part E

Rich Johnson, and I (Burman and Johnson 2007) outlined a proposal to replace Medicaid coverage with a new Medicare Part E that would pay for universal long-term care services, both at home and in an institutional setting. Unlike traditional Medicare, this new entitlement would be financed by a modest income tax surcharge that would effectively add about one percentage point to income tax rates for people covered by the program. This funding mechanism would exempt the bottom two income quintiles whose incomes are too low to be affected by an income tax surcharge and who would also not gain anything from the new entitlement since it would simply replace the free long-term care insurance that they are currently eligible for under Medicaid. Revenues from the surcharge that exceed outlays would be

deposited in a privately managed interest-bearing account. This off-budget trust fund would grow quite large as the new program phased in, since it would be decades before a large fraction of participants were drawing long-term care benefits.

The advantage of the proposal is that it could increase national savings by enough to pay for future long-term care benefits, vastly improving federal and state finances and significantly reducing the federal debt, all else equal. Smaller deficits should translate into lower interest rates over time, which would boost investment and productivity. (Gale and Orszag 2004) The proposal would reduce the strong disincentive for saving inherent in the current program by removing the floor on retirement consumption, as illustrated in Figure 6. Also, since the proposal would be fully financed with a tax surcharge, it would, on average, eliminate the boost to lifetime income that would otherwise be created by the new entitlement. However, the income tax also penalizes saving because both current earnings and the return on deferred consumption are taxed, which would diminish the saving incentive somewhat.

An alternative option to finance Medicare Part E would be via a VAT. As discussed above, this would virtually eliminate the saving distortion (although it would create a small work disincentive), however, it would hurt low-income individuals who would gain nothing from the new entitlement but would have to pay the regressive VAT. This drawback could be mitigated by providing a new refundable income tax credit equal to the tax that would be due at a consumption level equal to the poverty income threshold, with an appropriate adjustment to the VAT rate to offset the cost of the tax rebate. This approach has been suggested by advocates of a national retail sales tax (Jokisch and Kotlikoff 2007) and is also similar to the mechanism proposed to offset the VAT's regressivity by Michael Graetz (2010) and me (Burman 2009) as part of tax reform.

This proposal obviously faces political challenges in creating a "government run healthcare" program in what appears to be a toxic political environment after the highly partisan debate about health reform. But a more serious challenge may be trying to sequester the savings to pay for future long-term care benefits in way that does not enable larger deficits in the short term. For decades, Social Security has been running surpluses that have been dutifully deposited in an interest-earning trust fund. Notwithstanding this arrangement, the federal government's unified budget accounting allowed Social Security surpluses to mask a portion of the deficits attributable to other spending and revenues. The consequence is that when Social Security starts drawing on the trust fund, there will be no real assets set aside to meet Social Security's deficits. The shortfall will have to be offset by current taxes, cuts in

other spending, or additional borrowing. Put differently, casual observation suggests that the trust fund contributions had little or no effect on deficits or national saving.

Burman and Johnson (2007) suggest that the Medicare Part E trust fund be invested in market securities—a diversified portfolio of publicly traded stocks or bonds, for example. This would “work” in principle because purchases of securities are treated as outlays under federal budget rules.¹⁴ The outlays would exactly offset the revenues from the income tax surcharge (or VAT), providing no tempting imaginary surpluses for policymakers to spend.

The risk is that policymakers could change the budget rules to treat the transfers and income earned on the asset portfolio the same as the trust fund to facilitate more spending or tax cuts (and larger deficits). In that regard, experience with budget rules is not encouraging. Congress seemingly cannot resist the temptation to undermine them, unless there is strong external support for fiscal discipline (Penner and Steuerle 2004).

Expanding Private Long-Term Care Insurance

Burman and Johnson (2007) suggest a variant that might avoid these public choice problems. The new long-term care insurance entitlement could be run entirely through private insurers. This has the political advantage of turning a potentially powerful enemy—insurers, who would be put out of the long-term care business by the Medicare Part E proposal—into supporters of the new program. It might also garner some support from conservatives who favor privatizing social insurance programs. (However, the fact that participation would be mandatory would raise objections from some conservatives.) The federal government would make an annual payment to the insurer of choice, ideally with adjustments for difference in health status and expected utilization. The long-term care insurance industry would have to invent a system of totally portable insurance with protection from health care cost inflation, guaranteed issue and renewability, and a uniform set of minimum benefits. An accurate form of risk assessment would be necessary to deter cherry-picking, by which insurers seek to attract the lowest-risk persons to maximize profits.

With a major expansion of private long-term care insurance, there would be greater concerns about the ability of insurers to pay future claims. There would have to be strict requirements about reserves and permissible investments (no subprime mortgages or unhedged derivatives, for example). A more fundamental problem would be with insurers whose sole or primary line of business was long-term care. Currently, most long-term care insurers also sell life insurance and annuities, which allows for diversification of risks. Indeed, Mark Warshawsky (2007) proposed that

long-term care insurance be bundled with annuities because their risks tend to be negatively correlated (people who enter nursing homes are more likely to die than others of the same age, which terminates the stream of annuity payments early). Similarly, unexpected increased longevity can produce losses on annuities, but savings on life insurance. Requiring that participating long-term care insurers have significant lines of other types of insurance could reduce the overall risk of failure for any insurer. Nonetheless, there might be a need for reinsurance against systemic risks that could raise payouts on long-term care insurance.

Less sweeping changes might also mitigate the anti-saving, anti-private insurance risks in the current system, but incremental reforms would not lead to universal coverage. Brown and Finkelstein (2008) point out that providing a refundable tax credit equal to the expected present discounted value of Medicaid benefits that would be covered by private insurance could completely offset the implicit tax on insurance, in theory. In their model, the credit induces most people to purchase private insurance, but the authors acknowledge that factors such as high administrative loads, myopia, and adverse selection—the tendency of people at highest risk to be most likely to purchase insurance, which raises premiums—might cause coverage to fall far short of the model's predictions. Moreover, while the refundable tax credit would improve incentives, it would not, by itself, improve public finances since the government would be responsible for a larger share of long-term care expenses (including the cost of the new tax credit) and there is no proposed new stream of revenues to pay for it. However, by requiring the government to prepay a growing share of long-term care expenses, it would shift forward much of the cost of government financed long-term, which could create pressure to cut other spending or increase taxes, improving the long-term deficit picture. Unfortunately, as Brown and Finkelstein point out, the required subsidy, which depends on wealth and expected care utilization, could only be estimated with substantial error, which could make the program very expensive.

A fiscally responsible but politically more difficult variant of Brown and Finkelstein's tax credit would be a charge for the insurance value of Medicaid long-term care insurance for people who can afford to pay for it. Individuals who purchase qualifying private long-term care insurance would be exempted from the tax. This would be similar to the "pay-or-play" penalty that was a component of the recent health reform legislation. Unlike the credit proposal, this would raise revenues that could reduce federal and state fiscal imbalances. It could eliminate the implicit tax on private long-term care insurance, since those who purchase insurance would be exempted from the penalty. However, those who opt to pay the penalty rather than purchase insurance would still have Medicaid as a fallback option without the asset protection afforded by

private long-term care insurance, and would thus still face a disincentive to save. Unfortunately, this option suffers from the same measurement problems as Brown and Finkelstein's credit. And experience with the insurance mandate in health reform suggests that it could create considerable political opposition and possible constitutional hurdles, depending on how the penalty is structured.¹⁵

Conclusion

This paper has described the perverse effects on public and private finances of the current system for paying for long-term care through Medicaid. Because of the deteriorating long-term fiscal situation, the current structure of Medicaid might not be sustainable. The aging of the baby boom generation and continually rising health care costs threaten to make current commitments to Medicaid unsustainable.

It is clear that far better policy options exist. Providing universal access to long-term care could be an opportunity to improve individual welfare by eliminating major gaps in current coverage and reducing disincentives to properly save for retirement. Done right, it would also reduce or eliminate one of the major factors in federal and state governments' long-term budget woes—rapidly rising unfunded liabilities to provide long-term care through Medicaid.

In principle, the simplest way to do this would be via a universal public program financed by an income tax surcharge or a VAT. However, the political options facing a large new “government run health program” would seem to be insurmountable. And a new federal VAT would face daunting political hurdles.

A better option might be to repair the fatal flaws in the short-lived CLASS Act: (1) Expand the insurance to cover needed care. (2) Privatize the insurance to win buy-in from the insurance industry. (3) Regulate it to deter cherry-picking and guarantee that the insurance is portable and safe. (4) Provide subsidies big enough so everyone can afford it and dedicate a revenue source to pay for the subsidies. (5) Mandate coverage.

Of course, given the political firestorm that has surrounded health reform and the attacks on CLASS itself, this prescription may be hard to swallow. However, a more rational system of financing long-term care could boost personal saving and mitigate a major source of pressure on federal and state budgets. It could be worth pursuing despite the long odds.

Notes

¹ Medicaid is also heavily biased in favor of nursing home care, which is effectively a tax on home-based healthcare (Gleckman 2009). The issues surrounding the institutional setting for long-term care are beyond the scope of this paper.

² This is not a normative statement about the right level of spending on long-term care. Indeed, for reasons discussed elsewhere in this volume, the optimal public commitment may be higher than current spending.

³ This is based on the state and local projections by Government Accountability Office (2010) and federal projections of the Congressional Budget Office (2009).

⁴ 21 percent of individuals age 85 and older were in nursing homes compared with 5 percent of those age 75-84 and about 1 percent of 65-74 year olds (Stone 2000).

⁵ Some factors could lower costs over the long run, including declining disability rates and the growth in availability and use of assistive devices and technology. However, reduced availability and willingness of family members to provide care could increase costs.

⁶ Despite state balanced budget requirements, many states have exploited loopholes and accounting tricks to effectively borrow to finance current services, for example by mortgaging tobacco settlement revenues and underfunding employee pensions (McNichol and Lav 2006).

⁷ This model is a variant on Figure 2 in Hubbard et al. (1995).

⁸ The model assumes the individual lives for two periods (working in period 1 and retired in period 2) and has a lifetime income of Y_1 earned from working in period 1. Without the social insurance program, the present value of lifetime consumption equals Y_1 . That is, there are no liquidity constraints and no bequests. Second-period (retirement) consumption equals the amount of first-period income that is not consumed (saving) plus interest.

⁹ This ignores the necessity to eventually raise taxes to pay for the more generous Medicaid benefit. That would tend to reduce after-tax income and both first- and second-period consumption.

¹⁰ The implicit tax is higher for women than for men because women are more likely to need long-term care and need it for longer than men, primarily because of women's longer life expectancy. As a result, a larger percentage of women's than men's long-term care expenses are covered by Medicaid.

¹¹ According to Stevenson, et al. (chapter 9).

¹² Mila Kofman, a health policy analyst at Georgetown University, speculated that "30 years down the road, something better might come along, like some sort of video or robotic monitoring. That's something your policy wouldn't even envision today and may not pay for in the future" (Neighmond 2008).

¹³ Pauly (1990) argues that rational life-cycle utility maximizing individuals might forgo actuarially fair long-term care insurance if people who enter nursing homes rarely recover functional independence and they get no utility from bequests. In that case, preserving wealth upon admission to a nursing home is of little or no value.

¹⁴ President Clinton proposed converting a portion of the Social Security trust fund into a portfolio of assets in 2000, in part to reduce the measured surplus and also to bolster Social Security's finances since securities typically earn higher rates of returns than the

Treasury securities in the trust fund. (Elmendorf et al. 2002) (With the benefit of hindsight, it is clear that this approach would have produced very poor returns if implemented when it was proposed.)

¹⁵ As of this writing, the U.S. Supreme Court is deliberating on the constitutionality of the mandate to purchase coverage in the Patient Protection and Affordable Care Act (PPACA or health reform). The constitutional issues would likely disappear, however, if the penalty were designed as an explicit tax, rather than a fee. (Balkin 2012) Rather than a mandate, other options exist to encourage the purchase of private long-term care insurance. Tumlinson and Lambrew (2007) and Cutler et al. (2007) would each convert the share of Medicare that currently pays for long-term care into a subsidy for private insurance through different mechanisms. Medicare currently pays for about 20 percent of nursing home care. (Komisar and Thompson 2007) These proposals would not address the fundamental shortcomings of Medicaid funding, but would likely induce more people to purchase private insurance.

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CHAPTER 10

IT TAKES TWO TO TANGO: A PERSPECTIVE ON PUBLIC AND PRIVATE COVERAGE FOR LONG-TERM CARE *

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Introduction

Stakeholders hold divergent views regarding the potential role of private long-term care insurance in meeting the nation's future long-term care needs. For example, a recent treatise on long-term care reform released by the SCAN Foundation did not include options for promoting private insurance, stating "we do not consider promoting private long-term care insurance (LTCI) to be a priority for investment of public resources" (Komisar et al. 2009). In contrast, those with Medicaid budget responsibility express a different view. The National Governors Association position on long-term care reform states that "policies are needed to encourage greater reliance on long-term care insurance rather than Medicaid" (National Governors Association 2009).

The private long-term care insurance industry last year paid over \$4.3 billion in claims (Conning Research and Consulting Inc. 2009), and one in six persons over age 65 with annual incomes over \$20,000 have private long-term care insurance (Long-Term Care Financing Strategy Group 2005). Yet, the growth in the private market is largely regarded as disappointing; sales and market penetration have leveled off or declined since 2003, with new sales occurring in a narrowing market of upper income Americans. Even though the average price of insurance (about \$2,000 per year, or \$165 per month) could be considered within the reach of a large percentage of American households, long-term care insurance is not perceived by most to be a valued investment of discretionary income on par with automobile, homeowners, life, health, disability and other risk-pooling products.

* A more condensed version of this article was recently published in *Health Affairs*, Volume, 29 No.1, January 2010.

In this paper, we review the current state of the private long-term care insurance market and explore factors underlying its relatively modest size. We address the affordability debate and why more Americans have not elected to secure insurance protection. We then review public policy options for promoting industry growth and discuss the intersection of private coverage and public policy with a focus on how public insurance (i.e., a program like the recently examined CLASS Program) and private insurance can work together to provide all Americans protection from catastrophic long-term care costs.

Why Insurance?

A starting point in discussing how to finance our country's long-term care needs is to emphasize the insurability of these services and supports. Most of us will have supportive service needs as we age, but there is tremendous variation across individuals in how extensive these needs will be and in the magnitude of spending for formal (paid) services. Upon turning 65, for instance, 42 percent of Americans can expect to have their long-term care needs addressed with non-paid sources and spend nothing on formal long-term care during their lifetimes while 16 percent can expect to spend more than \$100,000 and paid caregivers (Kemper, Komisar and Alecxih 2005).

Although this distribution of financial risk implies an appropriate role for insurance as an efficient mechanism to spread risk, insurance currently plays a minor role in financing long-term care. Most of the almost 10 million individuals who need supportive services get by at home, receiving unpaid help from family and friends. For those who require paid supportive services, the vast majority lack coverage for these expenses. Neither Medicare nor private health insurance covers long-term care, and only a small portion of older people purchase long-term care insurance. Instead, the safety nets of family caregiving, out-of-pocket payments, and the means-tested Medicaid program support the bulk of long-term care in this country.

By all accounts, the current approach to financing our country's long-term care needs does not work well. In particular, the system does a poor job in spreading financial risk, in supporting access to high quality care in settings where people want to live, and in equitably sharing financial responsibility for care across individuals and their families. (For example, families that choose to try and support a disabled person to remain in a home setting tend to have less available public support for doing so compared to those who have an elderly relative receive care in a nursing home.)

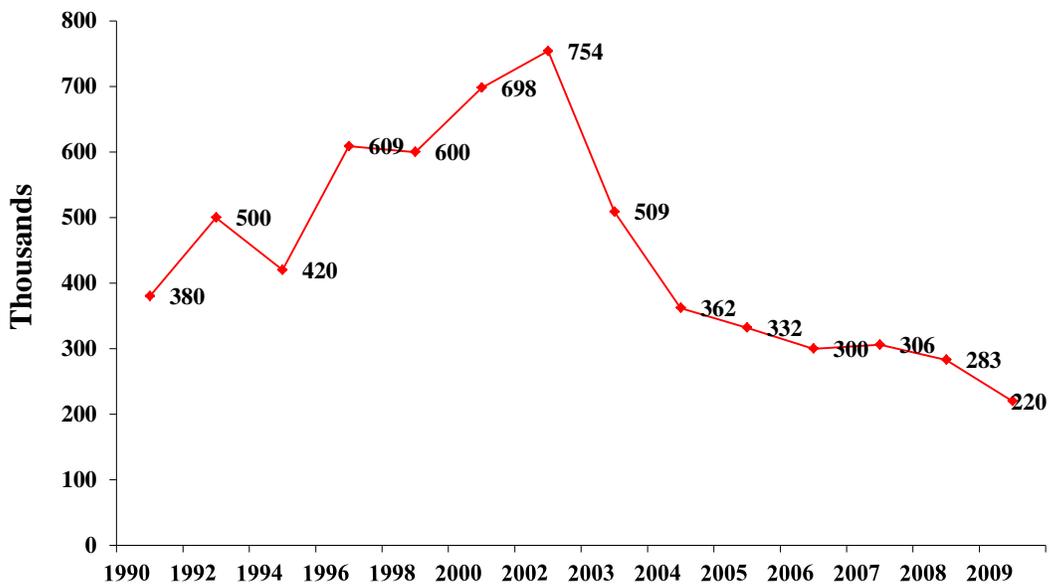
State of the LTCI Market

Today, there are around 8 million private long-term care insurance policies in force. While significant, the size and complexion of the market have not lived up to

optimistic trends and projections of a decade ago. The market grew by roughly 18 percent annually from 1987-2001, but sales growth has since slowed considerably. Specifically, while the group market grew at an annual rate of about 15 percent from 2000-2005, sales in the individual market—which account for more than 2/3 of this market—declined by 9 percent per year over the same time period (LIMRA International I 2000-2005). Much of the rapid growth in the group market was fueled by the Federal employees long-term insurance program which attracted upwards of 250,000 policyholders. Also, a growing number of employers began sponsoring plans for employees and given the small base of employer plans at the beginning of the decade, even modest increases in the number of insured translated into high rates of growth.

Figure 1 shows growth in the individual market over the past 20 years. Between 1990 and 2003 the market experienced steady growth, reaching its peak in 2003. Since that time, however, along with the decline in the stock market, sales have declined very rapidly so that by 2005, sales were below 1990 levels. By 2009, sales had declined to slightly more than half of 1990 levels.

Figure 1: Annual Sales of Individual LTC Insurance Policies (1990-2009)



Source: Authors Calculations based on Life Insurance Marketing and Research Association and LifePlans, Inc. data.

Although market penetration has remained relatively static in recent years, the attributes of policies sold have changed substantially from 1990-2005. This is shown in Table 1. In particular, policies sold now include significant innovations and enhancements such as expanded coverage for home and community-based care, increased parity in daily benefits for facility-based and home care, and greater inclusion of inflation protection. Consumers today have more choice with respect to the type and amount of coverage and can customize coverage to their specific needs, preferences, and pocketbook.

Table 1: Individual Long-Term Care Insurance Policy Designs, by Purchase Year

Policy Attribute	2005	2000	1995	1990
Policy Type (%)				
Comprehensive	90%	77%	61%	37%
Facility or Home Care Only	10%	25%	39%	63%
Policy Duration (%)				
2 years	11%	17%	24%	23%
3 years	22	23	20	12
4 years	17	14	18	15
5-8 years	27	16	8	17
Lifetime	23	30	30	33
NH Daily Benefit (\$)	\$142	\$109	\$85	\$72
HHC Daily Benefit (\$)	\$135	\$106	\$78	\$36
Choosing Inflation Protection (%) ^a	76%	41%	33%	40%
Average Annual Premium (\$)	\$1,918	\$1,677	\$1,505	\$1,071

Source: Authors calculations based on data from AHIP (2006).

^a Note that 6 percent of new policyholders had a guaranteed purchase option for benefit upgrades. This 6 percent is not included in the total percentage of individuals who purchased inflation protection.

Typically consumers are offered a number of choices regarding the nature of their coverage including a maximum daily reimbursement amount for service costs, the number of years of coverage, whether they want benefit payments to increase to keep pace of inflation, and how long they must wait once they are disabled to begin receiving insurance coverage for their costs—an elimination period. A typical policy may provide up to \$150 a day in coverage for a period of three years, with a 90 day elimination period. Thus, the policy would make available to an individual roughly \$165,000 in benefits to be spent on home and community-based care, assisted living, or nursing home care. If the individual chose to include an inflation option in their policy, then each year the average daily benefit would increase by the specified amount, say 5 percent compounded. Thus, if a person had a policy for 10 years and then required services, they would be eligible to receive \$244 per day ($\$150 \times (1.05^{10})$) for a total benefit pool of \$267,545 ($\$244 \times 3 \text{ years}$). Given that most people tend to spend less than two years in a nursing home, the vast majority of policies provide durational coverage (see Table 1). In terms of total liabilities covered, that would depend on the value of the daily benefit chosen at time of policy purchase and the prices faced at the time of nursing home entry.

Concurrent with coverage changes, the profile of the typical long-term care insurance buyer has also changed (see Table 2). Today's buyers are younger, wealthier, and more educated. Since 1990, long-term care insurance buyers are drawn increasingly from the highest income and asset categories (America's Health Insurance Plans 1990-2005).

These trends are driven in part by substantial—and, one could argue, appropriate—declines in policies purchased by individuals at the lower end of wealth spectrum. More troubling, however, is that sales also eroded among middle-income individuals who ostensibly represent the market that companies and policymakers would most like to tap.

Why don't more middle-class Americans purchase long-term care insurance? Critics argue that the product is simply not "affordable" to a broad cross-section of Americans. Indeed, in a study of individuals who chose not to purchase long-term care insurance, 53 percent cited cost as the most important reason they did not buy coverage (AHIP 2007), a finding echoed in other analyses as well (Wiener, Tilly and Goldenson 2000). Nonetheless, the concept of affordability alone is not particularly useful because it implies that there is some definable level of cost relative to income that makes a product "affordable" to an individual. In fact, whether someone exercises a preference for a product is a function of the cost relative to its perceived value.

Clearly, the product is not viewed by consumers as providing sufficient value in light of its cost.

Table 2: Income and Asset Profile of Individual LTC Insurance Buyers

Socio-Demographic Characteristics of Buyers	2005	2000	1995	1990
Income Status				
Average Income	\$62,825	\$49,700	\$36,600	\$36,250
Less than \$20,000	3%	9%	21%	29%
\$20,000-\$24,999	4	8	16	13
\$25,000-\$34,999	9	19	24	20
\$35,000-\$49,999	13	22	18	17
\$50,000 and Over	71	42	20	21
Total Liquid Assets				
Average Assets	\$95,475	\$91,425	\$68,750	\$72,125
Less than \$20,000	4%	6%	18%	16%
\$20,000-\$29,999	3	5	10	8
\$30,000-\$49,999	6	7	13	11
\$50,000-\$74,999	6	5	10	12
\$75,000 and over	81	77	49	53

Source: Authors calculations based on data from AHIP, 2006

There are a number of potential reasons why a “perceived value gap” exists in the long-term care insurance market. First, research has shown that individuals who do not buy policies underestimate their risk. Roughly 70 percent of individuals who turn 65 will require long-term care support, either from family, friends, or paid caregivers at some point in their lives, and a sizeable minority of these individuals will face substantial financial liabilities and/or place large burdens on their families for

informal care (Kemper, Komisar and Alecxih 2005). Yet, only slightly more than half of non-buyers considered themselves to be at risk for needing significant long-term care services, and most believe that they would not be personally liable for the costs of care (i.e., the government or other health insurance would pay) (America's Health Insurance Plans 2007). At the same time, non-buyers overestimate premium costs and underestimate long-term care costs, reinforcing the barriers to purchase. Specifically, 70 percent of individuals considering a policy who chose not to purchase underestimated monthly costs of institutional care, compared to only 14 percent of people who bought policies (America's Health Insurance Plans 2007). We know this to be the case because in the referenced survey of buyers and non-buyers, each was asked to estimate the costs of nursing home care in their community and this estimate was compared to the actual costs of care in their community.

Another theory for why individuals do not attach sufficient value to long-term care policies given their price is that the Medicaid program “crowds out” the purchase for many middle-income Americans. Although Medicaid is not considered a typical insurance product, since it offers little or no financial protection for long-term care costs—although it does guarantee services to the indigent—some have argued that the existence of a robust “Medicaid planning” industry attests to the fact that Medicaid can provide some degree of protection for those who are well-schooled in Medicaid eligibility policy (Moses 2005). Using simulation models, Brown and Finkelstein (2008) estimated that even if insurance markets were operating in a perfectly efficient manner, the implicit tax imposed by Medicaid would keep more than 60 percent of the wealth distribution from buying a policy (Brown and Finkelstein 2008), implying that the non-purchase of private long-term care insurance by middle-class Americans may reflect, to some degree, a rational decision. At the same time, however, it should be noted that reducing the implicit tax of Medicaid on long-term care insurance purchase would likely be an insufficient mechanism to expand the market (Brown and Finkelstein 2009). For example, related empirical analyses based on econometric modeling have shown that even if all states moved to the most stringent eligibility standards allowed by federal law, private long-term care insurance purchase would rise by only 2.7 percentage points (Brown, Coe, and Finkelstein 2007). More empirical work on these questions is needed.

Another issue relevant to perceived value concerns whether consumers trust that insurers will pay benefits when care is needed and keep premiums relatively stable over time. While data from NAIC-mandated claims denial reporting and independent research show low claims denial rates—more than 95 percent of claims are approved—there have been serious allegations that the claims practices of certain

companies are suspect and designed to make it difficult for people to access benefits (Duhigg 2007). These issues do not appear to be widespread however, as 94 percent of surveyed individuals who had filed claims said they were satisfied with their experience in claiming benefits (LifePlans Inc. 2006). These individuals were asked whether they had any disagreements with their insurance company at the time that they filed their claim and if they did, whether such disagreements were satisfactorily resolved. In addition, in the absence of insurance, claimants felt they would have needed to rely more on family support (53 percent), pursue institutional care options (48 percent), receive less care (57 percent) or simply not be able to afford their current level of care (61 percent) (LifePlans Inc. 2006). Thus, for those individuals accessing benefits, their claims experience appears to be a positive one. Even so, a general distrust of the health insurance industry in general among many people presents a further drag on market growth.

Rate increases are another important concern for consumers. Rate increases between 15 percent and 50 percent have been requested on some blocks of business and new products are typically priced 10 percent to 15 percent higher than just a few years ago.¹ These rate increases have, for the most part, had to do with imprecise lapse and interest rate assumptions; some companies also have failed to employ adequate risk management strategies to assure a stable risk pool. The challenge of keeping premiums stable has led to more stringent actuarial standards related to pricing policies. Moreover, carriers now have a broader experience base from which to draw for more accurate pricing, and there is widespread agreement as to the value of prudent underwriting and claims management approaches for assuring rate stability. Thus, one could expect greater premium stability in the future.

Finally, the purchase of insurance is complicated and requires a certain level of financial literacy and understanding of a variety of current and future contingencies. This is particularly true in the case of long-term care where services can be provided by family, friends and formal (paid) caregivers. Because there are a variety of ways that care can be provided, it is difficult for someone to know how much care they made need in the future, whether family members can provide financial or caregiving support, and what level of private coverage would be sufficient to cover future care needs. All these factors complicate the decision and therefore, the perceived value of the policy needs to be high to mitigate these confounding factors and lead to a purchase.

Potential for Expanding the Long-Term Care Insurance Market

While there is no consensus on the potential size of the private market, there is general agreement among private insurers, industry analysts, and many policymakers that

significant untapped market potential remains. Ultimately, the potential to expand the private market hinges on multiple supply and demand factors. Identifying public policy mechanisms to address all barriers is beyond the scope of this article; however, it is worth highlighting three such strategies: subsidizing the purchase of policies, fostering informed consumer choice, and bolstering consumer confidence.

Subsidization of purchase

One of the most direct ways for policymakers to alter the value equation for long-term care insurance is to lower the effective price of policies. An approach implemented at the federal and state levels has been to subsidize the purchase of long-term care insurance through tax incentives. At the Federal level, the Health Insurance Portability and Accountability Act of 1996 offers limited tax advantages for long-term care insurance by clarifying the treatment of premiums for qualified plans as medical expenses for individuals deducting medical costs beyond 7.5 percent of their gross income and by not taxing benefits paid out up to certain limits. States have also used tax policy to encourage purchase, with more than half of all states currently offering a tax incentive for the purchase of long-term care insurance (Kaiser Family Foundation 2008). In lowering the price for insurance, government is trading off lost tax revenue against the possibility of reducing projected public (Medicaid) long-term care spending over the longer term. There has been surprisingly little empirical study of the topic, but existing analyses generally have concluded that these tax incentives have a modestly positive impact on take-up, but that tax incentives alone are unlikely to generate a substantial demand response (Cramer and Jensen 2006) (Johnson et al. 2008). One caveat to these analyses is that tax incentives implemented to date have been small. For example, if one is able to deduct a full \$2,500 premium in a state with a 5 percent income tax rate, the value of the incentive is only \$125. An example of a more substantial incentive would be to allow long-term care insurance premiums to be paid with pre-tax dollars by consumers and employers. Specifically, this would help sales in the group market, where price would also be reduced by the younger purchase age and lower marketing costs.

Product standardization

Although expanded choice has been an important sign of progress in the long-term care insurance market, consumer decision-making about whether to purchase and what type of coverage to buy can be difficult, with a wide array of options. Expanded public support for objective sources of information could aid potential buyers with their purchase decision. Product standardization, similar to the changes made in the Medicare supplemental insurance market in the early 1990s, has also been suggested by consumer advocates as well as some policymakers. In addition to instituting a

range of consumer protections, standardization of Medicare supplemental insurance products was aimed at reducing the variation and number of products on the market and stimulating competition on key product features. Insurers were limited to marketing one of ten standardized policies with precisely defined benefits. After standardization, sales increased considerably and consumer complaints declined (Hahn 2006). Although standardization of long-term care insurance products could simplify consumer choice, some argue that the market still needs continued product innovation to better meet consumer preferences and their evolving supportive service needs.

Consumer confidence

Strong regulatory oversight of private long-term care insurance is critical to its integrity and acceptance in the marketplace, particularly given the extended time that premiums are held in reserve. The federal government has some regulatory authority over tax-qualified long-term care policies, but states have primary oversight. State regulatory standards and enforcement vary considerably. Currently 19 states either have adopted or are in the process of adopting model policy and regulatory standards developed by the National Association of Insurance Commissioners (NAIC) (America's Health Insurance Plans 2009). NAIC standards include financial penalties to discourage companies from under-pricing policies, requirements that rates be actuarially-certified as reasonable and sufficient to ensure long-run solvency, as well as other provisions to protect consumers and ensure rate stability. NAIC standards require insurers to follow suitability standards to ensure appropriate sales and outline several policy-oriented consumer protection features, including mandatory offer of non-forfeiture benefits and inflation adjustment, protection against unintentional policy lapses, and a standardized outline of coverage. Despite the variation across states in adoption and enforcement of the most recent NAIC standards, most insurers offer a uniform product— with respect to consumer protection— in all states in which they offer coverage. While these protections are in place, consumers may not be aware of them, reinforcing the need for ongoing education. Another approach is federal legislation, which has been proposed to ensure uniform protections in the long-term care insurance market across the country (e.g., Confidence in Long-Term Care Insurance Act of 2009).

Integrating Public and Private Insurance for Long-Term Care

Medicaid

The interface between Medicaid policy and the private long-term care insurance market is complex. Designed as a safety net for low income individuals, Medicaid has

emerged as the leading third party payer for long-term care. Medicaid has paid for nearly half or more than 40 percent of all long-term care spending for the past few decades (Burwell and Crown 1994; O'Shaughnessy, Lyke, and Storey 2002).

Because of the prominent role of public coverage in the long-term care sector, there is inevitably some tension and uncertainty about the extent to which public coverage impedes the development of the private market. Public policy has been somewhat equivocal on the issue. On the one hand, Medicaid eligibility policies have become somewhat more generous over time (e.g., through increased spousal asset limits), arguably cutting expansion of the private market. At the same time, Congress has enacted a number of changes designed “close loopholes” in Medicaid eligibility policy, the most recent of which were contained in the Deficit Reduction Act of 2005. Such loopholes were being exploited by Medicaid planning attorneys and consumers who were able to shelter assets for heirs while accessing public coverage for long-term care costs.

One innovation designed to marry Medicaid and support for the private market is the Long-Term Care Partnership Program. Under the Partnership Program, persons who purchase Partnership Qualified (PQ) policies receive guaranteed asset protection under Medicaid if they first buy and use private long-term care insurance. For every dollar of private insurance benefits used by the policyholder, the policyholder receives one dollar of increased asset protection from Medicaid after their private insurance is depleted. While not a direct subsidy of long-term care insurance premiums, the Partnership Program incents purchasers to buy “shorter and fatter” policies that are more aligned with their individual financial risk (i.e., the amount of their net worth they wish to protect). As of July 2009, 36 states had adopted Long-Term Care Partnership Programs and over 100,000 policies were in force (National Long-Term Care Partnership Data Repository 2009). At this stage, it is too early to evaluate the impact of these programs on market penetration or on Medicaid program costs.

Public Voluntary Insurance Programs: The CLASS Program

The Patient Protection and Affordable Care Act was signed into law by the President on March 23, 2010. Among other things, this act established a national voluntary insurance program, the CLASS Independence Benefit Plan. The purpose of the program—which was to be offered through employers—was to provide community living assistance services and supports to working individuals who have a functional limitation expected to last more than 90 days due to an inability to perform either 2 or 3 activities of daily living (ADLs), a cognitive impairment, or a level of similar limitation prescribed by the Secretary of DHHS. An eligible beneficiary of the program would have to pay premiums for at least 60 months before qualifying for

benefits, premiums would have to be set at a level consistent with program solvency for a 75-year period, and daily benefits would not be allowed to go lower than \$50 per day. Public subsidies would be available to specified eligible population groups to assure the affordability of program premiums.

The Department of Health and Human Services (DHHS) was charged with the task of developing the mechanisms to implement the CLASS program and meet the objectives laid out in the law. On October 14, 2011, the Secretary of DHHS announced that after 19 months of planning and analysis efforts the Department did not “see a viable path forward for CLASS implementation at this time.” Thus, there are no efforts being made to implement the program and it is not likely to become part of the fabric of long-term care financing for the foreseeable future.

Program supporters of CLASS had expressed a strong desire to see the current private insurance market work in concert with the new CLASS Program. Moreover, the program was not designed to replace Medicaid but to work in concert with the program; a certain percentage of CLASS benefits are to be designated to the program if an individual is receiving home and community-based care under Medicaid (for a more detailed discussion of the CLASS Act see Gleckman’s chapter in this volume).

Based on the experience of the private market to date, one can point to several issues that would be important to address to assure better integration of the private the long-term care insurance market with a voluntary or even mandatory public insurance Program as well as with Medicaid. First, to meet the challenge of educating the public about the need to protect against long-term care costs through insurance mechanisms, the issue must be framed as one that is considered part of an overall strategy for retirement security and not simply as an extension of health reform. Similar to the manner in which Social Security payments, pensions, and personal savings combine to provide individuals retirement security, the public needs to understand that such is the case with long-term care needs; that is, that these needs must be met through a combination of resources, and that the distribution of risk suggests insurance as the most efficient mechanism for funding this risk. Reframing the challenge in this manner might help us move forward in debates about the roles of public and private resources, including insurance, and to devise innovative approaches to integrating public and private programs as well as new approaches that can work in a complementary manner across programs and markets.

Second, the first point presumes that there is a real effort at public education. Clearly, public education is vital to ensure that consumers and their families understand the long-term care risks they face, the importance of planning ahead for these needs, and

the planning options that they have. An important outcome of efforts such as the Federal government's "Own Your Future" campaign is to ensure that consumers have a clear understanding of where public coverage begins and ends -- something that would be particularly important in the context of the somewhat limited disability insurance benefit offered by the CLASS Program.² In other words, in the context of partial public coverage (whether through a public insurance program, Medicaid alone, or in combination with some supplemental benefit), individuals need to understand the limits of that coverage and, in turn, the value of any wrap-around protection.

Regardless of whether it is the CLASS program or any other voluntary public insurance program, it is critical that policymakers, consumer advocates, and providers emphasize the point that no single program is likely to be designed to address all long-term care needs for all people and that it is only likely to be one piece of the necessary financing solution. The risk is that without doing so clearly and forcefully, individuals will falsely assume that a public insurance program like would have represented the solution to all of their long-term care needs. Hence, the need to examine supplemental or even primary coverage such as long-term care insurance will significantly diminish and individuals will still be at risk for facing catastrophic costs.

Third, in thinking about the design of public voluntary insurance programs, policymakers should take note of lessons learned in the private market, several of which have relevance to the program. First, due to such program's voluntary nature there will have to be a balance between concerns about adverse selection (i.e., attracting only those at higher risk of needing services) against broad goals pertaining to covered populations. This presents a very real regulatory challenge to policymakers since program premiums must be sustainable over a very long period. A related point is that the program must be implemented in a manner consistent with assuring that premiums are no more costly than for similar plans that can be purchased privately. If not, additional selection issues could threaten the solvency of public voluntary insurance programs, if no underwriting is allowed.

Moreover, employer-based voluntary programs covering long-term care in the private sector have achieved relatively low participation rates— typically well less than 10%. Thus, a sophisticated education and marketing campaign will be necessary to convince employers to invest in the effort needed to put the program in place and to convince employees to participate.

Second, in all programs a well-defined risk management approach is needed to verify initial and ongoing eligibility for benefits so as to ensure premium stability. Because the structure of such programs is likely to be based on a cash disability benefit, there is a substantially increased risk of significant moral hazard, a fact reflected in

substantially higher private market premiums for similar structured policies. Clear regulatory guidelines relating to benefit eligibility triggers need to be established to protect program solvency and rate stability, make any wrap-around private insurance policies feasible, and provide confidence to consumers that they understand the circumstances under which they will qualify for benefits. If in the implementation of a public voluntary insurance plan the benefit eligibility triggers differ from those that are the basis for payment of private insurance benefits it is going to be difficult for the two markets to work in tandem. Confusion in the marketplace regarding the precise eligibility triggers will stifle growth in the private market and depress participation in the public program. Finally, even with a cash benefit, there is a need for assistance to help consumers navigate a fragmented long-term care system. Research in both the private and public Medicaid market suggests that without assistance to navigate the complex provider system, even in the presence of insurance unmet and undermet needs will persist.

Conclusion

As the baby boom generation ages, policymakers continue to struggle with the challenge of designing effective policies for encouraging long-term care risk protection. This complex problem is exacerbated by the fact that long-term care presents a risk both in terms of unpaid or family care burdens and the costs associated with paid care. Insurance pools can help reduce catastrophic risk and offer the most efficient way to protect against this liability. To date, private risk pools have demonstrated an ability to provide adequate coverage for long-term care but at a price that many Americans believe to be too high relative to their perceived value of the coverage. At the same time, publicly financed long-term care through the Medicaid program has exhibited important deficiencies of its own, including recurring quality of care problems, a bias toward institutional care and insufficient funding of home- and community-based care options, and costs that impose a sizeable constraint on state budgets. The CLASS Program represented a new strategy for making available a public risk-pooling program for long-term care, but the details around implementation.

Clearly neither a public or private financing approach on its own can meet the long-term care needs of all Americans, and no one has yet argued that a voluntary public insurance program and Medicaid represent a comprehensive solution to the long-term care financing challenge. In all likelihood, both public and private insurance models will need to work together to mitigate the catastrophic risks of long-term care. The CLASS program might have provided an opportunity to test if and how well these markets can work together, but at this point, we can only conjecture, since the

program is no longer on the policy agenda. Even so, policymakers still need to focus not on whether a public or private insurance model works best, but rather on how public programs can be structured and implemented to assure that in conjunction with an evolving and supported private market, efficient and equitable outcomes for taxpayers and consumers can be achieved.

Notes

¹These figures are based on information derived from personal communications with state insurance departments. There is no reliable aggregate information on all rate increase findings across the country.

²The program has reached over 20 million households and based on results to date, response rates greatly exceeded expectations and individuals who received the education were significantly more likely to take some type of planning (Long-Term Care Group and LifePlans, Inc. 2006).

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CHAPTER 11

LONG-TERM CARE COVERAGE FOR ALL: GETTING THERE FROM HERE

NANCY FOLBRE AND DOUGLAS WOLF

The United States would benefit from having an equitable, efficient and universal system of publicly-funded long-term care insurance that recognizes and rewards the provision of family care. Dramatic increases in public and private spending on health care have delivered important gains, including greater life expectancy. But they have also been accompanied by rapid escalation of the costs of meeting the less acute, chronic problems of aging and disability, many of which are borne by spouses, adult children, other family members and friends. Indeed, the unique challenge of designing long-term care coverage for all lies in the intersection of paid and unpaid care. The demands for various publicly-funded services are clearly contingent on the configuration of family and other informal-care resources available to those in need of care, while the supply of informal care responds to the incentives created by publicly-funded long-term care programs.

Our current system of long-term care is fragmented, inadequate, and inequitable, often leaving the elderly, individuals with disabilities, and family members who care for them economically vulnerable. The CLASS Act initially passed by Congress as part of the Affordable Care Act, represented a tentative (and hotly-contested) step in the right direction. Paradoxically, the CLASS Act in effect created a Federally-operated long-term care insurance system, despite the intense controversy about, and ultimate failure of, any attempt to include a “public option” in the accompanying Affordable Care Act legislation. But the CLASS Act was conceived as a voluntary rather than mandatory program, and therefore merely hinted at the possibility of universal coverage. It also raised problems of adverse selection, which seem to have been the principal factor in the Administration’s October 14, 2012 announcement that there is no “... viable path forward for CLASS implementation at this time.”¹

In this chapter, we build on the earlier contributions to this volume to discuss both problems and possibilities that could inform efforts to move toward more comprehensive reform. We begin with a review of the current institutional and political context, summarizing criticisms of existing policies and discussing some possible explanations of the particular difficulties facing long-term care reform. Next, we make a case for a universal system of long-term care insurance, arguing that seemingly utopian principles can help shape political realities. Finally, we discuss a number of theoretical and practical precedents for a universal long-term care

insurance system in the U.S. that could go well beyond the scope of the original CLASS Act. Our conclusion reiterates the need for a long-run strategy to implement comprehensive change but also acknowledges the obstacles such a strategy will face.

The Institutional and Political Context

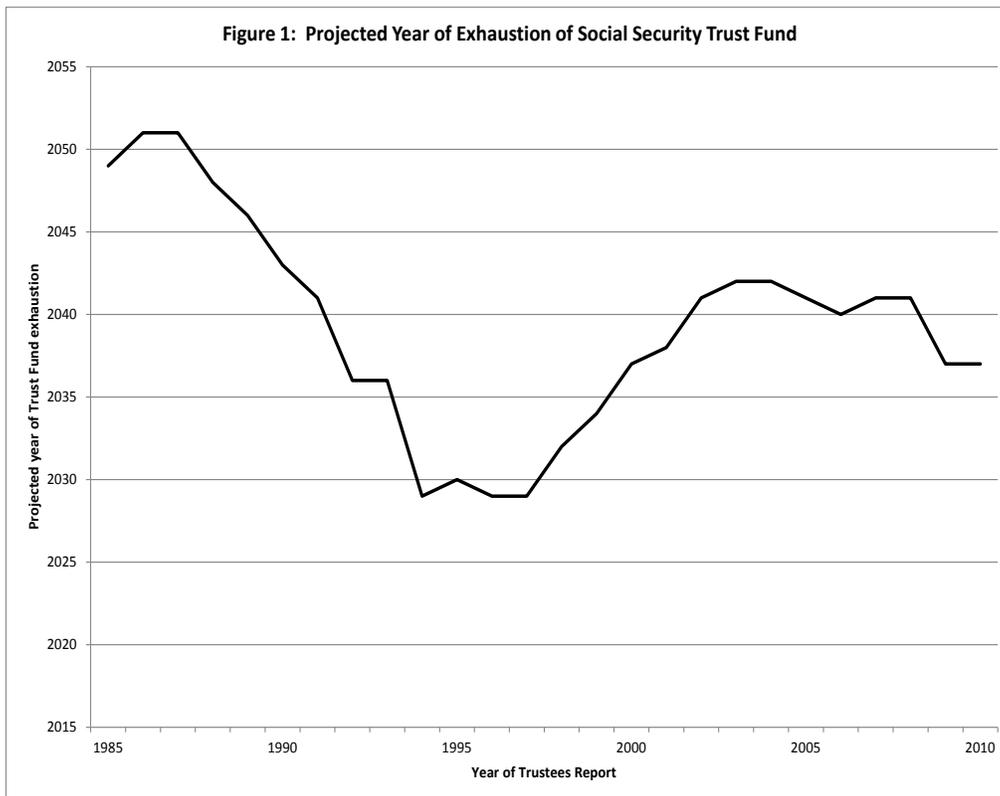
Discussions of the impact of population aging span the political and cultural spectrum and often deploy the word “crisis.” Stephen Crystal published *America’s Old Age Crisis* in 1984. Carroll Estes and James Swan published *The Long Term Care Crisis* in 1992. The World Bank published *Averting the Old Age Crisis* in 1994. Celebrity Martha Stewart has referred to “The Other Health Care Crisis—America’s Elderly” (Stewart 2010).

Yet neither the American public nor its political leaders seem to have adopted a “crisis” mentality. Several possible factors could explain this disconnect. One could argue that the most serious problems of elder care remain a bit farther down the road, and we are now dealing with more urgent concerns. Further, the annual changes appear small compared to the cumulative effect: if we contrast the programmatic or budgetary implications of demographic profiles at the beginning and end of a sufficiently long time period—2000 and 2030, for example—the contrast is indeed alarming (Knickman and Snell 2002). Yet the path from the crisis-free present to the crisis-laden future entails small, incremental steps each year, and it is impossible to isolate the point at which we pass from not-yet-crisis to crisis.

Moreover, while population aging—among other factors—may clearly suggest the likelihood of a policy crisis at some point in the future, the timing of such a crisis seems to be a moving target. This point is nicely illustrated in Figure 1, which plots the projected years of exhaustion of the Social Security Trust Fund—i.e., the year in which Fund balances will drop to zero—taken from annual reports and covering the period 1985 through 2010. The Trust Fund’s Board of Trustees is required to assess, and to report annually on, the fiscal health of Social Security over a 75-year time horizon. In 1984, the year after the most recent major legislative “fix,” the Trust Fund was projected to maintain a positive balance for at least 75 years, but beginning in 1985—only one year later—that was no longer true. The number of years to fund exhaustion has fluctuated, reaching a high of 65 years (in 1986) and a low of 32 years (in 1997), averaging 42 years over this 25-year period. It is easy to rationalize avoidance of painful programmatic changes when doomsday is both so far in the future and so uncertain.

Another possible explanation for our collective avoidance of the long term care issue lies in the uneven demographic impact of long-term care shortfalls. Individuals and

families at the very top of the wealth distribution can effectively self-insure, drawing from financial assets to finance both medical care and long-term care.



Low-income families, often confronting more immediate problems, may be unable to cope with unanticipated long-term care costs, become even more indigent, and be forced to rely on whatever form of state provision remains available. Middle-class families may face considerable variation in both anticipated and actual demands for long-term care. Better-educated individuals seem to cope better with disability than others, using both more assistive technology and more paid help (Cutler et al. 2006).

Family income and education are not the only sources of diversity in ability to meet long-term care needs. Differences in family structure may also play a role, since the availability and willingness of family members to provide care represents a form of informal insurance. In the developing world, for instance, parents' desire to provide security for old age often influences fertility decisions (Nugent 1985). Availability of family members clearly influences forms of care in old age in the U.S., and some evidence suggests that elderly women without surviving children are more likely than others to become dependent on Medicaid-financed nursing home care (Wolf 1999).

Cultural differences may also come into play, since recent Hispanic immigrants to the U.S. tend to be younger on average, have more children on average, and expect to rely more heavily on family care in old age (Angel and Angel 2010).

Men face less serious problems with long-term care provision than women do, because many expect to be cared for by their wives, who are, on average, over 2 years younger than them,¹ and also have a longer life expectancy. Because women face a greater likelihood of living alone in old age, they are particularly vulnerable. Further, many rely on their daughters for care. According to a recent survey by the National Caregivers Alliance and the American Association for Retired Persons, women represent about 67 percent of all informal caregivers for the elderly and about 68 percent of all elderly recipients of informal care (NCA/AARP 2009).

Economists tend to assume that women simply choose to provide care because it gives them satisfaction. But more than 43 percent of all caregivers in the NCA/AARP survey reported that they felt that they had no choice. They stepped forward for a variety of reasons: because no other family member or friend was willing or able to provide adequate care or because paid services were economically out of reach. Those who felt they had no choice were more likely to report emotional stress, poor physical health and financial hardship. About 45 percent of women, compared with 38 percent of male caregivers, put themselves into the “no choice” category (NCA/AARP 2009). Many women would prefer to share care responsibilities more equally with others, but if they can’t, will take on them regardless, as a moral duty central to cultural ideals of womanhood.

A more immediate determinant of the political context derives from partisan conflict over the role of entitlement spending, intensified by concerns over mounting public debt resulting from the Great Recession. Proposals to repeal the Affordable Care Act have been accompanied by budget proposals that include significant cuts to Medicare and Medicaid spending, along with an organizational shift toward more market-based voucher approaches. Concerns about long-term care are currently overshadowed by a political debate of epic proportions.

Yet the problems of long-term care provision are obviously relevant to this debate. Medicaid is biased toward institutional rather than home and community-based care and fails to meet the needs of many families (Harrington Meyer and Hausauer forthcoming). It discourages private savings and may also contribute to low private long-term care insurance rates (Burman this volume; Stevenson et al. this volume). Moreover, the asset-recovery features of Medicaid amount to ex post imposition of user fees, undermining any notion that the program provides collectively-shared risks against the costs of adverse outcomes (Harrington Meyer and Hausauer forthcoming).

The Rationale for Universal Coverage

The rationale for universal long-term care insurance, like that for universal health care insurance, is based on both moral and economic principles. Like the families of which it is constituted, society has an obligation to help care for those who cannot care for themselves. The need for care as a result of disability or advanced age is somewhat unpredictable and unevenly distributed. At the oldest ages, when the probability that someone will need this type of care grows quite rapidly, the costs of providing the needed care can become extremely high. The earlier in their lives that prudent individuals set aside funds in anticipation of these late-life needs, the smaller the amount that must be set aside. However, individuals typically lack the foresight to engage in this type of self-insuring savings, and many simply can't afford to. Social insurance can overcome these problems, providing a means of pooling the risks of long-term disability for both caregivers and care recipients. It can potentially improve the level and quality of overall care provision while reducing its average cost. Private insurance also provides a potential, but only partial solution to the risk-pooling problem.

Benefits of Pooling Risks

Insurance, and especially mandatory—that is, universal—social insurance, produces economic benefits in two ways. First, in any group of individuals, each of which faces an uncertain risk of experiencing an unfavorable outcome, the pooling of risks through insurance makes everyone better off, on average. Individually, in the absence of insurance, some people will experience a loss while others will not. It is unlikely that many people could set aside assets sufficient to cover those losses. By pooling risks through insurance, the amount that must be set aside to cover expected losses—i.e., the insurance premium—is reduced. A “law of large numbers” operates, such that as the insurance pool grows larger, the average claim on the common pool of assets approaches the average loss among those covered (Weimer and Vining 1989). In the limit, the “margin of error” between average claims and expected losses vanishes.

Second, and more importantly, as we approach the ideal of universal coverage, the problem of adverse selection is fully overcome. Adverse selection refers to the fact that insurance coverage is likely to be more attractive to those with higher-than-average expected losses, and less attractive to those with relatively low expected losses. If insurance premiums are set so as to cover expected payouts—i.e., they are actuarially fair—then those who believe that they face below-average expected losses will opt out of coverage. This, in turn, will necessitate raising premiums to cover the above-average expected losses among those who remain insured. But as premiums are raised, more people will find it attractive to opt out, producing a “death spiral” of

ever-increasing premiums to cover the expected losses within an ever-decreasing pool of higher-risk covered individuals.

The benefit of overcoming the adverse-selection problem through universal coverage is illustrated in recent work by Munnell and Hurwitz (2011). Munnell and Hurwitz developed a simple analytic model for estimating the costs of the CLASS Act. In their baseline scenario, which assumed an overall voluntary participation rate of 6 percent among eligibles, a \$75-per-day benefit (as in the Congressional Budget Office's official cost estimates), and risks of qualifying for benefits determined by disability rates found in recent population surveys, the average premium needed to cover anticipated costs over the 75-year planning horizon stipulated in the CLASS Act legislation was \$194 a month. In an alternative mandated-coverage scenario—i.e., under universal coverage—the required monthly premium fell by nearly half, to \$94 per month.

The Limits of Private Insurance

Private insurance companies want to avoid the costs associated with adverse selection, while at the same time charging premiums low enough to attract customers. Consequently, they adopt practices such as underwriting and noncoverage of preexisting conditions, as a way of limiting their exposure to uncertain costs. Nevertheless, expansion of private insurance might have helped compensate for the voluntary nature of the CLASS proposal, supplementing its modest benefits, particularly for nursing home stays (Stevenson et al., this volume). However, several factors limit the potential scope for wide private coverage.

Important among these is the difficulty that individuals face in assessing the level and quality of assistance that they will need (a factor which would also limit take up of a voluntary public program like that found in the CLASS Act). Behavioral economics suggests that individuals tend to discount the future in somewhat inconsistent and inefficient ways, and to underestimate levels of future need (Thaler and Sunstein 2008). In addition to uncertainties about their own ability to age in a healthy and independent way, individuals generally lack information about the potential and actual supply of assistance from other family members. Even raising this subject for discussion can be stressful, contributing to tendencies to avoid and procrastinate. Qualitative research suggests that individuals are aware of a high level of denial and fear in their responses to long term care issues (Curry et al. 2009).

Indeed, some individuals may fear that purchase of long-term care insurance will discourage or crowd-out more desirable family care. Spouses, daughters or sons may be less willing to supply care services if a substitute can be easily purchased, creating

a kind of intra-family moral hazard problem (Pauly 1990). While this principal-agent problem, modeled in more detail by Zweifel and Strüwe (1998) also applies to support for public choices, it bears more heavily on decisions of families for whom incentive effects are likely to be large. High wealth families can use strategic bequests to counter the problem (Bernheim et al. 1985). Among low-income families, the need to earn wages for self-support (and lack of available space to bring elderly or disabled family members into the home) may constrain the ability of family members to provide direct care, reducing the impact of their incentives to do so.

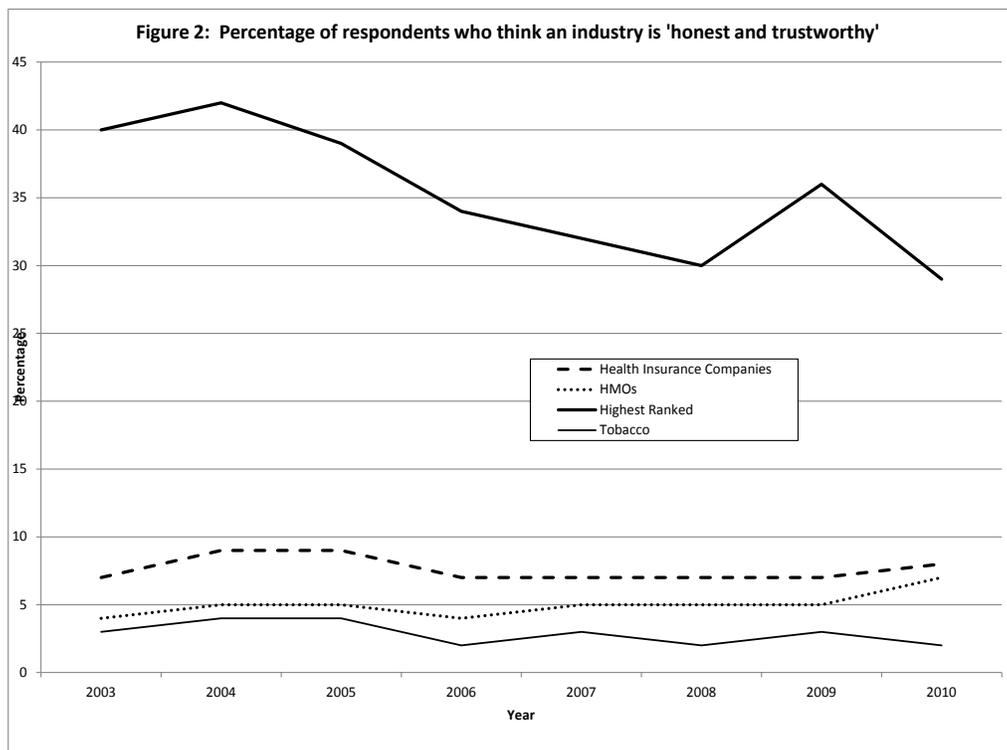
Several studies have found that individuals with living children—in other words, potential future caregivers—are less likely to buy private long-term care insurance (Kumar et al. 1995; Cramer and Jensen 2006; Johnson et al. 2007). In all cases, these studies include extensive controls for income, assets, and the cost of insurance.

More immediate explanations for low take-up rates for long-term care insurance are high cost and reliance on Medicaid as a fall-back (Stevenson et al. this volume). Low trust also deters take up. Most consumers express a low opinion of health insurers—a group that overlaps with long-term care insurers—and are, consequently, disinterested in spending more on their products. The Harris Poll has, in recent years, asked respondents which among a list of 17 industries are “... generally honest and trustworthy – so that you normally believe a statement by a company in that industry.” Health insurance companies have consistently been ranked near the bottom, ahead of only HMOs, oil companies and—in last place—tobacco companies (see Figure 2). During 2003-2010, only 7 to 9 percent of respondents felt that health insurance companies were “honest and trustworthy.”² The respondents’ reasons for holding these views were not sought, although one imagines that denials of coverage or claims might be among those reasons. Although private long-term care insurance policies are offered mainly by life insurance companies rather than health insurance companies, consumers’ views about the experiences they can expect with long-term care insurance may be shaped by their experiences with health insurers, given the role of health problems in producing long-term care needs. These results must be placed in a context of general mistrust: the most trustworthy industry in most years (supermarkets) were viewed as honest and trustworthy by 29 to 42 percent of respondents (in 2008, the highest ranked industry was “hospitals,” and in 2010 hospitals and supermarkets both were viewed as honest and trustworthy by 29 percent of respondents).

The Benefits of Universality

Beyond the economic benefits of risk pooling discussed before, which are maximized as the risk pool grows to include the entire population, there are social and political

benefits to universality of social policy. Waldfogel (2009) points out that while targeting program benefits on those with the greatest needs—as, for example, in the case of Medicaid’s long-term care benefits—may seem to promote efficiency in the use of public resources, that efficiency imposes costs in the form of high administrative costs, stigmatization of beneficiaries, and adverse behavioral incentives. Universal benefits, however, “... have the advantage of promoting social solidarity and social inclusion” (p. 40). The latter point echoes Kuttner’s (1984) earlier comment, that when “... the middle class shares basic public services with the poor, the middle class demands high quality and dignified treatment; the middle class is also reminded that poor people are human. Thus, does universalism in public services cement the political constituency for egalitarian social policy” (p. 231).



Source: see note 2.

The social solidarity promoted by universal programs seems to be reflected in the widespread negative reactions to policy proposals that would cut back on Social Security and Medicare, which are the two programs that most closely achieve universality in the U.S. at present. Skocpol (1995), for example, points out that “[m]ost Americans feel that they have built up a stake in the retirement insurance

system, and will profoundly resent politicians who go back on what is considered a sacred social contract” (p. 308).

Waldfogel (2009) points out that universal programs may be less effective than targeted programs in achieving redistribution, because universal programs provide benefits to those at all income levels. However, Social Security benefits manage to achieve some redistribution through the “tilt” in the benefit formula, such that those who have made minimal contributions obtain a higher rate of return on their contributions—that is, a “replacement ratio”—than those with high incomes (Clark et al. 2004). In a universal long term care insurance program, progressivity in the determination of benefits does not seem possible, because benefits are likely to be tied solely to the need for care and not to cumulative contributions to the program. However, it is easy to envision a progressive formula for determining contributions in a mandatory payroll-tax based program.

The Problem of Moral Hazard

“Moral hazard” is a generic problem when people can insure themselves against adverse contingencies. This issue is typically framed in two ways. First, the insured will overuse the covered service because it seems to be “free”—the usual example here being medical care (a problem often counteracted by copayments which require users to pay a portion of the cost). Second, the insured will engage in risky behavior which raises the probability of adverse outcome, because insurance coverage reduces the cost of the adverse outcome—the usual example in this case being automobile insurance, which induces people to be poorer drivers. A third form of moral hazard, alluded to above, applies particularly to long-term care: family members may be less willing to provide care services for free if they learn that it will be provided and paid for by a third party.

Some argue that moral hazard militates against universal coverage of long-term care (e.g., Garber 1996). We disagree, for three reasons. First, the types of services provided through long-term care insurance, such as help dressing, eating, bathing, or using the toilet—that is, Activities of Daily Living (or ADLs)—are not services that people are eager to consume; they prefer, and expect, to do these activities independently if possible. Insurance for housekeeping and meal services may be more susceptible to overuse and therefore a more apt example of possible moral hazard. But this problem can be at least partly remedied by conditioning insurance benefits on the more severe, and personal, even intrusive, needs associated with ADLs.

Second, it is hard to envision people adopting behaviors that increase the probability of needing help with ADL tasks, or even to identify what those behaviors might be,

especially for the most severe of conditions underlying LTC needs, namely Alzheimer's disease. Third, paid care services are unlikely to significantly "crowd-out" unpaid family care services, because family members typically provide these out of a sense of moral obligation and personal connection and virtually all have the capacity to opt out if they so choose (whether through abandonment or divorce). An important recent survey shows that utilization of privately paid home care workers does not reduce hours of care provided by family members, but typically supplements these, because families typically do not hire paid home care workers unless the care recipient's needs exceed the level of baseline support they are able to provide. In other words, paid care services largely result in an increase in the total hours of care rather than a reduction in the hours of family care (Christianson 1988; Wiener and Hanley 1992; Pezzin et al. 1996; Home Instead Senior Care 2010). Further, as pointed out above, families constrained by low earnings may be unable to provide family care services unless they are able to gain some remuneration for them.

Previous Universal-Coverage Proposals

A number of universal long-term care insurance proposals have been offered, none of which have fared well in the legislative process (Gleckman, this volume). Here we review some key features of several past proposals that we consider particularly important. Our review is organized along substantive dimensions—population served, services provided, and financing, for example—and concludes by contrasting the provisions of the CLASS Act with those of past proposals. We are also interested in the extent—if any—to which the various proposals recognize the role of family caregiving. We do not include proposals aimed principally at increasing private long-term care insurance coverage (e.g., Cutler et al. 2007; Stone-Axelrod 2005). However desirable that policy goal might be, programmatic incentives to purchase private insurance are unlikely to achieve anything close to universal insurance coverage. For a more extensive review of these and other long-term care financing proposals see Feder et al. (2007).

Threshold Need for Care

An important feature of any long-term care plan is the severity of the need-for-care threshold upon which program benefits are conditioned, because that threshold, or "trigger," will influence the size of the population potentially served by the program. For example, according to data from the 2004 National Long Term Care Survey, 16.6 percent of people 65 and above had at least one ADL limitation, while only 11 percent had 3 or more (out of a possible 6) ADL limitations (Manton, Gu, and Lamb 2006). However, an additional 2.4 percent of the older population had problems with one or more of the generally less-serious IADL activities; a long-term care plan that targeted

those with IADL as well as those with ADL needs would therefore serve a larger population.

The proposals we reviewed are remarkably consistent with respect to the severity of needs addressed. The 1983 American Health Security Act (the “Clinton Health Reform Plan”), for example, included long-term care provisions targeted at people (a) needing help from others with 3 or more from a prescribed list of 5 ADLs: dressing, bathing, eating, toileting, or transferring into and out of bed; (b) with a severe cognitive or mental impairment; or (c) with severe or profound mental retardation (White House Domestic Policy Council 1993: 171-172). Edward Norton and Joseph Newhouse (1994), writing at the time that the Clinton Health Reform Plan was still under active consideration, proposed a public long-term care insurance program in which benefits would depend on “... minimum dependency in ADLs or need for constant supervision” (Norton and Newhouse 1994: 1524), but did not spell out a more specific list of ADLs recognized, nor did they specify what the minimum threshold of dependency might be. In Burman and Johnston’s (2007) proposal for “Medicare Part E,” access to services would be contingent on medical certification of either a severe cognitive impairment or of limitations in at least two ADLs. It is important to recognize that while all of the criteria used to define the target population entail rather severe needs, for which providing assistance can be demanding, these are all tasks in which family and other “informal” caregivers are heavily involved at present.

Covered Services

The Clinton Plan would have provided “expanded” home and community-based services, and extended institutional coverage beyond that already provided by Medicaid. Thus it represented incremental expansions of coverage, overlaid on the existing system of Medicaid- and private-insurance-covered services. In contrast, Burman and Johnson’s “Medicare Part E” proposal is for “comprehensive” services; i.e., Burman and Johnson would replace the entire Federal-State Medicaid system with a new universal entitlement.

These proposals consider only the direct provision of services, generally with reimbursements to service providers from public funds, much like acute-care services in Medicare. Beneficiaries do not see or handle the funds used to pay for their services. Programs that cover only “formal” services, provided by paid service providers, can potentially raise questions concerning the substitution of formal for family and informal care: if those with long-term care needs perceive these services to be “free” they might overuse those services, and family members who would otherwise be ready to provide them informally will have less reason to do so. On the

other hand, as emphasized above, formal and informal care may be complements rather than substitutes.

Financing

The proposals we reviewed exhibit the greatest diversity in the area of financing. In Norton and Newhouse's approach, beneficiaries would have to pay a deductible the equivalent of "several months" of nursing home costs, and financing would be through general revenues, extended through the full taxation of Social Security benefits. Norton and Newhouse envisioned the development of a supplemental private insurance market, analogous to "Medigap" insurance, to cover the extra costs of higher-than-minimum nursing home quality (i.e., cost) thresholds, for those that can afford it. The Clinton Plan for long term care services included increased Federal matching rates, to accompany the required expansions in coverage of services and of the population served; the financing, therefore, would (like the existing Medicaid program) be funded by current revenues at the Federal and state levels.

Burman and Johnston (2007) proposed the financing of comprehensive LTC service provision through a mix of general revenues and an earmarked income tax surcharge. Coverage would be universal, thus there would be no need to establish eligibility by achieving a threshold of covered employment, as is the case for the existing parts of Medicare. Deductibles and copayment provisions would be used to help control costs. This approach would basically solve the problems of Medicaid by eliminating the need for the Medicaid program. However, due to its mixed financing approach, this proposal cannot be viewed as a pure "social insurance" program. And, thanks partly to its explicit welfare component and partly to the fact that its benefits are defined in terms of services—institutional or in-home care services—it (like all the proposals we have reviewed) would presumably be plagued by the same cost-control issues that continually plague the present Medicare program.

Generally, past proposals have attempted to achieve a comprehensive package of long term care service coverage, either through incremental additions to the present system (as in the Clinton plan) or through scrapping the current system and replacing it with a new and more comprehensive system (as in the Burman and Johnson plan). Any such proposal, given its goal of producing a major expansion of covered services, must cope with a need to generate a major expansion in funds to cover those services. In contrast, the "tradeoff" idea developed by Chen in a series of papers (Chen 1994; 2003; 2007) focuses almost exclusively on funding, remaining silent on questions of eligibility and nature of services covered. His proposal relies strongly on private LTC insurance, thereby presumably leaving unchanged many aspects of the current LTC scene. However, Chen proposes an interesting funding concept, namely allowing

individuals to “trade off” some of their Social Security benefit—he suggests five percent—for a LTC insurance policy. Because this coverage is achieved through one’s eligibility for Social Security, itself a compulsory program, his proposed “SS/LTC” plan is a form of “compulsory social insurance.” Chen implicitly recognizes that this level of Social Security benefit won’t buy a generous LTC insurance policy, especially considering that initial purchase would occur no earlier than age 62. In order to expand the amount of coverage, he also suggests applying the same “tradeoff” principle to private pensions: workers could accept a reduced defined-benefit pension payment in return for a defined LTC benefit.

There are interesting fiscal implications to the Social Security part of Chen’s proposal. His proposal puts no additional resources into the overall retirement-security system. If we assume that covered individuals can opt for the LTC benefit only at the point of becoming Social Security beneficiaries, then it actually reduces a beneficiary’s Social Security payment, possibly for many years, given that needs for long-term care are relatively low throughout the 60s and 70s. Once such a system matured, and presuming correct actuarial adjustment, payments would be the same with or without the system. But, unlike many other proposals, Chen’s would actually reduce Federal budgetary pressures during the transition period from program initiation to its reaching maturity.

The CLASS Act: Strengths and Weaknesses

One of the strengths of the CLASS Act lay in its relatively modest, incremental approach. However, this very strength was also a weakness. CLASS was designed to be voluntary rather than universal, and therefore did not create a new entitlement. Moreover, it was legislatively restricted to be self-financing, and therefore adhered strongly to the insurance principle. Rather than paying for services, it would have put money in the hands of qualifying beneficiaries, leaving to them the task of deciding which services will be purchased. The cash benefit to be paid by CLASS was small, far smaller than the average cost of a day in a nursing home or even several hours of professional home care. Therefore, CLASS was far from “comprehensive” with respect to services covered, although there is no reason that its proposed daily benefit could not be increased.

Integration of Family and Informal Caregivers

CLASS was flexible in that it allowed beneficiaries to use their cash benefit to pay family members for the care they provide. Therefore, while CLASS did not build into its design an explicit recognition of the role of family caregivers, it did implicitly integrate informal care into the bundle of covered services. This feature distinguishes

CLASS from all the proposals we reviewed. Indeed, the lack of attention to the role of informal caregivers in these proposals is striking.

Informal family care is often motivated by deep personal affections and based on person-specific knowledge of individual needs. As a result, it often contributes to provision of high quality care, both directly and through monitoring of the quality of paid care services. While family care can be a source of economic and psychological stress, it can also provide personal satisfaction to both caregivers and care recipients. Cultural norms of obligation and duty toward family members are central aspects of social solidarity. For all these reasons, public policy should support, but not coerce, family care provision. Still, even in a world of generous and universal care insurance, family care will continue to play a central role. As Bell and Bowes's chapter point out, Scottish families continue to provide care despite the availability of completely free publicly paid home care services. And, as Gibson's chapter shows, German families continue to choose family-provided care even when state-provided care is an option.

The difficulties of assessing family care resources make it difficult to engage in accurate means-testing of benefits. Private and public judgments about what are properly treated as "means" might differ substantially. For instance, Norton and Newhouse (1994) note that the value of an insured long-term care service, such as the cost of a nursing home, may vary according to one's "family status." Someone with no family members able and willing to help them may, at some level of ADL dependency, have little choice but to enter a nursing home, and for such a person the value of insurance coverage is quite high. At the same level of care need, someone with a spouse or other family members able to provide care may receive the care they need informally, reducing the value of the covered benefit. On the other hand, a married person with severe care needs and no insurance coverage is faced with the prospect of asset depletion prior to establishing Medicaid eligibility, rendering insurance coverage highly valuable as a way to protect the spouse's economic welfare.

While accounting for one's family situation when determining eligibility for benefits might be desirable, it also raises serious practical difficulties. Differentiating eligibility for benefits, or the generosity of benefits, according to the presence or absence of a spouse, or the existence of living children—two of the most obvious potential dimensions of family situation—can easily create problems of equity or fairness, or produce undesirable behavioral incentives, or both. There is, however, a way to allow for the coexistence of family and formal care without conditioning eligibility or benefit levels on one's family situation, and that way was perfectly embodied by the CLASS Act : an unrestricted cash benefit, conditioned solely on the level of care need, leaves in the hands of the beneficiary the possibility of

“compensating” a family caregiver either through direct payment or through asset accumulation, against a possible future of nursing home costs (the latter has the potential to preserve inheritances to some degree).

Indeed, a number of states already have adopted “cash for care” programs, on a limited basis, for Medicaid beneficiaries receiving home care. Studies of the decisions made by participants show that more than half chose to hire relatives to address unmet personal assistance needs, while less than 6 percent hired workers who were not previously known friends or family. Focus group and interview data reveal that participants preferred hiring relatives because they found them more reliable and sensitive (Simon-Rusinowitz et al. 2011).

Ways to increase participation in CLASS-type Programs

The CLASS Act would have created a voluntary program, and was therefore at best a very small step in the direction of universality. It also offered a very small benefit. Among those with long term care needs at a point in time, the proportion whose needs could be paid for in full by the \$50 per day benefit promised by CLASS is probably quite small. And for those with advanced care needs, especially those that require nursing home care, the CLASS Act’s benefit would have fallen far short of daily costs.

However, we feel that three elements of program design are important when imagining a universal-coverage world, as well as the pathway to it: (1) universality; (2) comprehensiveness of service coverage; and (3) integration of family or informal care. We give CLASS high marks for its capacity to integrate family care, while acknowledging that it is neither comprehensive nor universal. But we feel that achieving universality is of more immediate importance than providing comprehensive services, and so we are mainly interested in identifying ways to maximize voluntary participation. In the limit, a voluntary program can become, de facto, one that covers everyone.

One way to increase participation would be to induce employers to offer it among their fringe benefit packages, as one among the several employee-paid benefits generally offered. Another possibility would be to require all Federal contractors to offer CLASS. Additionally, employers who aren’t Federal contractors might be required to offer CLASS as a condition for accepting selected favorable tax treatment provisions.

If CLASS were to be implemented, and if it were to succeed in its intended goal of helping beneficiaries remain at home, then it could delay entry into a nursing home and therefore reduce Medicaid institutional-care costs. The Congressional Budget

Office estimated that CLASS would have reduced Medicaid costs by \$2 billion during its first 10 years of operation (Mulvey and Colello 2011). Projected savings such as these could provide the basis for encouraging participation in a CLASS-type program by letting participants pay at least some of their premiums out of their Federal income tax obligations, in effect diverting some of what would have been the current-revenue sources used to pay current Medicaid costs into a prepaid pool of funds used to pay future long-term care costs. This idea differs from a tax credit, in that it wouldn't reduce the taxpayer's tax bill. Rather, it would reduce current tax revenues but place those lost revenues in CLASS's pool of reserve funds. The obvious problem with this idea is that it would contribute to current fiscal problems. But this is a problem with any "transitional" period.

It should also be possible to get the states to help finance an improved LTC insurance system, if—as should be the case—Medicaid costs go down, at least in relative terms, under the new system. For every dollar of saved Medicaid costs, about half the savings accrue to State governments. Because states should, in principle, be happy to experience savings of any sort, it might be possible to modify the Medicaid cost-sharing formula so that states pay a somewhat larger share of a smaller total expense under a universal LTC program.

A related idea, which might also encourage increased participation in a CLASS-type program among working-age people, is to create a sort of "caregiver's tax credit," in the form of a "virtual" payment of CLASS premiums rather than an explicit adjustment to a caregiver's tax liability. In other words, someone who met an appropriately-defined criterion for providing unpaid long-term care services would be deemed to have enrolled in, and made premium payments to, CLASS for each month of their care provision. This would create a future CLASS benefit liability, without any offsetting payment of actual premiums, which may seem like a very bad deal for the government. However, anyone who established their eligibility in this way would have to switch to making cash premium payments as soon as their caregiving episode ended in order to maintain eligibility; if not, their policy would lapse, negating the future (unfunded) benefit liability. Caregiver tax credits have been proposed many times, but never enacted (for a discussion of such proposals see Wolf 2004, p. 115). The form of "virtual" credit proposed here might appeal to many caregivers, serving to draw them into the program; moreover, it would likely have much less fiscal impact than a true tax credit, even if it were extended to participants without a tax liability (and therefore beyond the reach of a nonrefundable credit).

An even more sweeping modification of CLASS would be to turn its cash benefit into a tiered benefit, possibly in the form of a voucher. Under this scheme, modeled on

Germany's system (as discussed in Gibson's chapter), the voucher could be redeemed for a specified amount of unrestricted cash—keeping open the beneficiary's ability to offer “cash for care” to family members—or for a larger sum if used exclusively for formal care services.

A final suggestion for broadening participation in a CLASS-type program borrows from Chen's (2007) proposal to permit people to divert some of their Social Security benefit into a prepaid (private) LTC insurance plan. We suggest, instead, that at the point of applying for their Social Security benefits, those entitled to a worker's benefit be allowed to designate a portion of their benefit as a CLASS Act premium. While this might seem to invite a good deal of adverse selection, the potential for adverse selection could be controlled by limiting eligibility to those who have reached the age of entitlement for full, rather than reduced, benefits, and requiring them to have been employed for the three years immediately preceding retirement. They would, in effect, be treated as if enrolled in CLASS during those preretirement years. It is not clear how many new beneficiaries might be willing to give up a substantial portion of their Social Security benefit. For example, in 2009 the average retired-worker benefits paid to 66 year olds (most of whom, it seems safe to assume, were newly retired in that year) were \$1,221 per month (Social Security Administration 2011, Table 5.A1.1). The Munnell-Hurwitz estimates, reviewed earlier, found that the actuarially-fair CLASS Act premium for a 66-year old (in the baseline, 6 percent participation scenario) is \$241 a month. This represents nearly 20 percent of the average Social Security benefit payment, a proportion that a substantial proportion of beneficiaries are likely to find prohibitively high. On the other hand, that \$241 monthly premium buys a lifetime \$2,218 per month cash benefit for those that experience a decline in function sufficient to trigger beneficiary status—a tradeoff that many might find attractive.

Can We Get There from Here?

Although the CLASS Act seemed to be a small, uncertain, and—in key analysts' minds, at least—unworkable step in towards universal coverage of long term care needs, its suspension seems like a large backwards step. Conditions like those that contributed to its passage (as described in Gleckman's chapter) aren't like to recur any time soon; indeed, the political climate has subsequently evolved in ways that make bold collective initiatives even less likely. Thus any pathway towards universal long term care coverage features significant obstacles. Concerns about the “graying” of the federal budget, first expressed many decades ago (Hudson 1978) seem to be intensifying. Benefits directed primarily at the elderly promise universality in the long-run, since everyone hopes to grow old. However, increased public debt resulting

from severe recessions and tax cuts raises questions about economic ability to deliver on future promised benefits. A general slowdown in economic growth tends to increase distributional conflict.

Further, high levels of income inequality in the U.S., combined with the other sources of heterogeneity outlined in the first section of this chapter, probably reduce the social trust necessary to collaborate on development of universal care programs. Cross-country surveys suggest that countries with higher levels of inequality are associated with lower levels of generalized trust (Rampell 2011). Income inequality has increased significantly in the U.S. as well as many other countries in recent years (Saez 2010). A survey released at a recent World Economic Forum indicates that trust in both business and government has declined more steeply in the U.S. than in other countries as a result of the recent financial crisis (Folbre 2011). All these factors probably contribute toward a recent shift toward a political paradigm emphasizing intergenerational conflict over the public purse (Binstock 2010).

On the other hand, the sheer magnitude of the long-term care problem, combined with the potential efficiency of universal insurance, could increase the pressure to devise policy solutions. Further, as emphasized in the preceding sections, good models of universal long term care have emerged in a number of different political contexts. In our view, a concerted effort should be made to help translate the currently somewhat abstract benefits of public insurance systems into calculations that would allow individuals to develop a better picture of net lifetime benefits. This effort will require improved accounting systems that explicitly take into account the value of non-market household work and family care, activities that contribute to economic growth but typically go unrewarded by the market. Most models of “intergenerational accounting” focus primarily on taxes, ignoring benefits provided directly by the state and indirectly through the creation and nurturance of future tax payers (Folbre 2009). For instance, the time and effort that parents devote to raising the next generation of workers and taxpayers—if fully accounted for—leads to a very different picture of intergenerational transfers than one based on money transfers alone (Wolf et al. 2011).

Effective political leadership combined with careful advocacy should find a receptive audience, even for what may seem like an extremely expansive policy shift. A national poll conducted in 2004 found a majority of respondents expressing concern about the costs of their future long term care needs, with 70 percent agreeing that that government should do more to help people with those costs (Hart Research Associates 2005). A more recent 2010 survey limited to voters in California reached similar conclusions: 95 percent of voters 40 and older indicated the importance to them of affordable long term care options that would help them avoid nursing home care, with

two thirds saying that these objectives should be a high priority for “state elected officials” (Lake Research Partners 2010).

The strongest potential argument for a universal and mandatory long-term care system in the U.S. lies in a better conceptual and empirical analysis of intergenerational reciprocity. We owe the older generation a high quality of care in return for the care they have provided us, not just as parents, but also as taxpayers helping finance our education and health care. As a purely voluntary and self-financing program the CLASS Act had no true intergenerational component, since current participants would have prepaid for their expected future claims against the pool of funds held by the insurance program (the intertemporal transfers—from those paying premiums now, to those collecting benefits in the future—would not have necessarily been intergenerational). By covering working-age disabled people quickly, while delaying entitlement to others during the period of qualifying, CLASS might even have led to downward rather than upward transfers.

But if CLASS provisions were made mandatory, along with redistribution from those with sufficient resources to those with incomes too low to pay the premiums, it could be designed to conform to principles of intergenerational and gender equity, with those who contribute relatively more to the rearing of the younger generation or to the care of disabled or elderly family members eligible for significant deductions from the taxes they pay to help provide for care in their old age. It could also be designed with a view to intergenerational sustainability, balancing the needs of all dependents (children, the disabled, and the elderly) against the ability of the working age population to provide support for them.

Most of us want to be cared for, to provide care, and to see that those who need care get the care they need. Our individual resources are often inadequate, or are poorly timed, to deal with those needs, creating a rationale for insurance. The most economically efficient, and the most socially sustainable, insurance takes the form of mandatory universal social insurance. A number of failures—failures of foresight and imagination, at the individual level, failures of coordination at the family level, failures of markets and of political leadership—stand in the way of achieving the seemingly utopian ideal of universal coverage. But the longer we wait, the harder it will be to see our way to taking even small steps towards that ideal.

Notes

¹ See “[Secretary Sebelius’s letter to Congress about CLASS](#)” (online document).

² See [“Reputation of Pharmaceutical Companies, While Still Poor, Improves Sharply for Second Year in a Row”](#) (Harris Interactive Website).

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