

CHAPTER 1

INTRODUCTION

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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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