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The Accumulated Challenges Of Long-Term Care

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ABSTRACT During the past century, long-term care in the United States has evolved through five cycles of development, each lasting approximately twenty years. Each, focusing on distinct concerns, produced unintended consequences. Each also added a layer to an accumulation of contradictory approaches—a patchwork system now pushed to the breaking point by increasing needs and financial pressures. Future policies must achieve a better synthesis of approaches inherited from the past, while addressing their unintended consequences. Foremost must be assuring access to essential care, delivery of high-quality services in an increasingly deinstitutionalized system, and a reduction in social and economic disparities.

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Changes in long-term care in the United States during the past 100 years reflect a number of trends. These include the growing size, affluence, and urbanization of the population needing such services; the transformation of medicine and social attitudes about such care; and the unintended consequences of the accumulated efforts to restructure that care. We believe that policymakers who are interested in reforming the system can benefit from a greater familiarity with how the pieces of the current system were put together. Greater familiarity with past achievements and their adverse impacts may help policymakers build on past successes, while reducing the unintended negative consequences of their actions.

We view the current U.S. long-term care system as consisting of threads from the past, woven together into a frayed and inadequate safety net. The family-based informal care system that originally provided all long-term care is now seriously strained. The efforts of home care agencies and hospitals in providing long-term care services have been limited by relatively low reimbursement. The bulk of the nation's supply of nursing home beds, created during the private investment boom triggered by the implementation of Medicare, is now near the end of its useful life. Private assisted living centers boomed in the past decade, but that sector is now threatened by slow economic growth and the lingering mortgage crisis. There is a growing divide between middle- and low-income Americans, and their more affluent counterparts, in access to and quality of long-term care.

In short, long-term care faces perhaps its most serious crisis in a century. Yet this crisis affords an opportunity to revisit and restructure 100 years of accumulated partial solutions. This paper briefly explores a selective broad outline of this history, and the challenges it presents for current policy, to help facilitate those processes.

Evolution Of The U.S. Long-Term Care System

In 1910, provision of long-term care was still undifferentiated from the treatment of medical and social ills in general. Voluntary community hospitals served largely as charities caring for the infirm who lacked the resources and family supports to be cared for in their own homes. The "less deserving poor" of all ages were committed

to public poorhouses.[1] We conclude from our review that roughly every twenty years since then, concerns about a particular problem propelled reforms that moved long-term care in a new direction. At the same time, each wave of reform created unintended problems that defined new concerns and prompted the next cycle of reform. As noted in Exhibit 1, these cycles of development successively focused on controlling care costs for the indigent, eliminating poorhouses, assuring access to medical services, controlling provider abuses, and providing the types of care that people want.

Controlling Indigent Care Costs: The Indoor Relief Solution (1910–1930)

The organization of long-term care between 1910 and 1930 focused on addressing communities' desire to minimize the cost of maintaining the indigent. People requiring long-term care because of disabilities or medical needs were undifferentiated from others requiring public assistance. It was believed that if relief could be made sufficiently punitive and stigmatizing, only the most desperate would seek assistance, thereby minimizing the cost to local governments. Long-term care was, in essence, the last holdover of the Elizabethan poor-law approach.[2]

Three approaches for controlling the indigent had evolved in the United States in the nineteenth century and were still in force. These continue to be the three basic approaches used in the current long-term care system. One could provide care through "outdoor relief" in the form of cash assistance; through "indoor relief" in the form of either poorhouses or poor farms; or through an "auction system." In the auction system the indigent person became the ward of the lowest bidder, who assumed responsibility for his or her supervision. This system had two advantages: it discouraged indigence by means of public humiliation, similar to that caused by admission to the poorhouse, but at a lower cost; and it provided a source of income for those on the edge of being indigent themselves.

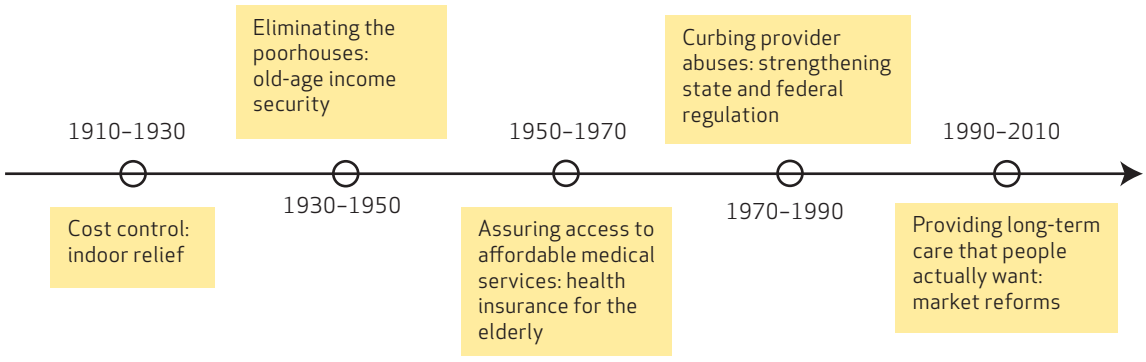
Most municipalities and counties, however, relied on creating poorhouses or poor farms that furnished indoor relief. Although this approach was more costly per beneficiary than providing cash assistance or outdoor relief, officials were concerned then, as they are now, about the "woodwork effect," as more eligible beneficiaries came forward if offered assistance. The total cost of providing indoor relief was lower, because few people requiring help were willing to endure the public shame of what amounted to incarceration for destitution.

The proportion of elderly residents in local poorhouses grew from 23 percent in 1890 to 67 percent in 1930, as reform movements emphasizing child welfare and mental health altered the population incarcerated in these institutions.[3] In 1930, roughly 2 percent of the elderly population was housed in either local poorhouses or state psychiatric hospitals.[1] The poorhouses had, in effect, become the precursors to the nursing home.

Lodges and fraternal orders responded by attempting to rescue elderly poorhouse residents. Such self-help groups had previously established some of the early voluntary homes for the elderly, which later evolved into the nonprofit nursing home sector. They produced exposés of conditions in the poorhouses, insisting on the moral necessity for their replacement with an old-age

EXHIBIT 1

Cycles Of Concerns And "Solutions" In Long-Term Care Over The Past Century: A Timeline



SOURCE Authors' analysis.

pension system.[4] Many of the elderly inmates of poorhouses were not capable of living independently; nevertheless, reformers succeeded in framing the focus of the subsequent policy debate.[5]

Eliminating Poorhouses: The Old-Age Income Security Solution (1930–1950)

The Great Depression and the massive jump in the indigent population made extending indoor relief to all who needed it temporarily impossible. At the same time, the notion of punishing people for indolence became implausible.

In New York, reform efforts led to the passage of the Old Age Security Act of 1930, which provided cash assistance to the low-income elderly. Other states soon followed suit. This approach was adopted nationally under Title I of the 1935 Social Security Act, called the Old Age Assistance program.

Enactment of the federal program had an immediate impact, providing matching funds to states for cash payments to low-income elderly people. Reflecting the concerns of reformers about the punitive nature and shameful conditions in the poorhouses in the 1920s, Title I specified that no federal aid would be extended for aged people cared for in public institutions.[2] Local officials, eager to reduce the financial burden on local government, relocated their public charges to private boarding homes where they would be eligible for federal Old Age Assistance, then proceeded to shut down their poorhouses and poor farms.

Many of those who ran the private boarding homes were themselves struggling with the impact of the Depression, and this source of income provided assistance to them, much in the way the auction system had. Private boarding homes evolved into for-profit nursing homes—a sector that continues even today to serve a larger proportion of the indigent population than do nonprofit homes. The older voluntary old-age homes generally found this new source of residents and payments less attractive than residents who could pay for their care privately , and those homes accounted for few of the poorhouse transfers. These differences also persist today. In 2008, the care for 64.5 percent of all residents in for-profit nursing homes was paid for primarily by Medicaid, compared to 59.2 percent in nonprofit homes that also had a higher proportion of private-pay patients.[6]

Many of the elderly poorhouse residents transferred to the boarding homes had chronic health problems—an issue largely ignored in implementing the Old Age Assistance program. The boarding homes were ill equipped to address the unanticipated medical needs of their new charges—a development that soon became a growing concern.

Assuring Access To Affordable Medical Services: Health Insurance For The Elderly (1950–1970)

The failure to enact proposed universal health insurance in 1948, along with growing reliance on employer-based private insurance, produced a mounting crisis for the elderly and their care providers. It culminated in the passage of the Medicare and Medicaid legislation in 1965. The provisions of federal law that created these programs, known as the Social Security Act Amendments of 1965, combined the Social Security model of universal entitlement financed through payroll deductions (Medicare) and the Old Age Assistance model of an income-eligibility state program with federal matching funds (Medicaid). For covered populations, the advent of these programs eliminated most of the seemingly intractable economic and racial disparities in hospital and physician use within a decade.[7]

Medicare and Medicaid, however, distorted the evolving long-term care system in two ways. First, adopting the private health insurance model, they increased the medicalization and institutionalization of care. In the private insurance approach, one is concerned about the tendency of the insured to overuse their benefits (a variation of the earlier concern of local governments about the woodwork effect of providing cash assistance). This so-called moral hazard could be minimized by narrowly restricting the benefits to medical events the insured would prefer to avoid. A benefit providing helpful personal assistance (such as housekeeping, meal preparation, and shopping) to insured people in their own homes presents a clear moral hazard. At the same time, admission to a hospital for a risky surgical procedure, or a nursing home for custodial care reminiscent of a poorhouse, does not. Second, in what was perhaps the most significant unintended consequence of the 1965 Social Security Act Amendments, Medicaid emerged as the default payer for long-term care. This was partly the result of the last-minute creation of Medicaid, a lack of attention to long-term care in the overall reform package, and the historical tradition of states' assuming the responsibility for the administration of welfare programs. The ultimate effect was to relegate long-term care to a welfare system largely segregated from the mainstream of medical services.

Responding to the increase in public dollars available through Medicaid, the number of nur-

sing home beds in the United States increased by more than 50 percent.[8] This statistic actually understates the nursing home boom, because it does not capture the sizable portion of construction devoted to replacing boarding home beds for Old Age Assistance recipients that did not comply with new Medicaid nursing home facility code requirements. In particular, the number of publicly traded for-profit nursing home chains grew from a few to ninety in the five years leading up to 1971.[3] The newly established state Medicaid programs were generally ill prepared to oversee this unanticipated massive expansion. As a result, the need to expand oversight to prevent both patient care and financial abuses became a focus of concern.

Controlling Provider Abuses: Strengthening State And Federal Enforcement (1970–1990)

During the mid 1970s, financial and patient care scandals in the Medicaid nursing home system produced a regulatory backlash against nursing home providers.[9] An Institute of Medicine (IOM) study's recommendations became incorporated into the national nursing home reform legislation passed as part of the Omnibus Budget Reconciliation Act (OBRA) of 1987.[10] The bill created a minimum national set of standards for care in nursing homes certified to receive Medicare and Medicaid funds. The standards resulted in some steady improvements in the monitoring and reporting of quality, as exemplified by the implementation of the Online Survey, Certification, and Reporting (OSCAR) system of the Centers for Medicare and Medicaid Services (CMS). They also helped stimulate subsequent efforts to explore alternatives to nursing home care.

Efforts to further restrict the payment system for both acute care hospitals and nursing homes provided added impetus for seeking alternatives to nursing homes. Medicare, along with many state Medicaid programs, adopted prospective payment methods that created financial disincentives to providing institutional care for less medically complex patients. These programs often reimbursed nursing homes at less than the cost of the care for such patients. Nursing homes responded. Their occupancy rates declined, and the number of people with long-term care needs living in the community grew. The unintended consequence of the shift in standards and reimbursement was to create a growing and increasingly competitive market for alternatives to nursing home care.

40%

Medicaid Long-Term Care Spending

Medicaid spending for long-term care services provided outside institutions was 40% in 2007, up from 10% in 1988.

Providing Long-Term Care That People Actually Want: Market Reform (1990–2010)

During all previous cycles of development, a major concern was controlling the growing use and cost of long-term care. Consequently, the last thing on most policymakers' minds was exploring ways to make these services more attractive to consumers. Although the increased oversight of nursing homes had increased the standardization of care, it also tended to stifle innovation and flexibility in improving the quality of life for residents. Developers of residential living arrangements for those needing long-term care during this most recent period attempted to correct for the failure to attend to the preferences of the users of services and to respond to the unanticipated growing number of people with long-term care needs living in the community.

State Medicaid programs took advantage of home and community-based waivers to fund personal care and other services that would enable nursing home–eligible recipients of services to live at home or in other residential settings. Many Medicaid long-term care beneficiaries were now offered the choice of applying for a slot in this alternative to nursing home care. For many of these beneficiaries, whose early impressions of nursing homes were shaped by county and municipal poorhouses, it would not seem a hard choice to make. The Supreme Court's 1999 *Olmstead* decision that services should be offered in the most integrated setting appropriate to a person also added impetus to this shift to home and community-based care.[11] The expectation that, carefully designed and controlled, home and community-based care could be budget-neutral or even save money added to its attractiveness to states. As a result, while only 10 percent of Medicaid long-term care expenditures were for noninstitutional services in 1988, that share had risen to 40 percent in 2007.[12,13] If this trend continues, it is likely that the majority of Medicaid long-term care spending will soon be for non–nursing home services.

During this same period, the private-pay long-term care market went through a similar transformation. Many people who would have previously been private-pay nursing home residents took up residence in private assisted living developments. These less regulated environments target middle- and upper-income seniors by offering what elderly consumers, or their adult children, are willing and able to pay for out of pocket. Many assisted living facilities offer residents their own apartments, with optional personal care services that allow for a degree of aging in place, at a price roughly equivalent to or lower than private-pay nursing home rates.

As we enter the next cycle of long-term care development, some may fear a return to the grimmer world of the poorhouses a century ago.

Through their location, physical appearance, and amenities, assisted living facilities actively try to counteract the lingering poorhouse memories and nursing home aversions of potential customers.

In 1989 the Assisted Living Federation of America was formed as a four-member trade organization. Less than a decade later, it had 7,000 members and represented an industry that included 30,000–40,000 facilities.[14] Between 1990 and 2002, assisted living facilities more than doubled in capacity, and they now accommodate more than one million residents. In contrast, the number of nursing home beds has remained relatively stagnant.[15]

Mirroring the boom-and-bust pattern of investment in nursing homes after the passage of Medicare and Medicaid, capital for expansion initially flowed freely to newly created, publicly traded assisted living companies. Since the beginning of 2008, however, this new industry has faced financial difficulties, including bankruptcies, and growth has stalled, partially as a result of the recent recession.[16,17]

Perhaps in part prodded by these shifts in the public- and private-sector long-term care markets, some providers and advocates have pushed for fundamental changes to assure as rich and fulfilling a life as possible for nursing home residents. A variety of groups have formed to support such a transformation. The Pioneer Network has served as a forum for facilitating these efforts.[18] The Eden Alternative movement has focused on transformation of the nursing home culture.[19] While the Robert Wood Johnson Foundation–supported Green House model has focused on the culture as well as the physical redesign of facilities to more closely resemble small home-like environments.[20]

Some public demonstration programs and private initiatives have reflected another desire: reintegration of long-term care into the mainstream of medical care, returning in part to the more undifferentiated system of care that existed a century ago. Payment systems created to support this shift include the CMS-sponsored Program of All-Inclusive Care for the Elderly (PACE), Wisconsin's Family Care Partnership Program, and the Chronic Care Medical Practice Model developed at Seattle-based Group Health.[21–23]

The Next Cycle Of Reform: Long-Term Care Challenges (2010–2030)

The shift away from nursing home care, exacerbated by the recent recession and the graying of the baby boomers, suggests that three emerging concerns will preoccupy policymakers in the next twenty years.

First, the number of people in need of long-term care services, but lacking them, is likely to grow. The impact of this growth is now beginning to be felt, even as the economic slowdown reduces the ability of many to pay out of pocket for such services.[16]

Second, quality-of-care concerns once again appear poised to fuel a cycle of scandal and reform. Transformations during the past twenty years have essentially shifted long-term care away from relatively standardized and regulated providers toward relatively unregulated ones—including assisted living facilities, adult homes for public assistance residents, and home care—some of which may function as unlicensed nursing homes. The added financial pressures of the recent recession on purchasers and providers of long-term care are likely to exacerbate quality problems.

Finally, and perhaps most troubling, increasing inequities in the ability to obtain care and the quality of care people receive by income strata could be the major consequence of the more market-driven changes of the past twenty years.[24] In the absence of expanded federal assistance for long-term care, lower-income people in need of these services will face more access and quality-of-care problems, forcing policymakers to confront the same moral issues that reformers raised about the poorhouse system a century ago. Middle-income people, caught in between an increasingly two-class system of care, will face many of the same difficulties.

Nursing home closings in the current financial environment also seem likely to increase. The higher the proportion of Medicaid residents in a facility's census, the more likely it is to close. Nursing homes with the highest proportion of

Medicaid residents tend to be located in low-income minority communities.[24,25] These same communities are most likely to face shortages in acceptable home and community-based alternatives, which tend to be concentrated in affluent communities where residents can afford the private-pay, out-of-pocket costs.

As we enter the next cycle of long-term care development, some may fear a return to the grimmer world of the poorhouses a century ago. Yet, for all the adverse consequences, previous reform efforts have achieved their overarching goals. There is little question that the disabled elderly of today, especially those with low incomes, are better off than their forebears of a century ago. The accumulated knowledge we have gained about how to improve long-term care, and the insights we have gained into the potential adverse effects of reforms, suggest that the next round of reform can lead us into a still better future. ■

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